PWS Community Voice

Our Request to the Food & Drug Administration: Apply Regulatory Flexibility and Review an NDA for DCCR, a Potential Treatment for Prader-Willi Syndrome.





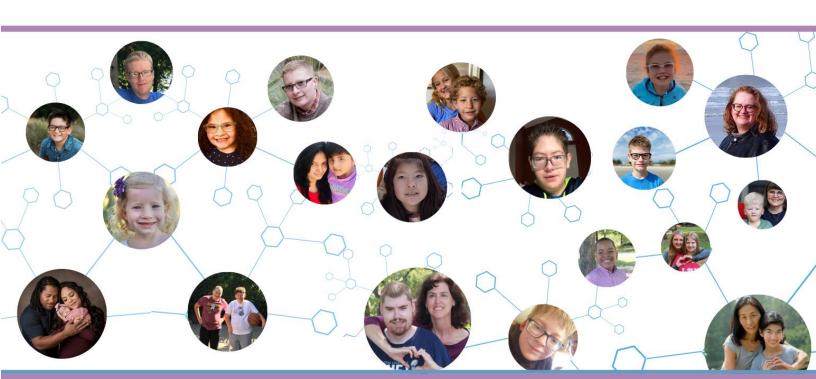


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PWS Community Response Letter to FDA





April 7, 2021

Re: Request for Regulatory Flexibility & Review of NDA for DCCR, a Potential Treatment for Prader-Willi Syndrome; Unique Impact of COVID-19 on Prader-Willi Syndrome Clinical Trials

Dear FDA Leadership,

We represent the Foundation for Prader-Willi Research (FPWR) and the Prader-Willi Syndrome Association | USA (PWSA | USA), two patient advocacy groups that support thousands of individuals with Prader-Willi syndrome (PWS) and their families. We are writing on behalf of the patient community to bring to your attention a recent decision by FDA regarding a potential new therapy for PWS, and to request further dialogue and consideration. Specifically, the decision by the FDA advising Soleno Therapeutics that additional efficacy trial(s) for DCCR (diazoxide choline extended release) are needed prior to an NDA submission has raised concern that access to this promising therapeutic will be unnecessarily delayed. We are asking the FDA to reconsider in light of the unprecedented circumstances of the past year. More broadly, we appreciate that the FDA has a long-standing policy to exercise regulatory flexibility, and a history of doing so in rare disease; however, we propose that the full potential of regulatory flexibility to efficiently advance orphan product development in PWS has not been realized. We are asking for additional dialogue to convey the unique challenges of PWS clinical trials and to collaboratively work with the Agency to find solutions for Soleno's product as well as other clinical packages before the Agency.

PWS is a rare neurodevelopmental and metabolic disorder caused by loss/inactivation of a contiguous set of imprinted genes on chromosome 15. Clinically, PWS is characterized as a constellation of symptoms including multiple endocrine deficiencies, a challenging behavioral phenotype, hyperphagia, and, in environments where food is not strictly controlled, morbid obesity. PWS is associated with increased mortality compared to the typical population, with a median age of death of 29 in the largest study to date (1). Common causes of death include complications of obesity (respiratory failure, cardiac issues), hyperphagia-related accidents (e.g., getting hit by a vehicle when running away to get food, choking while rushing to eat food), gastric rupture and pulmonary embolism. To keep children and adults with PWS safe and restrict food access, families must create a completely locked down environment, establishing an institution-like environment within the home, leading to a poor quality of life for the person with PWS and the entire family. Currently, there are no FDA approved treatments for PWS-associated hyperphagia.

Our community has worked diligently to build resources that address the FDA's call for patient experience data, demonstrating high disease burden and the need for effective therapies addressing hyperphagia. We have demonstrated through family stories (2), surveys (3), and a more formal, best-worst scaling study (4) that hyperphagia is "the" aspect of PWS that families want addressed through new therapies, followed by other critical behavioral issues such as anxiety and aggression. We have demonstrated the tremendous unmet medical needs of individuals with PWS (2, 3), and the considerable burden of disease, showing that caregiver burden in PWS exceeds that of caregivers for traumatic brain injury and Alzheimer disease (5) and that higher levels of hyperphagia are associated with increased caregiver burden (6). We have also demonstrated that caregivers are willing to accept considerable risk in exchange for modest improvements in hyperphagia (7, 8). In the absence of a 'cure', families would welcome treatments that alleviate PWS symptoms. Finally, as suggested by the Agency during a Critical Path Innovation Meeting, we have also solicited input from individuals with PWS, speaking on their own behalf. Although this was challenging (not all individuals are capable of expressing their views), Dr. Elizabeth Dykens and her team elicited opinions from young adults with PWS on treatment preferences and disease burden, which nicely align with that of caregivers (9). This patient experience data is complemented by natural history studies that provide critical information to support clinical trials, including an NIH study funded 2006-2014 (10) as well as an ongoing registry-based prospective study of behavioral changes over time and serious medical events (11).

COVID-19 had a profound impact on the conduct and outcome of ongoing PWS clinical trials. Two large Phase 3 clinical trials evaluating new drugs for PWS were underway at height of the first COVID-19 wave of infections and related public health measures (e.g., stay at home orders). Beyond the cross-cutting issues that the clinical trial enterprise faced as a result of the pandemic (e.g., missed/delayed clinic visits), there were unique impacts on the PWS community that, we believe, could have led to confounding of clinical trial data upon the onset of the pandemic in the US (March 2020). PWS is defined by an extremely complex behavioral phenotype, with hyperphagia, anxiety, temper outbursts, rigidity and obsessive-compulsive behaviors interacting in the setting of social cognition and intellectual deficits (12). The primary outcome measure for most PWS clinical trials is the Hyperphagia Questionnaire for Clinical Trials (HQ-CT), a caregiverreported outcome measure assessing observable hyperphagia behaviors. While we believe this measure is appropriate for the PWS population and it has generally performed well in previous clinical trials, a limitation of the measure is its potential to be impacted by environmental changes. We believe this limitation became insurmountable in the face of the pandemic. Indeed, we have collected data on the impact of the COVID-19 pandemic on the US PWS patient community, with a survey administered through the Global PWS Registry. This survey documented increased caregiver stress, increased anxiety for individuals with PWS, as well as overall changes in food-related behaviors and activity due to COVID, with behaviors changing in sometimes unpredictable ways (13). These findings are corroborated by a similar study of PWS families in Europe (14). While the uncertainty and unexpected changes to routine that were experienced across the US had a profound impact on everyone, the particular sensitivity and inability of individuals with PWS to cope with unexpected change is well documented and would be expected to negatively impact the consistency and reliability of a measure such as HQ-CT.

In a Phase 3 trial by Soleno Therapeutics, pre-COVID data showed significant improvements in HQ-CT scores; families reported positive outcomes with continued improvement in the open label extension. Publicly released data from Soleno Therapeutics demonstrated that PWS participants receiving DCCR showed a drop in HQ-CT scores. While the reduction in HQ-CT scores did not reach statistical significance for the

overall study, a significant improvement was detected for the prespecified, severe hyperphagia group [LS Mean Difference DCCR:Placebo -5.41 (2.09), p=0.0124]. In addition, significant improvement in hyperphagia was detected in the entire cohort when data from the pre-March 1, 2020 cut off (e.g., the start of the pandemic lockdown period) was considered [LS Mean Difference DCCR:Placebo -3.13 (1.48), p=0.037]. While we understand that prespecification of analyses protects against bias and improves reliability of findings, we believe that the robust pre-pandemic findings should not be dismissed, particularly given the unique circumstances of a global pandemic, paired with our community's significant unmet medical need, which makes us accepting of less certainty of treatment benefit.

Importantly, objective secondary endpoints (DEXA scans, biochemical markers) showed significant improvements (e.g., p= 0.001 for change in body composition as assessed by lean body mass: fat mass ratio vs placebo), which continued to improve in the open label extension, while subjective measures trended consistently in the right direction. This is consistent with what we hear anecdotally from participants in the trial and their families. To this end, more than 26,000 comments from PWS families and supporters in the community were submitted to our organizations in a recent call for input regarding DCCR's potential for treatment in PWS. Notably, site Principal Investigators and more than 80 family members of those enrolled in the trial provided their perspective (see appended comments for full quotes). Among these:

"As a PI, I have noticed considerable improvements in body composition, energy intake, hyperphagia, and quality of life for my patients participating in the DCCR trial.... Both patients and caretakers expressed a sense of relief from having less conflict and rigidity around food routines. They expressed gratitude that they could now do things that families not living with PWS take for granted, such as go out to eat, travel, participate in after school activities, and socialize outside the home without the constant fear and anxiety surrounding unwanted food access...." P. Salehi, MD

"The effects of DCCR on the patients in the trial were multifactorial. While it definitively decreased the hyperphagia drive, it also significantly improved body composition and metabolism. Other changes that were noted by parents and patients, included decreased anxiety, both around food and overall, decreased compulsive behaviors, and improvements in socialization.... It was abundantly clear to patients and PIs that the impact of COVID-19 directly negatively impacted the results of the study with regard to the questionnaire data. Therefore, I ask that the FDA reconsider the request for an additional study with this life-changing medication, given the negative impact of the COVID-19 pandemic on the results of this study and, perhaps more importantly, the fact that there is currently no available treatment for the horrific symptoms of this syndrome...." J. Miller, MD

"... Our son no longer pushes, fights, argues, runs away or gets angry because he no longer experiences hyperphagia. DCCR has given him the chance to graduate from high school and seriously consider college in his future. DCCR has allowed him freedom to no longer need supervision 24/7. He now has a chance to live a more healthy and productive life. Taking DCCR away will only cost him our family and society much more in the future.... (age 17)

"Our son's entire physique has changed while taking DCCR. His endurance for physical activity has escalated and he's able to ride his bike for 5+ miles, take hour long walks, complete workout videos. It's night and day difference." (age 8)

"We have noticed a remarkable difference with DCCR. Our daughter's anxiety has decreased tremendously. We have been able to stop locking up food because she has a better control over her hunger and her food seeking. She has stopped having outbursts and temper tantrums that disrupt our home and cause stress on our entire family. ... The difference this medicine has made for our child is night and day in her behavior and her ability to have a more normal life." (age 15)

While we appreciate that these stories are anecdotal, they deviate remarkably from the documented natural history of PWS. Based on the publicly available data and feedback from our community, we are encouraged that DCCR is having a positive impact in PWS and propose that FDA review and analysis is warranted to speed access to this potentially impactful treatment.

This drug has a well characterized safety profile and no unexpected serious adverse events were reported. DCCR is an extended release version of diazoxide, which has been used clinically for more than 40 years in infants, children and adults. Importantly, diazoxide is well tolerated with a well characterized safety profile. The risks associated with this drug appear to be relatively low and can be readily monitored in the clinical setting. Given the serious consequences of PWS and the clear and significant unmet medical need, we believe our community's risk tolerance is much higher than the risks presented by DCCR.

Additional large clinical trials for this drug in the PWS may not be feasible. While the FDA advised Soleno Therapeutics that additional DCCR clinical trial(s) are needed prior to NDA submission, as shared publicly in a March 8, 2021 press release, we are concerned that conducting an additional large efficacy study is not feasible in our population for the foreseeable future. COVID-19 disruptions continue and it is unclear how long it will take for our vulnerable population to be comfortable traveling to clinical trial sites. Further, the behavioral issues associated with the disruptions of routine will continue and are likely to be triggered again as vaccines become more widely available and daily routines change again, making the initiation of a new study in PWS susceptible to risk.

In addition, there has been widespread discussion about DCCR in the PWS community, further challenging placebo effect issues that can be difficult in any setting, but are particularly challenging in a close, rare disease community. Finally, our community is acutely aware that only a small number of clinical sites can effectively manage the challenging and sometimes extreme behaviors that characterize PWS. Potential trial participants are limited by the ability of their caregivers to manage these extreme behaviors during travel and at clinical trial sites.

We request additional flexibility, consideration and dialogue, given this unprecedented situation. Given the unanticipated impact of the COVID-19 pandemic, the life-threatening nature of PWS, the tremendous unmet medical need of this rare disease, and the extreme difficulties of performing traditional clinical trials in the PWS population, we are imploring the FDA to utilize its long-standing policy of applying reasonable, science-based regulatory flexibility in its evaluation of results from PWS clinical trials. We believe it is reasonable to expect that critical review of the DCCR data will establish that there are real and meaningful benefits with limited risk, and a degree of uncertainty that is appropriate for our community. Also, given that initiating a new trial during the ongoing COVID-19 pandemic is not advisable, there is no path forward for the foreseeable future. Therefore, we ask that you consider the full totality of the DCCR clinical trial results by conducting a fulsome and careful review of an NDA for this product.

Finally, we would welcome a robust dialogue between the FDA and the PWS community to convey the nuances and perspective of PWS families as it relates to unmet medical need, risk tolerance, acceptance of uncertainty of benefit, and challenges in the conduct of clinical trials, for DCCR as well as other products before the Agency for the treatment of PWS. We believe that such a discussion would advance the critical solutions needed for our community.

Sincerely,

John Walter, CEO

Foundation for Prader-Willi Research

Signall

Paige Rivard, CEO

Paige Rward

Prader-Willi Syndrome Association | USA

Theresa Strong, PhD

Theresa F.

Director of Research Programs

Foundation for Prader-Willi Research

PWS COMMUNITY RESPONSE LETTER TO FDA

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- 3. Impact of PWS on Individuals and Their Families and Views on Treatments: Results of an International Online Survey. Survey of >750 families re: impact of PWS and unmet medical needs, with open text comments: https://www.fpwr.org/pws-patient-voices
- 4. Tsai et al Caregiver priorities for endpoints to evaluate treatments for Prader-Willi syndrome: a bestworst scaling. https://www.tandfonline.com/doi/full/10.1080/13696998.2018.1528980
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- 11. https://clinicaltrials.gov/ct2/show/NCT03718416 Natural History Study of Serious Medical Events in PWS (PATH for PWS)
- 12. Schwarz L et al. Behavioral Features in Prader-Willi Syndrome (PWS): Consensus paper from the International PWS Clinical Trial Consortium (submitted/in revision)
- **13. Impact of COVID on the PWS community** blog of survey results: https://www.fpwr.org/blog/pws-registry-data-impact-of-covid-19-on-pws-families-infographic (data attached)
- **14.** Wieting et al., Behavioral change in Prader-Willi syndrome during COVID-19 pandemic. JIDR 2021, doi: 10.1111/jir.12831

IMPACT OF COVID ON PWS FAMILIES

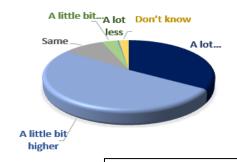
Impact of COVID on PWS Families – A survey in the Global PWS Registry

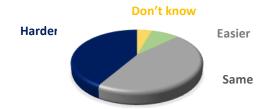
(US/UK parents of children & adults, ages 4+ May-August 2020, n=322 responses)

See also:: https://www.fpwr.org/blog/pws-registry-data-impact-of-covid-19-on-pws-families-infographic

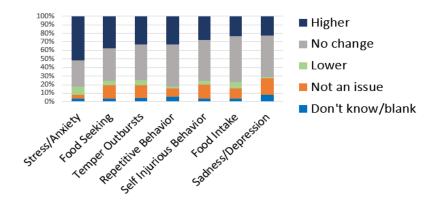
85% of caregivers report higher levels of stress.

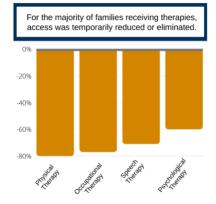
Overall, behavior has been more difficult to manage.

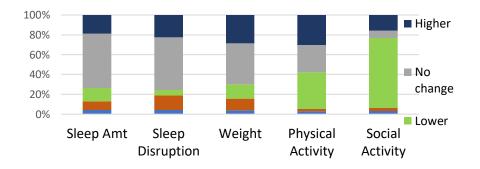




Change in behaviors for the person with PWS.







PETITION SIGN-ON

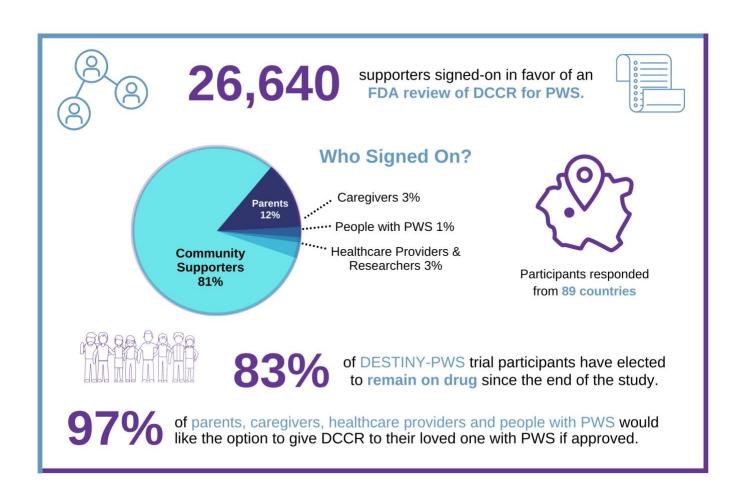
Please apply regulatory flexibility and review an NDA for DCCR.

Sign-On Background

Over a period of 7 days, from March 12-19,2021, members of the PWS Community were invited to lend their voice and experience through an online sign-on in support of a request that the FDA apply regulatory flexibility and to review the DNA for DCCR, a potential treatment for Prader-Willi syndrome. **26,640 individuals from around the world completed the sign-on** with 79% of signatures representing US residents. **Parents and caregivers represented people with PWS ages 0 to 62 years old.**

97% of parents, caregivers, healthcare providers and people with PWS would like the option to give DCCR to their loved one with PWS if approved by the FDA.

Over 80 DESTINY-PWS trial participants provided insight into their experience with DCCR. The majority of these trial participants continue to take DCCR. Comments from these trial participants, along with feedback from the PWS community on what a treatment for their loved one with PWS could mean for them and their family, are provided on the pages to follow.



PETITION SIGN-ON

Please apply regulatory flexibility and review an NDA for DCCR.

Sign-On Survey

 What is your relationship to PWS? Parent Caregiver (non-parent) Healthcare provider Scientist Person with PWS Other (please specify)
What is the current age of the person with PWS you are advocating for?
Based on the data that has been presented, would you want the option to give DCCR to your loved one? • Yes • No
What would an approval of DCCR mean for your loved one with PWS and your family?
Did your loved one participate in the DCCR trial? • Yes • No
If your loved one participated in the DCCR study, are they still taking DCCR? • Yes • No
If your loved one participate in the trial, please feel free to share your experience and observations.
Name Country E-mail Phone

COMMENTS FROM STUDY PI'S

WHAT BENEFITS DID YOU OBSERVE DURING THE DESTINY-PWS TRIAL?

Comments from the PWS Community

DESTINY-PWS Principal Investigators

As a PI, I have noticed considerable improvements in body composition, energy intake, hyperphagia, and quality of life for my patients participating in the DCCR trial. In terms of positive health outcomes, patients who started with an obese BMI significantly improved their BMI with minimal change in food intake or daily activity. Lean patients in the trial who already had a normal BMI due to extremely supervised calorie intake and food access restriction also saw considerable physical benefits. Anecdotally, they were able to increase their daily amount of calories to maintain a normal BMI, have more flexibility in their food routines, and less conflict with their families regarding food. These latter effects were not properly captured in the outcomes of the trial but were consistent and significant. In addition, the impact of this medication extends beyond the patient to include their caretakers and families as decreased hyperphagia and anxiety surrounding food has improved quality of life for all. Both patients and caretakers expressed a sense of relief from having less conflict and rigidity around food routines. They expressed gratitude that they could now do things that families not living with PWS take for granted, such as go out to eat, travel, participate in after school activities, and socialize outside the home without the constant fear and anxiety surrounding unwanted food access. There is no other medication currently available for this population that has these beneficial outcomes. Access to such a medication would significantly improve the lives of individuals with PWS and their families. Seeing both physical and psychosocial benefits for participants in this trial, I support this current request for flexibility around the decision of making DCCR more widely available to the PWS community.

Parisa Salehi, MD

Associate Professor of Pediatrics, University of WA, Department of Pediatrics, Division of Endocrinology Clinical director SCH Prader-Willi Syndrome Clinic

The effects of DCCR on the patients in the trial were multifactorial. While it definitively decreased the hyperphagia drive, it also significantly improved body composition and metabolism. Other changes that were noted by parents and patients, included decreased anxiety, both around food and overall, decreased compulsive behaviors, and improvements in socialization. These patients were able to do things they had never been able to do prior to starting DCCR: they attended school dances with their peers, they had sleepovers at friends' homes, two were able to start drivers education, and they went out to dinner with their siblings. All of these things were unimaginable prior to DCCR. So many parents commented that this medication gave the child back to them who had been there prior to the development of the hyperphagia that is part of this extremely difficult syndrome. Parents told us that for the first time ever, they were not anxious about what would happen when their child was at school, the children were able to learn better in school and grades improved. These positive effects were likely due to the decreased interest and anxiety about food, and I was stunned to see just how far-reaching the changes in hyperphagia could be. It was abundantly clear to patients and PIs that the impact of COVID-19 directly negatively impacted the results of the study with regard to the questionnaire data. Therefore, I ask that the FDA reconsider the request for an additional study with this life-changing medication, given the negative impact of the COVID-19 pandemic on the results of this study and, perhaps more importantly, the fact that there is currently no available treatment for the horrific symptoms of this syndrome. DCCR offers unique hope to this patient population.

Jennifer Miller, MD, MSCI

Professor, University of Florida, Pediatric Endocrinology Director, Prader-Willi Syndrome Center of Excellence

OF INDIVIDUALS WITH PWS WHO IDENTIFIED AS DESTINY-PWS TRIAL PARTICIPANTS

Parents and Caregivers of Individuals who identified as DESTINY-PWS Trial Participants

If your loved one participated in the trial, please feel free to share your experience and observations.

It has helped my daughter reduce need to food seeking and behavior outbursts. They are still there but not at the same frequency.

Showing positive results.

Helps with hyperphagia. Allows my daughter to skip snacks and I can be late with meals. I don't have to lock up the kitchen. Allows her to focus on fun things.

We have seen ZERO harmful side effects from DCCR. We've seen helpful benefits, but the questions about notifying any changes since she started the drug have been difficult to answer because she started the extension in mid-March 2020, when pretty much the world turned upside down and everything changed. So it's been hard to distinguish what is DCCR-related and what is COVID-related. But H has remained a happy, otherwise healthy child while on DCCR.

Our son's entire physique has changed while taking DCCR. His endurance for physical activity has escalated and he's able to ride his bike for 5+ miles, take hour long walks, complete workout videos. It's night and day difference.

This medication has helped her a lot. It has helped her to not food seek, it has helped with her behavior, it has helped to behavior to better understand why or why not regarding food.

Weight loss and less hunger.

We have seen a significant improvement in our son's behavior regarding his behavior with food. He tolerates being told no when asking for food much better now.

We have noticed a big difference in our son behavior. His anxiety around food has changed for the better. He doesn't seem as obsessed as he was. I have hope he may be able to live independently and peaceful without this hunger burden and obsession with food someday.

It is a life changing treatment that allows our daughter not to have to constantly worry about eating. It allows her to focus on being a 3rd grader, have peace, experience life like most 9-year-old kids.

She is less focused on food, she is no longer sneaking food, she often leaves food on her plate, and is ok with skipping snacks. None of this was typical behavior before she was started on DCCR.

Our son has been taking DCCR for over a year now and we have noticed a tremendous difference in his loss of appetite. He's no longer obsessing about meals like he used, he can wait to eat and he also rarely puts up a fight anymore when we limit his food intake. We need to keep taking this drug for him to keep his hunger and anxiety at a low level!

We did not notice any differences in our daughter during the trial, but we know many who have had amazing experiences. We want this drug on the market because it has the possibility of helping the majority of individuals with PWS.

Our daughter's body composition has improved and after asking her directly how a DCCR has helped her, she said without hesitation, 'it helps me feel full.' That's ALL I need to hear in order for me to know this medication works and is a game changer for our community.

Our daughter had majorly reduced anxiety, a reduction in food seeking and a rise in energy and endurance. It has been life changing for her.

There was a clear difference when she started taking DCCR. She wasn't asking for food as much. She seemed much more focused on the task at hand. She was able to participate in activities that other children her age did without much of an issue. Whenever we miss a day of taking it, we can see her slip back into her old self

DCCR has given my child a better quality of life such that her every waking thought does not revolve around food. It has made her life's challenges much more manageable, with no adverse side effects. We desperately would like to continue the medication!!!

We moved during covid and I don't know how my daughter would have handled all the change without being on DCCR. Also, where her hyperphagia would be without DCCR.

It has made a huge difference in food behaviors; we have also seen a jump in reading and writing at school. It has also reduced the amount of nonstop talking from a kiddo with pws.

The impact on her quality of life has been immense. As a direct result of the drug, my daughter had a significant reduction in anxiety, significant improvement focusing. significant increase in the ability to accept schedule changes, the ability to skip snacks and be late for meals with no issue at all, just to name a few. Especially during the pandemic, I can't imagine how life would have been for her or our family without her being on this drug. Virtual learning has been a million times better than we could have ever imagined, again that is due solely to the positive impacts of the drug. For the first time in my daughter's school career, this past Monday (first day of in-person learning in over a year) I put her on the bus and wasn't in tears with overwhelming worry, fear and anxiety. Fearful of my phone ringing because she snuck food or whatever other PWS related issue reared it's ugly head. Again, that is due solely to the positive impacts of this drug. After seeing the changes in my daughter over the past year, I know that DCCR was the answer to my prayers. Not only my daughter, but the whole family. Although it's only one individual with the diagnosis, the whole family lives everyday with the unique and overwhelming stress of PWS. To think of my daughter not being on DCCR is unimaginable.

We feel it has been helpful and are worried about losing this medication option.

He is no longer consumed by food and picking his skin as he was before the trial. His anxiety around food has dissipated tremendously and we attribute this to DCCR.

The changes in her behaviors, compulsions, socialization, and overall attitude has been astonishing. She is more easy going, less anxiety, and less obsessed with food. Her picking has decreased significantly. She is able to learn so much better in school because her head is free of all those

OF INDIVIDUALS WITH PWS WHO IDENTIFIED AS DESTINY-PWS TRIAL PARTICIPANTS

distractions. She is more flexible in her thinking and when plans change. She can enjoy family gatherings and parties even when there is food available. She has started to decrease the amount of food she eats and if engaged in an activity she will even delay meals to finish the activity. I have observed my daughter during being stuck at home during the lock downs for Covid deal with the situation so much better than if she was not taking the medication. This medication over all has been such a positive aspect and gives us hope that she can enjoy life and have a future that is happy and functionable.

It has been life changing for my son, his ability to retains muscle mass has increased and his fat mass has decreased, a extremely important and life changing situation for him. His relationship with food has definitely changed, he has more control over his need for food and has a lowered obsession with it. His food seeking habits have drastically decreased to the point of almost never happening now. His chance to lead a somewhat normal day to day life without having the constant need for food has changed his life. He looks better than he has in years and not approving this drug would erase all of that. Please reevaluate! Do not take this life changing opportunity away from him.

Less food related anxiety. Less general anxiety. Incredible decrease in negative behaviors, both related and unrelated to food. Improved body composition. Improved quality of life. He is happy. He is thriving. He is living.

Less food related anxiety. Less general anxiety. Incredible decrease in negative behaviors, both related and unrelated to food. Improved body composition. Improved quality of life.

She has lost close to 20 lbs. She has stated on more than one occasion that she was full from eating. We've had less instances of her stealing food or trying to get food outside of the allotted times. She seems to be more confident in who she is. There's so much more. Please see response to previous question as well.

Major changes in satiety, food seeking behaviors, emotional regulation, concentration, body mass. It has been a game changer in an otherwise bleak situation.

DCCR is a game changer in every way possible. We are living a very close to normal life and it brings me to tears thinking there is a chance DCCR will be taken away. I have a new child because of this medicine. When my son was 8 years old he tried to commit suicide. He is 13 now, and before DCCR he would talk about killing himself or dying because living with Prader Willi Syndrome is so hard. Since he started taking DCCR those thoughts have diminished 95%. Can you imagine having a child that went from wanting to die everyday to wanting to live? & wanting to live happy. To wanting a future with a job & life goals? DCCR is the breakthrough drug our community needs. Please don't take that away from us.

It is a very slow process to see results- but and then you sit there and realize all things that there has been no meltdown over. I would over anything to be able to see the results of DCCR during normal times with normal routines!

The results were slow at first but we gradually saw an improvement in her body mass. She leaned out. More importantly she feels satisfied. She has missed snacks and even leaves food at meals. She can be left alone with food and it not be a distraction. Her emotions and outbursts have lessened and there is less emotion over food. Life changing in our experience

We have seen the results and are hopeful this gets approved.

It has help him a lot with his body structure, hunger and behavior. Please don't take it away!!

Our experience has been noted in question 4 of this survey. DCCR has been life changing for my daughter and our family. We would be devastated if this safe and effective treatment was not approved.

Our daughter (PWS) has shown impressive gains in improving her quality of life, most specifically a decrease in anxiety and food-seeking behaviors.

The medicine has been an amazing lifesaver for our son and has positively and materially changed his anxiety levels and allows him to participate normally in school and with his friend socially.

Our son seems to have more control, understanding and reasoning on many aspects of life.

We have noticed a remarkable difference with DCCR. Our daughter's anxiety has decreased tremendously. We have been able to stop locking up food because she has a better control over her hunger and her food seeking. She has stopped having outbursts and temper tantrums that disrupt our home and cause stress on our entire family. Our daughter has been able to concentrate on her schoolwork and not get so much anxiety when she has a test or a difficult assignment. The difference this medicine has made for our child is night and day in her behavior and her ability to have a more normal life.

Our daughter has improved by leaps and bounds while on DCCR. She is able to maintain her emotions. We have less outbursts, less fighting, less anger, less problems with behavior, and are able to have a more normal family environment because of DCCR.

Before taking DCCR my son could not stop eating. Gaining weight and having extreme temper tantrums. He was lethargic and had little energy to do much. After being on DCCR for over a year, the results are dramatic. He doesn't ask for food like before. He eats less and is losing weight. The tantrums are so minimal now. He has energy and enjoys life so much more. He needs this drug as all do who has PWS.

The medication has changed my child and our family's life. It's truly been a blessing and miracle.

Less craving, weight loss.

We have noticed improvements in all aspects of behavior, with most notable in self-regulation.

All I can say is that it is absolutely life changing. No locks on anything anymore. No more anxiety about food. We can have food sitting out on the counter. Our PWS child now cooks, when he couldn't even go into the kitchen before. Our whole family is less stressed, and we had hope for the future until we received the news that DCCR was not approved. We are absolutely devastated. There is no way that our child

OF INDIVIDUALS WITH PWS WHO IDENTIFIED AS DESTINY-PWS TRIAL PARTICIPANTS

will be able to handle going back to the way things were before DCCR. We are devastated.

Because of DCCR we have been able to remove locks from 2 refrigerators, 1 freezer, 2 pantries and numerous cupboards. Our son no longer pushes, fights, argues, runs away or gets angry because he no longer experiences hyperphagia. DCCR has given him the chance to graduate from high school and seriously consider college in his future. DCCR has allowed him freedom to no longer need supervision 24/7. He now has a chance to live a more healthy and productive life. Taking DCCR away will only cost him our family and society much more in the future. This decision by the FDA cannot, must not and will not be allowed.

It's been a miracle drug for us. My daughter's sense of hunger and major behavioral issues has been decreased by more than 50%! Her body composition has improved, and she's excited to exercise. Our family life has improved, since her urgency to eat and forage food has decreased. We can actually have a life now not driven by food every second of the day. Amazing!

This medication has CHANGED OUR LIVES!! My daughter has gone through over 2 years of traveling 12 hours one way, 25 times for this trial. It has had a positive effect on her health, her relationship with food and her overall body composition. She has had nothing but positive outcomes from this drug. I feel that the risks far out way the benefits when looking at the lifelong impact for her, her health and our family. Please consider making this medication available to her for her life. She has already put in so many hours towards this trial, please do not make us do it again. It is too much to ask,

when the data is there and available for review.

My child has been able to increase the amount of food she is eating without gaining any weight. In addition, her stamina has increased, and she is able to go on very long walks without tiring easily, she does not need to nap during the day because she is tired and she is able to say she is full and also wait long periods of time between meals

Her anxiety is lowered. Her weight is stable. She is better at accepting NO when it comes to seconds and she can be around food with much less anxiety.

The effects have been remarkable! She has gone from needing to eat breakfast every morning exactly at 7 AM to often being able to sleep in and wait until 10:30, 11:00 or later for her first meal of the day. There is no longer the same urgency and intensity for eating meals on a perfect schedule and no longer any tantrums if meals are delayed. We are fairly certain we were on the placebo for the first portion of the trial when we saw no effects for six months. But in the past year, since definitely being on the drug, our daughter has lost 12.5 pounds and her BMI has gone from 24 to 22.1 -- a reduction of 8%. She has had no negative effects from the drug -- just wonderful improvements that we attribute to DCCR.

My loved one experienced no side effects, decreased food drive and weight loss and then healthy weight management.

It has been a life-changing improvement for her and for our family. This is a vital medication. more flexibility around meals, willing to wait for meals, not so rigid about what she eats and when. also if she is having a social get together she can have snack at another time so it doesn't cause stress. Also she has lost weight and her body shape has changed, less abdominal fat. she can eat more than before and not gain weight. It is pretty amazing!

Our son had a slight reprieve from his feelings of hunger. No ill side effects at all. He was on a very low dose and I truly believe an appropriate dose would be a game changer.

This drug has given my child confidence, better behavior, and he has fun with his siblings, for our family we have gone from high stress all the time to more relaxed and having friends over and not having to stress over having people come and go my kids can have friends over and not worry about Matthew embarrassing them or me being so stressed out I don't allow them into the house. Seeing his muscle grow and his confidence and mental state get to a point where he is almost normal makes me wonder how we ever lived life before he is caring and sweet and now, he understands his self-worth in life

Christina's life-threatening drive for food has decreased significantly. She will tell you she feels better and more in control of her impulses. She is more independent, more dependable, more relaxed, calmer. She has lost ten pounds. She no longer requires an afternoon snack to make it through the day. She is happy, vibrant, and energetic. This medication has greatly improved her quality of life.

Appears to be helping to manage her hyperphagia.

What would an approval of DCCR mean for your loved one and your family?

Parents and Caregivers of Individuals in the US

What would an approval of DCCR mean for your loved one and your family?

It would help improve his eating habits which would avoid any health problems that he may have in the future.

Quality of life and independence

The chance to reduce hunger, OCD about food, improve behaviors, and improve body composition.

Right now we have no medical treatments for hyperphagia other than diet. We hope to have a safe effective treatment like DCCR approved to allow our daughter to live a full and complete live.

One of the scariest aspects of a PWS diagnosis is that there is no cure. DCCR was the glimmer of hope that our child would not suffer from the most devastating symptom, hyperphagia. Please give our child a chance at a more independent life.

Hope, Motivation, Optimism that she could one day live a fully independent life as an adult.

For our loved one: Improved developmental outcomes (socially, academically, physically, psychologically, and emotionally) when not plagued by symptoms such as hyperphagia and obsessive compulsive disorder. Social acceptance from peers, a sense of belonging, a chance at a normal life and independence. For our family: Reduced emotional and financial stress, fears about health problems, morbidity, behavioral issues, and long-term care in our eventual passing. More time to enjoy family outings, gatherings with friends and family, and celebrating typical life milestones.

We are devastated to hear that the FDA does not want to approve this drug. When our son was diagnosed with PWS we promised we would do everything we could to give him the quality of life he deserves. This drug has been proven safe and had given so many children with PWS hope. This drug is safe and effective in the treatment of hyperphagia and no other drug on the market can do that. Our community needs this drug now and it is imperative that we approve it for those children who are suffering from this rare and complex disorder.

Improved quality of live. My son is completely homebound.

This drug is potentially life changing. My 12 year old daughter does her best each day to

function in a world that moves at light speed around her. The primary issue that holds her back and makes those that love her worry about her safety when alone is FOOD. The drive to obtain food is strong. The belief she is hungry is strong. But she is strong and determined. Give her and the rest of our community a chance. It,Äôs an opportunity to reduce one more barrier to an independent life.

Hope

An approval of this drug would mean that my daughter could continue to have success with her health. That the success my daughter has had would not have been a waste of her time.

More quality of life!

It's would mean a miracle! Change lives, help our children pleased please approve it.

The possibility of becoming a family not suffering from the 24/7 disruptions associated with PWS behavior.

A chance at normalcy.

Could be life-changing for the better. PWS has so many horrible symptoms and DCCR could be a cure to some of the worst.

Life-changing opportunity

Cure to him

Everything

It could be absolutely life changing for my struggling daughter!!

The drug could potentially save the life of our loved one with PWS. This drug will treat a major component of her disorder.

The chance of a normal life for my baby.

Everything, satiety, decreased compulsions

We don't have medication options.

The chance for our son and other living with PWS to live a more independent life!

A chance to have a substantial impact on the quality of life by lessening a debilitating and life threatening symptom of Prader Willi Syndrome.

It would change my sons life. Hunger would may longer consume his mind.

My grandson would not suffer from the deviation of overeating!!

The Federal Government is on our side to assure a better and brighter future for whose who have PWS

Another step forward

Save my son's life.

Better quality of life for my son

Relief of hunger, anxiety, behavior issues

It would make a world of difference to her daily life activities. The challenges faced by a caregiver/grandparent of a PW granddaughter are difficult and painful. When you absolutely feel that you would rather take the place of her and not have her suffer at no fault of her own. This medication would make daily activities more manageable and have her focus on the regular activities all other children look forward to without the focus on her physical needs. She has begun taking a few hours of in person school, so this would also ease the worry of her having her focus on food rather than her learning and also the worry of not being there to consistently monitor her. We ask that you make a difference to all who deal with this difficult medical necessity.

A chance for a better and happier life.

Hope for my child to have at least some control over her hunger and development.

A sense of normalcy for her

A completely different life for her and our family!

Help her lose weight

This would allow for our adoptive child with PWS to never have to face hyperphagia and be able to live an independent life.

It would mean the world. This is the only medication that can improve the most critical symptoms of PWS. It has the power to save lives and make an amazing difference for patients, caregivers and families. It is crucial

What would an approval of DCCR mean for your loved one and your family?

that this medication becomes available as soon as possible.

A chance a better quality of life.

Relief from some of the worst and scariest characteristics of Prader-Willi Syndrome.

Significant change

He would not be constantly hungry and his behavioral issues would be diminished.

Chance for a more normal less stressed life

A chance for a normal life for my daughter.

A healthier life with having treatment for hyperphagia.

Give my child a chance to not suffer on a day to day basis over food. For him to be able to control his hunger and live a normal as life as possible is all I want for him.

Life. This drug could mean an independent, full life free of the effects of the most debilitating symptoms of this disorder

Our community needs this NOW, lives are depending on it.

Approval of DCCR means that my daughter would be able to live a more full, fulfilling and safe life. It means that there would be SOMETHING, FINALLY, that addresses many of the major obstacles a great life that PWS presents such as hyperphagia and behavior challenges. It means that her friends with PWS would have this same home. It would mean that I could tell new parents that I mentor that it really will be ok. That there is hope and that it is called DCCR.

My child would have a life.

Life changing. Our life is so hard with PWS. My daughter talks all the time about wishing there was something she could have to help change her food drive

A normal life otherwise, he will not be able to work abs be independent.

Relief from feeling starving all the time.

It could make a significant difference in our daughter's food related behaviors body composition and calorie intake. Any treatment, even if it is a modest improvement or does not work for all people with PWS is absolutely

needed as an option for treatment for a rare disease that significantly impacts quality of life.

Freedom for the PWS person to work, travel and be with the family.

Steps towards helping my loved one with PWS. There is currently no cure and we would give anything to help our son.

DCCR could be an answer to the LIFE-THREATENING aspects of Prader Willi's hyperphagia which is the leading CAUSE OF DEATH in PWS. If DCCR is approved, it would pave a pathway to our child's independence, contribution to the community with her gifts/talents, and remove the most dangerous factor in this syndrome.

That our son, and all people who are living with PWS, would have a strong chance at a normal, full life.

Independence for my child, him never feeling hunger.

DCCR would mean a future for our daughter. Independence. The chance to be a regular nerson

Potential independence in the future, the ability for him to live a full life

Everything!!!

A chance! to live a healthy life.

It would mean we would have another treatment option to consider.

My daughter would be able to live a normal life. The constant hunger is very difficult to live with as for her and all those around her. Please please approve for approval.

A longer, more independent, and full life for my daughter! And a more independent life for our family. It could mean life or death if hyperphagia starts.

A means to a cure

It would mean my daughter would not have to suffer and could grow up to live independently even after I'm gone.

A miracle. A chance for no more never-ending hunger.

Better quality of life and long life.

It would me that we could live our lives with more freedom and not have to live life revolving around food. This would help ease anxiety and allow for a more successful and free life for my daughter

My daughter has many issues related to her behaviors. She is hungry all the time. Anything that could address her hunger and the associated behaviors would improve her quality of life and ours. Please reconsider. It is difficult to imagine our lives but we need empathy and help.

Less anxiety and better interaction with the outside world

It would mean peace of mind. It would mean an an easier life It would mean the world to my loved one and my entire family.

My daughter is still at an age where hyperphagia doesn't control her life. I want it to stay that way! DCCR offers her that ability. You have the ability with this decision to change my daughter's future! My daughter WILL go to college, she WILL have a boyfriend, heck even a husband, she WILL drive a car, she WILL have a job, she WILL live independently, she WILL have the ability to be whoever she wants to be and do whatever she wants to do! She WILL not be defined by PWS!

Life changing!! Actually, life GIVING!!! It would mean a completely different outcome for her, one with unlimited possibilities!!

Better quality of life for sure and possibly life saving depending on the extent of symptoms she will face. This is the only drug that has any promise to treat this life threatening symptom and it is disgusting that regardless of how promising it is, there is a price tag on the health and well-being-being of those who suffer from this syndrome.

A better life!

Continued progress in fighting the insatiable hunger that comes along with Prader Willis syndrome.

Please keep in mind the emotional mental toll it takes on a family worrying and wondering about this stage in their child,Äôs diagnosis. The amount of worry for the parents, friends, family, of the individual, wondering if this will be the day that life as you know it will change. Knowing that this drug would be available gives everyone a sense of peace and restores a quality of life even before that stage in PWS begins. Approval of this medication would be life changing. Try to imagine for one moment if your child was hungry 24/7. YOU try skipping

What would an approval of DCCR mean for your loved one and your family?

meals for a whole day and then at the end of the day imagine that feeling in yourself, or the person you love most, every minute of every day. You would at least have the option to go eat if you wanted to. These kids and adults do not have that option. Please reconsider.

Freedom. Freedom to be able to live a more normalized life free of cabinet locks, family and friend gatherings without stressing over the buffet spread of food she can't have, and free of ER visits praying the non-food item she ingested won't cost us her life.

It would be life saving treatment for my daughter!!!

It would let my daughter live a life of more independence. It would give her an opportunity to be a regular kid!!

It would be life saving for my daughter, there is no other treatment like it available right now.

Harry would be better able to cope and live in the world. His regulating his emotions is a significant challenge. He can't live the life he wants with this level of disability. His food challenges aren't as serve as others with PWS. But this could open doors to independence for him as well.

Hyperphagia is not imaginable to the average person, but it is real and it interferes with the person's ability to participate in the world of work, school, family, relationships. Soleno is a something that could help bring some normalcy into our loved ones lives.

Change of life

This treatment can save lives and it is critical that it is on the market now please do not discontinue this drug and program

A better life.

Dramatic quality of life difference for the better. Constant stress everyday, hour, and minute, would be reduced or eliminated.

Hope for a better future for her and all those suffering from this disorder

An opportunity for my child to live in a better and normal life

A better and safer life

The drug therapy could open the door to an entire different prognosis than before! Imaging my little girl growing up not having to constantly battle the various symptoms of pws

would allow her to focus on so much more! It would be cruel to disallow this prognosis altering drug to not just my daughter but thousands of other children suffering with this diagnosis. This approval would mean so much to my family and loved one words cannot express enough. Please join our cause in fighting for a better life for those with pws and approve this!

DCCR approval would mean that our kids will have a chance to be 'normal'. To wake up with a clearer mind, less anxiety, less hunger, and better behaviors. It would mean some normalcy to our family. DCCR has given us a life, a life we never had as a family. We can go out to eat, run errands, attend social functions without a meltdown. I am fearful of what will happen if this is not approved. OUR KIDS NEED THIS, THEY DESERVE IT.

it would give our daughter the potential for a healthier, more independent life. We have been in several trials, one for liveliotide that was stopped due to ineffectiveness. The PWS community needs this drug. Not sure what else the FDA is waiting for.

Life quality improvement

It would mean finally a potential treatment of some of the symptoms of his PWS

Everything. It would mean a better quality of life for all of us and a full life for Sienna.

The possibility of helping others w/ PWS

It would mean an easier life for my son and I

We would get to have Nora at our home more often. There is often concern of her sneaking off to find food or overeating. She is kind and living and wonderful. She needs added help to enable her more freedom to connect with other children.

The possibility of my daughter's condition improving and helping her quality of life

It would mean giving my child hope! A chance to live a full and meaningful life! That's what all parents want for there children

HOPE

Improved quality of life for him and our entire family

My son Albert could have an independent life and achieve every dream that he has.

An independent life. Please.

Would help with unbelievable behaviors

Happiness!

Peace

I would a change for them to get some relief of the symptoms of this horrible disease so they can live a somewhat normal life

It has relieved levels of anxiety and behaviors that make day to day life much more tolerable

We have been on DCCR since November 2019 and would not have gotten through this pandemic without it. I cannot imagine not having DCCR for my daughter moving forward. This medication has given us a life as a family during these trying times.

One less struggle to feel helpless and hopeless for my son! One less battle we have to fight alone.

Hope that a potential and possibly effective treatment could be available for my son before my passing. Giving him an opportunity to live a more normal life that doesn't revolve around food his safety 24 hours a day.

Could potentially save lives for people with

To better manage my son's appetite.

More normalcy for our son

Everything, life changing, less of a daily struggle a full life

DCCR would give my daughter at chance at independence. At 3, Catherine is showing a high level of intelligence, indomitable determination, and joy of life. At this point, the only thing standing in her way would be the debilitating hunger associated with PWS. I urge you to consider her future when you review this data.

Approval for DCCR would enable our daughter to live free from the tyranny of food seeking. It is imperative that DCCR be approved by the FDA for treatment of Prader-Willi Syndrome.

It could mean life or death.

Improved quality of life. Increased strength and stamina would allow her to participate in activities alongside her peers. May allow increased calorie consumption that may reduce some food anxiety.

What would an approval of DCCR mean for your loved one and your family?

improved quality of life

Amazing things

Grace hasn't hit the hyperphagia stage of PWS yet but the idea of her future being consumed by it leaves us utterly terrified.

Everything

For our PWS family member to live a better life

Better management of hyperphagia and metabolism would be life changing, giving my child better health and more independence.

A change in the quality of life for our child and a chance to change her life trajectory. As we are faced with considering options as she moves toward adulthood in the next few years, availability of this treatment will have direct effect on those choices and outcomes.

My daughter could have a life with less hunger and an improved behavioral state. DCCR has been amazing for her quality of life and all with PWS deserve this possibility!

The approval of DCCR is SO important to our family. This would be not only life changing for our daughter, but for our entire family and so many others. Having a treatment for some of the most severe PWS symptoms will save lives. We need this!

A way to help control hyperphagia in PWS

Absolutely life changing a possibility of independent living and the reality that my child won't feel like she is starving for the rest of her life.

lower anxiety, frustration, aggression and hunger.

Everything

It would allow us relief and freedom from an unfair life for someone we love.

Less perseveration about food

Life changing potential. Without the constant fear of the 'Monster of hunger', my daughter may live a life of purpose and difference making

It would allow our daughter to live a near normal life.

We would have our life back. Our daughter can finally have a life where she is not always hungry, where she has friends and where she

can achieve her goals instead of thinking about how to attain her next meal.

Chance for my child to beat this

I cry almost everyday about my sons future I worry about if I'm seeing the hyperphagia yet in regular things every toddler does. Having this medicine approved would ease my mind if even just a little and help my son achieve the best possible future!

Everything!

New treatments could have saved her life.

It would free us up to live life not do locked down and unable to go on vacations. It would make family gathering so much less stressful

It is what he needs to lead a fairly normal life.

A chance at a better life

For him to live life (full). Chance to have a better life

My son is beginning to show signs of hyperphagia. This treatment could mean the difference for not only his physical health about overeating but also the psychological impacts to the family of fighting against his uncontrolled insatiability. This is the #1 issue with PWS.

It would change our lives. The struggle is a daily issue and it puts a huge strain on our family and our relationships. My husband and I can not convey more strongly how our worried we are about our sor's future if this major piece of his disability can not be curbed. We urge you to spend a day with a family with a child with PWS and then with a clear conscience try to deny this treatment to the individual.

Hope for long term independence!

An end to the constant feeling of being hungry

Life changing and life saving!!

Hope

The help we have been waiting for now for 25 years

This could save her life and others with PWS. It helps with most of major symptoms. They need to get this on market as soon as possible.

It would mean a lot if it helps. It gives me hope.

It could save her life! We need it approved.

My family and I would have our lives back. Every breathing moment is spent worrying about the behavioral manifestations of hyperphagia that my daughter displays. She is so anxious, scared she won't be fed, hungry all day long. It's sad, nothing we do is without stress. Hyperphagia holds us hostage. Everything and everyone suffers!

Hope

Life saving

My daughter has goals and dreams and has conquered every obstacle put in front of her. She's 7 but talks about college and moving out and being a doctor. I would love for these things to be possible but without a medication or treatment for hyperphagia/behaviors her future is limited when it comes to independence and the ability to provide financially for herself.

It would mean that our daughter can live a full life without feeling the excruciating effects of PWS

The approval of DCCR would mean less aggressive behaviors and more peace for my son and the family.

being able to focus on something other than food

Approval and hope

Норе

Provide some degree of normalcy for my child and the family

It would be life changing!

Improved quality of life

Lessen symptoms

It would be life changing. Amazing opportunities for my nephew and limit risks.

More normal living

If my daughter was taking DCCR, I would not worry that she was torturing herself with thoughts of food. I would not wake up in the middle of the trying to remember if I had locked the food pantry. I would trust her more and not feel guilty for not trusting her.

Any help to the PW person or community is great appreciated! Let's get this done.

What would an approval of DCCR mean for your loved one and your family?

The difference between being given an actual life or not.

It could save a child's life

It would mean my child might have a chance a more normal life.

Freedom from food seeking because of lack of feeling full.

Hope for a higher quality future.

Currently the only available treatment for hyperphagia, one of the most debilitating symptoms of PWS

A start to relieving their struggle with hunger and several other characteristics of PWS

Better life!

Nic is a smart, kind, and loving little boy. He is in the 4th grade and struggles to keep up with his "typical" peers. He has may struggles that he is trying very hard to overcome such as: His constant hunger for food/ food seeking, he has some outbursts that can cause damage to things and people around him, etc. His family and doctors believe that DCCR is one key that could unlock his future. Please reconsider their application and give PWS kids and their families this much needed medication.

Better control of PWS symptoms

It would mean making her life easier for her. Everything would be better for her. Her quality of life would improve 10 fold

Hope for a better future for our son and a lot less stress on our entire family

A brighter future for my son, one In which hyperphagia doesn't consume our family's lives

Lots of help

As a parent of a child with a rare disease, you are willing to do anything to allow your child to live their best life.. We can not wait for another trial, we need this treatment available now. We are willing to assume the risks of DCCR to give our child an opportunity to live life FULL. We urge you to reconsider the recent decision as it relates to DCCR for people living with PWS.

The approval of DCCR will help our daughter live her very best life. When we first heard the words Prader-Willi Syndrome we were devastated. We need options available to treat our children and DCCR is proven to be safe. We

can not wait years, we need these options available now.

The approval of DCCR would take an enormous weight off our shoulders, the weight of know that one day our sweet, silly, determined and loving little girl will never feel full again. We have been carrying this weight for over 2 years and many other families much longer. We can not wait another 5 years for another trial. We have fought so hard - attended hundreds of hours of medical and therapy visits - all to allow our daughter to live her best life. We will not stop fighting now. We need this treatment available now. We have been following the clinical trail very closely. It has been determined to be safe. We need this as an available treatment option for our daughter.

Hope. DCCR would give our child a chance at living independently once he's an adult. His options for a healthy, full life are limited without DCCR

It would be extremely crucial for him to be able to live life full and independently and thrive. We would like for all kids battling to have as many tools in their tool box to battle the side effects of Prader Willi syndrome and we believe this medication is that tool!

A new medication for our daughter would help relieve the constant stress we have worrying for her food security. We would know for certain that this medication can help in our constant hunger battle. It would reduce daily behavior episodes about food. It would truly be life changing for us.

It is a game changer for our family.

This drug will be life changing for my granddaughter, for our family and for many like us. Please read the research. Do the right thing.

Finally a proven treatment to curb the voracious appetite as well as behavioral issues. This would change their lives for the better.

Peace of mind

Everything. It would give us hope, faith in his future and strength to continue fighting to give him everything he wants and needs in life!

Is life changing for those with PWS

Quite literally, it would change everything. A fuller life without the insatiable hunger that will haunt my daughter every minute of every day. A more normal social life where she can go to birthday parties, lunch at school and family picnics without wanting to gorge herself to the

point of her stomach potentially bursting and ending up in the hospital. This drug would change her quality of life without a shadow of a doubt.

Put simply, a chance at a more normal life. Constant hunger, an insatiable appetite and uncontrollable obesity is a cruel future, especially if there is a drug that might help.

Ability to lose weight

It would give us hope. We've endured many years with no hint of anything close to something that could be this effective. Let us be part of the effort bringing us one step closer to a cure

Relief, freedom and more independence. Everything.

Tremendous hope for an otherwise very scary and untreatable symptom.

Hope

It would mean quality of life for my son. Some normalcy for the other members of our family. It would be a dream come true. Really, there are no words to express what it is like to be affected by PWS.

It would free my daughter to live a more independent life with less dependence on many other medications.

HELP...the answer

improved quality of life for whole family

A world where he would be able to hold a job and thrive rather than a burden to my other children or society.

Could possibly help prevent food seeking that causes obesity as well as heart issues due to obesity

Help with severe symptoms of Prader Willi Syndrome

Peace of mind that we can assist our son to reach full potential.

LIFE

It would be a great help managing my son's Prader-Willi behaviors.

Hope for a life without debilitating hunger for my son.

What would an approval of DCCR mean for your loved one and your family?

Allowing my daughter to enjoy being a child, instead of riddled with pain and anxiety from feeling hungry all the time.

It would change all of our lives for the better! This will make his life so much better!

This treatment could potentially save the life of my daughter and many others with PWS. It will help with the major symptoms she experiences with pws. This is a critical drug that needs to get on the market.

Independence. My son will have limited access to the basic joys of adulthood because of his hyperphagia

Being able to Live Life Full. My little friend and those who share in this affliction, their families and those who love them would greatly benefit from this. This could provide a better life...a fuller life, both, literally and figuratively.

Some chance at life for our whole family. PWS has profoundly diminished the lives of all of our family members.

The best alternative to improve health

DCCR It would make a huge difference in the lives of so many individuals.

This would help with Prader Willi!

This drug would allow my son to live a more independent, less stressful and ultimately a SAFER life! He will be able to play with his friends and not constantly worry about when he will eat next. It will give him a chance at a normal life.

Early intervention and medicine is key for my nephew with PWS to have a chance at a more normal life. It would mean the difference between a balanced life and no life at all.

It would mean everything from intangible hope and normalcy to tangible medical benefits! Hope for the possibility my nephew will be able to live an independent life. In a society where the discourse is so focused on creating progress for the vulnerable, independence and equalizing the field, could we have a greater responsibility to the PWS community to approve trials that could create such outcomes?) the tangible benefits I will leave to our talented medical community but I have seen the research and am so optimistic about my nephew - George(!!) - if we could get him on the medicine. The ability to control this aspect of his disease can ameliorate bullying, expand his options to remain in his household with his family as a young child but later on could pave the way for a more 'normal' life.

More options, chance for better quality of life, health

I would be a choice for help for our son who is having real problems now.

Less hunger and anxiety for a person and and just something to help him and his family to be less stressed when Zaidi and hunger happens and just knowing that he is being helped

It would help reassure me of my daughters well being! I want the best for her and I,Äôd give and do everything I can for her.

It would save my son's life.

A chance to live a better life

A life of hope, happiness and less stress. People have nooooo idea what stress the patient and caretakers endure. It really takes a toll on mental and physical health.

safety and a reduction in suffering

It could literally save my daughters life. There are currently no treatment options available for hyperphagia. This could give us hope. It would be a shame for the FDA to unnecessarily kill this trial that could potentially save lives

A chance at stability, safety, and increased normalcy.

To better their life

the opportunity for reduced anxiety which would bring peace to the family

A fresh start

It could potentially drastically improve our son,Äôs and entire family,Äôs daily experience by helping manage some of the most difficult and lifestyle-impacting symptoms of PWS.

An opportunity to have a good quality of life vs a constant painful hunger and 24 hour care.

A greater likelihood of living an independent life.

Our daughter is fortunate to be currently participating in the DCCR trial. This has been an amazing treatment for our daughter. It is helping her live as close to a typical life as possible. We feel it would be extremely detrimental to her health if this treatment option was taken away.

improved quality of life; improved health; improved mental health

Hope for life without the day to day challenges of the symptoms of PWS.

This would save the life of my loved one with PWS!

Hopefully it will help prevent dangerous and conflicting outburst of uncontrolled anger. Very hard to deal with and control in front of the younger children. It scares to them.

It would mean the world to us

Would possibly open up opportunities to live a more normal life.

That there was a treatment available to help my children with PWS deal with one of the most dangerous aspects of this disorder. There would be hope for the security of a healthier life

He is currently in a facility where he Cannot get to food. I would love for him to come back

My daughter doesn't have hyperphagia, but self injurious behaviors are serious concern. Having a drug to control that behavior would be a life changer for her and for us.

It would give our son a chance at a typical life.

It would mean hope for life change for my child and our whole family.

Approval of DCCR would mean everything! This treatment could potentially be life saving for our girl and others living with Prader-Willi Syndrome.

Better quality of life

A chance at a somewhat typical and successful life

Hope for a more fulfilling lifetime and longer lasting life for my daughter

Life changing.

It would potentially save my sisters life. She has always struggled with this and I would love for her to finally be happy and healthy. This has been an issue for her since we found her diagnosis at the age of 4.

Safety and independence

What would an approval of DCCR mean for your loved one and your family?

Life changing drug for my child with PWS and family for safety and health. It would reduce life and death risk and provide live family in the same house hold instead of institution or group home, it would make possible vocational training, work opportunity, meaningful life, more mobility as fulfill potential basic daily living. It also allowed family member's physical and mental health. psychological

A better future for my son

No longer being controlled by always feeling hungry and searching for food. Social life would improve.

Norah is a happy girl who loves her family and friends fiercely. She likes to Dance. Her biggest obstacle is her hunger. Her parents are constantly having to monitor her food seeking behaviors. The medicine would help ease her constant hunger improving her and her parents lives.

Taylor is a smart and sassy 1st grader who loves to read, loves skiing and has so many goals and dreams. She wants to be a doctor when she grows up. This drug can help eliminate some of the obstacles in her way of that dream. Her family and her doctors believe that DCCR is one key that could unlock her future. Please reconsider their application and give PWS kids and their families this medication.

A better life for everyone

Safety and mental health

Approval would me a better quality of life for my son. Worries about hyperphagia, aggression, and other characteristics would decline and provide my son with a more normal life and less stress for our family.

It would give my child a better quality of life and potential for a more independent future.

A chance at normalcy

Potentially save her life from the post debilitating part of this awful syndrome! Please don't add this stress to our loved ones and community!!!

It would mean EVERYTHING! It would mean that Lindsay would be able to continue to thrive socially, academically, and emotionally. She has been thriving due to being on this medication. The changes that have occurred have been a total game changer for her and our family. The growth and overcoming challenge she faced has been enormous. I have seen along with her teachers and camp counselors and therapists the positive changes both academically and

emotionally and it is amazing and gives us so much hope!

Controlling weight helps alleviate potential for other related issues. Extra help with emotional control helps with social interaction. The list goes on!

The approval of DCCR would be life changing to our family. This news has brought us all to heartbreak and tears. We had so much hope in this approval. Today I carried my one year old and cried because that hope I once had for this to help her is now gone. Having a sick child is the hardest thing a human will ever have to face and knowing there is something that can help them live a better life can,Äôt be used because of approval is the second hardest thing we have faced. Please reconsider your decision because one day it may be you or your loved one.

It would save her life. Help or eliminate hyperphagia that is life threatening

It will provide an opportunity to help our son Logan with this complex disorder. He goes through challenges daily and it will help provide some relief! We are willing to take on risk as there are few to none treatment options for kids and adults with PWS to help with treatment

Our son is in the DCCR trials and is literally a new child with this medicine one. In the past he needed an aide at school and constantly interrupted his class and had significant challenges at home and in school. On DCCR he can participate and socially engage as a normal 15 year old, does not need an aide, and his anxiety levels have dramatically dropped. Please support this medicine and allow our children to have as normal life as possible.

DCCR enables age-appropriate independence and interaction with peers without being subject to complete and direct control of the food environment. Relief from food anxiety provided by DCCR would continue to free her to focus on growth and maturity and learning and interpersonal interaction.

This would mean a chance at living an independent life. Without it, we have no chance

Hope for an improved quality of life for our son

A better life for him and us

It would get us one step closer to a cure for the hallmark symptom of PWS--not feeling full.

My Daughter would have a opportunity to live a normal life unafraid of the affects of PWS..

Normalcy

Hope for a cure, much freedom, relieve

Hope

It would mean everything. Until you have and live with PWS you have no idea on how stressful and how it is so hard on everyone who is involved. I feel it is very irresponsible to ignore so many who need this. My daughter doesn't so much have a food issue. She does have the weight issue PWS causes. I, her father worry everyday and will till the day I die. Everyone deserves the best if available. Don't take this away from the PWS community. We all hope for a CURE or at least a great alternative

The approval of DCCR would give us hope for our daughter to live life FULL. DCCR being available on the market would completely change the life of our daughter as well as ours (her parents) and our PWS family, for the better.

Relief

We do not want our child or our family to be prisoners in their own home because our son is always hungry. Can you imagine if you were starving 24/7? PWS is such a cruel disease and these children deserve a life! This treatment is safe and effective and our children should not have to wait years (if a new trial is even funded) for a chance to live without hunger. This means EVERYTHING.

A much less stressful and more "normal" family life. It would hopefully allow our daughter to participate in more social and employment opportunities which would make her much happier.

The availability of a safe option to help offset the symptoms of PWS is invaluable.

Everything! It could change the lives and save the lives of anyone with PWS!

This is first first medication that will help my child with this rare syndrome and save her life! We need this medication approved now please. It gives children with PWS hope

A possibility of an independent higher quality of life. The safety of being able to be alone. An ability to possibly save my sons life. There is no treatment and hunger is on his mind 24/7. He is obese which I worry will create a storm of

What would an approval of DCCR mean for your loved one and your family?

medical problems cardiac, diabetes and stroke to name a few.

It would mean a lot.

Hope to change a life of my niece to be independent, with less lifelong challenges.

A better quality of life.

Our daughter has been involved in the trial for DCCR. It has been life changing. It will be devastating to her livelihood if we have to remove her from the drug.

It means Samantha has access to another treatment option in the future when she reaches the next stage of PWS. Hyper is debilitating and life threatening. She deserves every opportunity to reduce that burden.

By taking DCCR, my daughter is allowed to be as close to a normal 10 year old as possible. That means so much to her

Better luck at a future for my child

Oh you have no idea how much this would help my daughter. We don't socialize very much due to the insatiable appetite my daughter as!

Hope. And for my son to live a regular life.

It might be life changing! Might help with the extreme hunger, and the anger associated!

There are currently no pharmaceutical treatments that specifically address PWS or its hallmark issue of hyperphagia. DCCR has shown incredibly promising results in clinical trials for people with PWS, including reduced hyperphagia, better bone density, and stronger/leaner body composition. We need DCCR for the PWS community—this drug could allow my friend to live a more normal, independent life by directly addressing the primary symptom of PWS. We need it now, not in 4-5 years, so younger children with PWS can get the benefits before the onset of severe hyperphagia. Please give Selby a chance at leading a more normal life."

To allow my child to feel full, to help avoid obesity and its related health issues, to reduce the stress and anxiety around food in general

A chance at life

It would allow my child to be free of the constant feeling of being hungry AAAALL the time. To be able to walk into the kitchen without locks and safety guards so she can't access food

Freedom from chronic hunger

Relief from some of the daily struggles that my daughter suffers from as well as helping her function more like her typical peers.

DCCR would give the sweet girl I babysit a better chance for a healthier life!

The possibility that my child have a future with less worry and stress of his diagnosis. Also the possibility that this would help to be able to live more independently as he gets older.

The difference between controlled and uncontrolled behavior.

Not battling with ginger all day every day

My granddaughter would have a better QUALITY of life or at least a chance of one. PWS is so devastating in so many ways. This drug can ease some of that for so many love ones.

Life saving

Life normalcy

A chance to help with hunger

It would mean everything for our kids that struggle from everyday basis with the effects of PWS

Hope for a productive, happy future!

It would be a game changer. This drug would significantly improve our financial situation by reducing lost data from work due to behaviors or medical reasons (from eating). It work reduce stress & anxiety place on siblings. It would improve the quality of life fir the entire family.

On March 2, 2020 we received a diagnosis for our then six week old daughter of Prader-William Syndrome (PWS). We were told she had a rare genetic condition which affects 1 in 15,000 live births in the U.S. We were understandably devastated for our little girl and our family. Since then, we have started daily growth hormone shots and a controlled diet. Out little girl is thriving. She is rolling, sitting, creeping and babbling. She smiles and blows kisses. She has mastered the straw cup. She loves on our dog and her big sister. She can have a very bright future. But we know that for her and other PWS patients there is the looming possibility of hyperphagia in her future. We are disappointed with FDA's decision to require another clinical trial for Diazoxide Choline Controlled-Release (DCCR), a drug conceived by Soleno Therapeutics and

proved effective in curbing excessive hunger and easing behavioral symptoms in PWS patients. If our daughter has the ability to benefit from DCCR, it could be life changing for her and other PWS patients. Hyperphagia can begin to set in as early as 8 years old with metabolism beginning to slow down as early as 2 years old. Our daughter is 13 months old. While she has some time, it is not a lot of time for trials and advancements. Every day matters for her. There are older PWS children, some of whom are seeing success from DCCR already and others who are at the point where DCCR is a must have for them. The FDA's requirement for another trial and more participant is creating a glass ceiling for these kids. It could amount to a death sentence. Patients who are part of the trial will need to stop taking the medication. Children who need the drug will have to wait. With the small patient population, there may never be enough trials and enough data to move forward. There will certainly never be enough time for these kids. The safety profile of diazoxide is well known, with more than 100,000 patient years of use, DCCR has been tested in 8 clinical trials involving nearly 300 randomized patients including more than 210 treated with DCCR. The tremendous positive results of the DESTINY PWS Phase 3 trial - reduction in hyperphagia, reduced anxiety, repetitive questioning, compulsive behaviors, and skin picking - brought so much hope in our life. This drug presents a lifechanging opportunity for our children with PWS, for their siblings, us as parents and for our extended families and communities. We ask that the FDA reconsiders its decision, which effectively condemns thousands of children all around the world to a life of excessive hunger, behavioral problems and a range of other issues, which will diminish their quality of life. PWS children already suffer from a rare genetic condition which is hard to treat. This decision from the EDA creates another setback for them. based on the rareness and small patient population which is unjustified.

It would be life changing for us. Hyperphagia is our biggest concern for our son with PWS and we were really hoping that DCCR can make the most significant difference.

It would mean a lot if it helps improve our daughters life

My daughter may not have to deal with hyperphagia for the rest of her life if this drug is approved!

It would give us a new hope for a better future for our PWS children whom we love so very much. The thought of a cure would be a miracle from GOD.

My daughter is about to go into the next phase of PWS. Hyperphagia, she NEEDS the DCCR to

What would an approval of DCCR mean for your loved one and your family?

try and have the most normal life possible. IT IS SO EXTREMELY IMPORTANT FOR THESE CHILDREN TO HAVE A FIGHTING CHANCE

A more stable life for our little one!

To control the hunger

This is a life changing/ saving needed treatment. It can help with several factors that affect these children let's give them the best chances possible to have a happy, healthy life!

Would very likely mean that our daughter will not need to go to a group home as we are getting older and she is getting harder to handle

Our daughter would be able to better keep up while playing with friends which has so many social benefits. Also, it would decrease the increased hunger drive.

PWS is a very difficult disorder to live with on a daily basis. DCCR would help us address difficult aggressive and rigid behaviors that are currently our biggest challenge. It would also help manage my child's hyperphagia. Our only solution at this time is to lock ALL FOOD ALL THE TIME outside of meal times.

The chance to live.

Everything

Hope, options, relief,

It would tremendously help out so many. It is SAFE! It WORKS! We need to help

Save the life of pws children and let her live a normal life.

A better life.

To have a normal life!

Could give our daughter a much better life

Peace of mind

The daily struggle of always feeling as if you're starving is real. It affects not only the physical, mental and emotional status of the person with PWS, but also the entire family and anyone that comes in contact with that person. All day, everyday every decision revolves around food resulting in behaviors that are often times challenging to say the very least. What a blessing it would be to the person suffering with the struggles of PWS to feel relief.

It would stop the constant hunger my son deals with daily. It would also help with his severe outbursts that are triggered by food related issues. It would help him to participate safely in events that his peers do as he would not be seeking food, distracted by severe hunger, or meltdowns.

Really important. Means a lot

The world!

It would mean a chance at education and emotion managing strategies; it would mean a real chance at a promising future!

Hope

It would give my daughter a better quality of life.

My daughter's food-seeking has lead to many police interactions, some where I have feared for her safety, as well as ours. We've had to have her institutionalized twice. A treatment for her would allow her to have a life, as well as letting me, her mother, also have a life. I am limited to working part time from home so as to monitor her and keep her safe. Think of the resources that could be better spent if we could just control her hunger and behavior surrounding that.

It would give her and our family a chance at a more normal life

An opportunity to be free from daily suffering

Less risk of or child developing obesity-related conditions

It would mean a better future for my daughter and to live life to the FULLest!

It could potentially save the life of my loved one.

It would me that Charlotte would have the ability to take a treatment that would help her with her dysphagia which controls her life currently.

Hope for the future!!

Hope, a future, independence, everything. This could save lives.

Stability and life! a chance at a better future. A chance at a future in general. This is a nobrainer. Our kids need help, there is no excuse at all not to do the the best we can for them.

They are our brothers, sisters, daughters, sons and our future.

This would mean our daughter could potentially live a longer life.

Peace of mind and less worry about Hyperphagia

It would potentially save her life.

A future closer to that of a normal child. Help reduce hunger and slow the onset of possible obesity.

This could potentially save the lives of people living with PWS. It has proven to be safe and effective and is the only kind of treatment that could make a difference in so many lives. It is critical to get this on the market ASAP!!!

It means a better possibility of weight loss for my son.

PWS is a devastating, dangerous disease. DCCR could mean the difference between life and death for people with PWS can literally eat themselves to death and they cannot learn to control their food urges.

It will mean a lot.

Improved life outcomes

It would change his life!!

The change to live life normally, like my other children. That means the chance to live alone, not in a group home, not with kitchen cabinets locked. Hyperphagia is a death sentence to my daughter's life and independence. Please help us beat this. There is no other drug available to help her or others with PWS.

Health and life

It would mean although we are currently in an excruciating struggle, battling behavior with little help, would change. Nobody can understand how hard it is living with a child with PWS except those living with it. Please help us.

This drug would likely remove, or at least reduce, the LARGEST roadblock to my son living a happy and independent life. It would be lifechanging for our family.

Eliminate the most significant challenges of this disorder. Improve quality of life for my daughter and family as a whole.

What would an approval of DCCR mean for your loved one and your family?

It would mean a better quality of life, a peace of mind, and feeling of hope.

A chance at a treatment/more normal life. A chance at embracing every day with optimism instead of fear and worry.

The potential for health and happiness.

It would mean he could live a better life with less problems

Everything! We would be able to live a happier life!

opportunity

Life

My daughter is three and already showing signs on hyperphagia; this affects behavior, relationships and her education. By having DCCR as an option for my child she could have the potential to live a happy FULL life.

Results that can occur when using this medicine could include being in a normal education setting, not requiring one-on-one supervision from childhood to adulthood, and the ability to live independently and support oneself through an education and career.

I believe this would save my son's life and also give him opportunities to enjoy more activities that he is currently restricted from due to his size.

Happy, healthy future for our son

Insatiable. Hunger. I want you to take a moment and make sure you understand what those words mean. You wake up in the morning and experience a dull ache, a nonspecific emptiness, a feeling, in the middle of your body, directly beneath the bottom of your rib cage. The feeling is located precisely in the center of your solar plexus, just a few inches above your belly button. It is deep inside of you. It originates from the very core of your being. It is ancient. You get up and you begin to walk. Where are you going? We all know where you are going. You are not thinking about it. You just do it. You ambulate to your kitchen and stuff something in your mouth. You are thinking about the day ahead. Maybe a bite of Danish, a strawberry, a doughnut, a cookie, something to tide you over while you start your coffee. You've been unconsciously motivated to engage in these behaviors and have been rewarded with the silent unnoticeable removal of the feeling. Coffee in hand, you have already forgotten about it. You are deciding what you are going to wear today. You continue your routine with a barely noticeable uptick in your

mood. Today is a new day, it could be a good day. With lifted spirits you go and prepare for this new day. You've been silently rewarded again. You will eat your breakfast, clean up, finish at home, and depart. You head out into the potential of the morning. Mornings. You just love mornings. That crisp fresh feeling. That new feeling. That's a good feeling. You wish you could always feel this way. That's what it is to be satisfied. Now understand this. You will never have that again. Never. No matter what you do. No matter where you go. No matter what you eat. No matter what you drink. Nothing. Nothing will ever bring you that feeling again. You will cry. You will scream. You will rage. You will beat yourself into the fever oblivion of fatigued and neurotransmitter-depleted sleep. Only, to wake again, to gut-wrenching gnawing emptiness. You will lie. You will steal. You will gorge yourself on whatever you can get your shaking panic infested hands on. You will collapse in your misery with a moment's respite. You are already feeling anxiety begin to mount as you sense it, muted but still there. It is already starting again. You weep, shuddering, on the floor. You see yourself. What you have done cannot be hidden and you are discovered. You are disgusting. And this will happen again and again and again and again. You will hate. You will hate your mother. You will hate your father. You will hate them. Because they stop you. Why? They keep it away from you. Do they not understand I need it? They lock it up. You will hate yourself. You will hate life itself. You will want to die, and that same instinct for survival, run amok, which creates this hell, will stubbornly keep you in it, forever. It's a terrible fate isn't it? Yes, but the FDA can do something to remedy it.. I urge the FDA to reconsider their decision regarding DCCR and to do what is right and help to mitigate this suffering. Now.

A chance at a better quality of life for my son, but also our entire family.

DCCR would provide better muscle tone and function for those with PWS

It would mean living life full. It could mean giving relief from the constant hunger, the worries about eating so much she dies. It would mean greater independence for her. It is a life saving medication.

That my daughter might not feel hungry all the time-this would help so much with her weight challenges

A chance for my son to have a brighter future, which is everything to me.

DCCR is the best hope for my beloved daughter. It is critical to keep her alive. Please get this approved

It would give my son a chance to live a normal life. Not having to worry about food, when and where is his next meal. The behavior issues would be under control. I would not have to worry about hitting, screaming, and sneaking food.

It would save the life of my 4 year old grandson. It would allow him to live a fuller life without the burden of the constant insatiable hunger associated with PWS. Being able to help control his hunger would change our families entire world.

I am a father of a UPD PWS child. It would completely changed how we live. We are RULED by PWS and hunger every day, nearly all day. Going out anywhere is not just difficult with a child with PWS, the hunger makes it nearly impossible to function as a family in a normal context. We routinely choose to avoid joining friends and family at special occasions due to the context of dealing with outbursts. We deal with PTSD associated with our daughters birth, and this can manifest itself at these times. This all sounds dramatic, but I assure you I was just like anyone else. I love my daughter dearly, and I would not choose to replace her or lose her. A drug like DCCR could make our ability to cope with living with June's PWS in a much improved context and possibly allow June some context of normalcy in her developing life. If we could get a prescription for DCCR tomorrow based on my research to date of the trials, we would. Please allow us this option as soon as possible if this drug had not been shown to be negative in the context of patient health outcomes associated with it's

An approval would mean the world to us. The drug is our only hope right now that our son won't have to live always hungry.

The chance for a more normal life.

A better quality of life for our child.

Help make my 4yr daughter live a more normal life without all of these complications she cant control herself and for every person living with PWS. They deserve a chance at a great life as any normal able body.

They would have their life back. Their child could be a little girl again.

Freedom

What would an approval of DCCR mean for your loved one and your family?

The chance for my daughter to reach her potential without having to experience the debilitating and life-threatening symptom of hyperphagia. And a chance at an independent life

With DCCR my daughter would have a real and meaningful opportunity to reach her full potential without ever having to experience the debilitating symptom of hyperphagia. An approval of this drug would mean an improved quality of life and a chance at independence.

A treatment that can help with the biggest Issue with PWS and help our kids have a higher quality of life

The world.

So much, just to give Maddy a chance of a life that we I take for granted.

Some relief from the near constant hunger pains and the anxiety over food because she feels hungry all the time.

Although my Adult PWS Son is not on DCCR, this Investigation might-well help our Younger (rare)PWS Population, so the Study should be Completed....

Everything

DCCR would literally save his life. It would ensure an independent future for him, which he and all children deserve. His future would amount to more than uncontrollable hunger. This drug is absolutely essential for his well being.

Everything, a chance at life.

She gets to live a more normalized life ... like we all would like for any of our children. Specifically, when it comes to body mass & the effects it will have on her for the rest of her life.

Independent and healthy life for the future.

There is a way to provide an early approval before a trial is even complete but this one is complete and has shown great success for this disease. It needs to be approved so those with this disease can be treated! It's not about money but about lives

Not having to ever know what hyperphagia feels like and endure the suffering and turmoil of it

A better future for my child

Everything! This is the only drug that has shown a real promise in being safe and effective as a treatment for the most debilitating, and potentially deadly, symptom of Prader-Willi Syndrome. We simply cannot wait. We need approval on this drug ASAP.

A better quality of life

Catherine is a vivacious & loving smart girl. This medication would help give her the life she deserves & would help her tremendously. Please reconsider the application & approve this drug for her & so many others. She needs this medication. Please approve!

Life changing fir those living with PWS

It would mean the chance of life to more than one child I know!

Potential lifesaving treatment

Freedom from locking ALL food sources

Ability to meet some of the most challenging medical needs of my son and to advocate more effectively for his care.

The potential to live a more fulfilling life.

More chance for independent living

Increased employment opportunities and community integration. Possibly the ability to live independently!!!!

It would mean less worries and more time to love my daughter

Even though my daughter is only 3, she has such an increased interest in food. It is a constant source of stress not just for her and me, but our entire family.

It would mean a less restrictive lifestyle

Greater freedom and flexibility. Less tantrums around food.

It would mean a chance at a typical life without constant hunger and constant stress. It would mean potentially a future without having to always have someone else present to make sure good decisions were being made.

We have been waiting for the opportunity to give DCCR to our daughter, in hopes of the many ways it will support her in realizing her full potential. We wanted to participate in a trial, and are also hoping for the opportunity to do so.

A little relief to a stressful life of my sister who we,Äôve had a tough time taking care of her as we,Äôve always had to watch her and what she eats as she,Äôs never been able to be alone around food everything we have is locked up

Treatment options are severely limited. DCCR could save the life of son and others and increase their quality of life. We can,Äôt wait years for DCCR. We need it now.

It would mean an independent future for my son could be a reality.

A better life

Help and a better life quality

Hope

Having control over the hunger would allow my child to engage with many more activities.

It would mean a better life for a person with PWS. I have heard so many times from PWS individuals they just want to feel normal

Health

It could mean saving lives at a minimum. At a maximum, it could be giving child a more independent life that we all enjoy. Imagine a life without independence in some form. Approval will help to limit that outcome.

Some relief from the hyperphagia, and subsequently his anxiety and temper, would be a blessing for both my son and the rest of our family.

A chance for a "normal" life

A piece of the puzzle to help with a complicated, devastating syndrome.

A chance for my son to live as normal of a life as possible.

It would allow us so much freedom! You have no idea how difficult it is to attend ANY function...almost all involve food of some type and this drug would help Silas be able to enjoy the things that most others don't even think about.

Everything would change, I'd feel more secure about food, I would worry less about the health and safety of my son.

Our daughter could focus on things other than food more successfully and would be at less risk

What would an approval of DCCR mean for your loved one and your family?

of dying from a food related incident such as stomach rupture, etc.

Everything

A life of independence for our daughter! Truly, there is nothing more important to us than the chance to give her a full and independent life.

lifesaving to the family as it provides relief to all mentally and physically.

Life changing!

Better health for my child

DCCR will help with the major effects of PWS and help our daughter as well as many others live a better life.

Improved quality of life for my son and a brighter future. For my family, peace of mind

All advances made provide a life changing option for those with PWS and their families.

If given the option, this could help my loved one function better on a daily basis.

Everything. Giving our children a chance to live as full of a life as possible

It would mean that my son would have the opportunity to live a more "normal" life

A healthier life with less risk of life threatening issues as he grows older. It would allow him to mainstream into the world and develop the skills that would result in a productive life.

Hope, freedom, opportunity

The opportunity to live an improved quality of life, perhaps independently of adult care. It would impact our entire family. It would mean our loved one would not experience the devastating impacts of Hyperphagia. This would be life-changing for his entire family.

The World. My Nephew deserves every chance at an improved life and we believe DCCR will have a great impact to all PWS kids.

A more productive life.

Our two adopted daughters have PWS. Our oldest, Chloe, has reached the hyperphagia phase and is food seeking. If we were to have medicine to help her manage that, it would ease so make of her anxiety and I as a caregiver

would feel more at ease knowing she was able to manage her eating and weight. She also struggles with outbursts frequently and being able to have more self-regulation would help us enjoy our day to day activities and perhaps enjoy more activities out in the community.

Self regulation of behavior

A more normal life with less pressure from being different.

It would mean a treatment plan that has already been approved that can be accessible in a timely manner because it is crucial to those with PWS.

Life saving

A chance at a dramatically better future, in which my son could hold a job, live alone, and have friends, with no drawbacks if it turned out not to help with hyperphagia.

We are terrified of the disease that our new born was born with, and even more yet, what the hyperphagia symptoms will do to our son in the future. If we have any chance at all, to head it off, or treat it; we have to take it. Please don't take this chance from us!

Initially, to aid in research opportunities, and ultimately, to create a better life for our PWS child

A greater chance at our best life possible!

My daughter would finally feel full and we would not spend hours a day with meltdowns and aggressive behaviors over food. She would be able to live a happier life that isn't controlled by food

Change their life dramatically!

A life not ruled by pws

Hope, progress

Independence, not having to rely on someone else to keep them safe, feeling joy that they are not perceived as different anymore

Life changing relief from catastrophic symptoms

It would mean the world! This is life changing. It could help with so many aspects of Jayde's day to day life and gives us hope for our future.

The relief that my son can live a safer, more normal life. It would mean everything!!!!

a more manageable life.

It would mean everything it would help see a light at the end of the tunnel and hope for a better tomorrow

Treatment like this for Prader-Willi Syndrome is a veritable life saver! Life without viable treatment options for individuals with the syndrome are as bad or worse than the world in a COVID pandemic has felt, but it goes on year by year without the hope or support that the vaccine's bring. Please review and allow reasonable treatments for Prader-Willi Syndrome.

Improved quality of life

Relief. Our son struggles sooooo much with constant feelings of hunger - every waking moment of his life. PLEASE do not require yet another trial.

Please review and allow DCCR for treatment. An option like this is a real life saver for our kids with Prader-Willi Syndrome and for us as parents and caregivers. We desperately need options!

This Would significantly improve the quality of her life, if not potentially save her life, as well as improve the quality of live of our family.

As a mom of TWO children with PWS, I beg that the FDA re-review the results of Soleno's Phase 3 study of DCCR for the treatment of PWS. There is currently NO treatments the most challenging aspects of PWS and requesting an additional study would cost cost our community years, or worse, the loss of a potential treatment for our loved one. We need this drug available now! It was super safe in the trial and has been the only effective drug for this large unmet medical need and it should be available for our kids who have no other options for possible treatments for hyperphagia right now!

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What would an approval of DCCR mean for your loved one and your family?

Any drug that gives our children with PWS a chance at a better and more fulfilled life would be so welcome.

Having some sense of Normalcy. Not having to worry wherever we go what to do about hyperphagia, help control weight and some of behavioral issues that come with hyperphagia.

Possibility of making our life a little more normal.

This drug has been such an improvement in our daughter and we consider it a life saver. She can be left alone and around food. She feels full and even misses snacks and leaves food at meals! In addition her body mass has greatly improved. Going off this drug will be a great disservice to her health and independence.

Hope for a more manageable and fulfilling future

Lifechanging

My son would not have outrageous because he is starving. Until you live with a child with pws you will never understand. Maybe the people making these decisions should spend a week in our shoes then you will pass this.

Approving DCCR would mean that my daughter may never struggle with the most debilitating aspect of her syndrome; hyperphagia. This would give her the opportunity to use her energy, mental capacity, and emotions on things like learning, playing, physical activities, and building relationships instead of focusing on when she gets food next. There isn't any other drug out there that provides this type of treatment and it would mean that our family would have the opportunity to have some semblance of normalcy in our lives. This drug is the ONE THING that could allow my daughter to LIVE LIFE FULL!

Hope for the future

Kimber is a smart, caring, and full-of-life toddler who unfortunately, has some incomprehensible obstacles in her future. This drug could provide her the support to tackle those obstacles head on. It would give her the opportunity to use her energy on things like learning, building relationships, doing physical activities, and overall just being a kid instead of constantly and overwhelmingly worrying about when her next meal is coming. Please reconsider your new restrictions on this lifechanging drug and help Kimber and her friends LIVE LIFE FULL!

Better medical treatments and options.

HELP and HOPE

An independent and fulfilling life for my child that may not otherwise happen

The possibility of an option to choose to potentially better my son utilizing the most recent technology and research.

A more normal life for both him and the rest of the family

As a father of a child with PWS, it is essential that I see everything that can be done is done. I see this as one if not the only viable treatment for the most major symptom of her disorder. Please bring this drug to market.

Having alternative pharmaceutical options would be a game changer.

Knowing that my child won't suffer from uncontrollable hunger and the mental strain of not understanding why she can't have it. Along with the mental pain watching your kid suffer.

The chance for my daughter to not suffer from the pains of hunger 24/7, the anxiety that comes with not being able to control her hunger, the chance to not suffer from obesity due to uncontrolled hunger, and the health consequences from obesity, including the possibility of death, and premature death, the opportunity to live a happy and fulfilling life free of this pain. For her family, the chance to not have to sit by and watch her suffer, not being able to help her. This takes a huge toll on the whole family, especially when we know there is a safe and effective treatment. We NEED this safe and effective drug. If this was your child, loved one, grandchild, niece, nephew, friend, and you had a chance to help them not suffer from a debilitating hunger. wouldn't you help them? Or could you sit by and watch them suffer, and possibly die? It's heartbreaking, and we want our daughter to be able to live a full and happy life, without hunger, anxiety, obesity, the struggle to just live day to day peacefully.

Better health and quality of life for my daughter, and peace of mind for us parents.

We got diagnosed at 5 months. Shortly after I learned about the trial being done. I was relieved because hyperphagia is the most nerve wracking part of this diagnosis. As a new mother I was so thankful that when/if we reach that stage that there would be something to help her. This is the only department I cant control and help with in the PWS world. Us mother's do everything in our power to ensure the best life for our children. We would move mountains if we could! Without this approval

you are taking that chance away from us not having that opportunity.

For people with this disease to live a better life

It could save my daughters life

It would mean an improved quality of life for our daughter. Reduction in anxiety, behavioral challenges related to food. Improved social relationships. Better ability to learn in school. For our family a much less stressful lifestyle with more relaxed rules and feeling about food and food control.

Life saving treatment for PWS!

It would greatly help our son

To change his life and give him a longer life

It would bring her closer to having a drug that might work for her as she still suffers from hyperplasia at 41 years old and it's impact on her life and well being

Reduced weight gain, some independence, and life saving therapy.

When I was given the diagnosis of my son I was devastated, faced with so many unknown for his future. DCCR would mean hope for us! It has the potential to eliminate obstacles that could prevent my son from living a full capable life. He is a warrior and deserves every opportunity to fulfill his dreams and I believe DCCR will help make that happen!

Everything! The possibility of a normalized life!!

A treatment / mitigation for the most restrictive and life-threatening component of PWS makes his mother and I very optimistic that we can provide the quality of life and potential future that all parents want for their children. My son is a happy and determined boy. We know that he can accomplish whatever he puts his focus toward - especially if the barriers of PWS are lessened or removed.

A chance at more normalcy.

A life of less stress, fear and anxiety for Jolie. A life where she doesn't have to spend her days dealing with the trauma of hyperplagia. Peace of mind and a life regained for this sweet little girl.

No hunger tantrums leading to a less restrictive life.

What would an approval of DCCR mean for your loved one and your family?

My 14 year old daughter is over 200 lbs. All she thinks about is eating. I'm wondering if this could help relieve the obsessive compulsion behaviors.

Could mean treatment and relief from effects of prader-willi

The treatment they need and a normal life for them. This is the only drug available that can allow a normal quality of life.

A life full of joy!!!

Better quality of life for my daughter. Ex. Not having constant hunger

enhanced quality of life

The opportunity to reduce or eliminate our daughter's hyperphagia. This will slow more independence for both her and the family.

It's vital for the quality of life and life-saving components it entails for individuals with PWS.

We need all the help we could receive to help with understanding of our love one, able a normal life journey.

Having more freedom as a family to be and do things in our community

This treatment can potentially save the life of my daughter and many others with PWS! It is the only viable treatment for the most major symptom of her disorder. It can save her life and many others! It is critical to get this drug out in the market now! Please!

Hope that the symptoms could be lessened, and she could live a life more like her sister and brother

Hopefully this would help with behaviors surrounding food.

Quality of life improvement

A full life!

It would mean the world to have a treatment that would stabilize the conditions of a PWS patient

A better life

Having met approval with the FDA would open a new life for people with Prader-Willi Syndrome. Hyperphagia consumes most of their thoughts, day and life. It would mean they will finally be able to live outside the prison of their uncontrollable need to satiate their NEVERENDING HUNGER. It would mean actually living, not consumed by thoughts of food and hunger. It would mean freedom. The constant fear of having your loved one with PWS dying from eating themselves to death. The emotional, mental and physical toll taken on those with PWS and their family, caregivers and medical community. A chance to thrive.

Hope

Improved quality of life for my son and our whole family.

Life saving and improved quality of lufe.

More manageable symptoms

Life saving

A better life. A more fulfilled life. No more hunting for food or excessive eating.

Would help with this treatment n save life's of PWS

Less anxiety in the entire family and more opportunities for our daughter with PWS.

A significant point of hope in managing this very difficult genetic syndrome and potential relief in some of the symptoms.

This medication is the difference between freedom and a life imprisoned by the limitations and triggers of PWS. Please reconsider. These medications could lead to greater freedom for individuals living with PWS, and ultimately lower costs for states in medical

There are so few treatments for children with PWS and NONE to deal with hyperphagia - one of the scariest symptoms of PWS. The insatiable hunger is not only heartbreaking for our child and it hard on our family trying to remember to keep all food locked down. A simple mistake of leaving a cabinet unlocked could lead to a lifethreatening situation. PLEASE for the sake of our beautiful daughter and the entire PWS family, review DCCR. Do not take this hope for some relief for our daughter from her struggle with hunger away from us.

A total life changer!! Our entire life is spent protecting our son from over eating. This is our #1 stressor in life and if a medication could mitigate this challenge, we would be overjoyed.

Independence for our son

It could potentially be the deciding factor in whether or not my son could live independently in the future. It could help my son live a near normal life.

Less diet restrictions, more social activities....

Personal health safety....

A chance for our daughter to live an independent life, to fulfill dreams that were once thought impossible.

a healthier and more full-filling life for my child

It would be a blessing

A chance at a life more like others, and not having to fight a constant battle within herself.

She can get the help she needs, my niece is my world.

The approval of DCCR would provide my daughter the first legitimate chance to avoid the painful, constant and never lessening feelings of starvation caused by hyperphagia. Not just feelings of hunger. Starvation. The approval of DCCR would mean that there is a possibility my daughter could lead a life free from 24 hour a day supervision. The kind of life that is available to most other people. The approval of DCCR would mean that my remaining children can live their own lives free from the worry that they may be called to care not only for their future families, but also for their sister. The approval of DCCR would mean that my husband and I could conceive of a time when we can live out our retirement years without the incredible emotional and mental burden of having to be " on guard" every second of every minute of every day in an attempt to keep my daughter safe from herself. To put it simply, the approval of DCCR means everything to my family.

This is a potentially lifesaving treatment and would allow for our family and child to have some peace and normalcy. This is the only drug shown as an effective treatment for this disorder.

A treatment for the most horrible part of this disease. It means hope for an independent future for Eden.

Freedom, normal life

A life style we are unaware of, how it could be; for him and his siblings and parents

What would an approval of DCCR mean for your loved one and your family?

We have been praying for DCCR as we know it has the potential to be life changing for our son, to slow for more independence and a higher quality of life.

Our nephew and his family's lives could be greatly improved with this medicine.

It would change my daughters life substantially! The suffering of feeling hungry every second would mean she can focus on other areas of life. She wouldn't be so angry and her behaviors would improve

The chance to prevent a lifetime of pain.

It would change all of my children's lives (child with PWS + her siblings. And I don't think it is over-reaching to say it would change my future grandchildren's lives as well. If my daughter's hyperphagia remains stable or continues to be manageable with DCCR, that will substantially ease the burden for her future caregivers.

Everything!

It would be life-changing, truly. Hyperphagia is the most significant and life-altering symptom of PWS and the symptom that all of us as parents fear the most. Since the day my son was diagnosed I have been looking forward with great hope for when DCCR becomes available for treatment. To have a drug that can treat the symptom of 24/7 hunger for my son would change everything for his future.

Everything. Absolutely everything. It can save lives

This would mean my daughter could live life full.

Some help and hope

A more normal and happy life.

It means my sweet little boy would not have to deal with the horrible hyperphagia that is lingering around the corner for him. It means he could live a full life not feeling like he is starving. Imagine your loved one always feeling hungry. It's horrible

Hunger and food seeking is one of the most limiting aspects of PWS. In fact, people with PWS MUST live and work in a food secure environment, in order for them to be safe. It truly is an issue of life or death A medication which curbs the food seeking would enable our PWS loved ones to live far more independently.

Making the PW children's life and lifestyle better.

Life changing and would greatly improve lifestyle and health of daughter.

It would provide my family an option with treating my daughter who has PWS. We need options to treat the major side effects of PWS such as hyperphagia.

Our community needs this NOW, lives are depending on it.

It would mean that the individual with this condition could have better quality of life over all. I believe a child should be able to live their life fully and without this drug it will be very hard for her to function in everyday scenarios.

It would give him the opportunity to live a productive & healthy life. It has shown to be safe and effective.

It would mean my son is one step closer to living life full!!! It means hope!

It would help my grandchild in suffering with insatiable hunger allowing him to focus on being a child and functioning normally in his life.

Help needed

Some hope that we can overcome the worst part of this disease PWS.

better quality of life for my son and of his extended family & friend who otherwise need to be hyper aware of his activities, diet and behaviors

Our endocrinologist needs as many tools in her tool belt as feasible to treat our daughter. This may mean INDEPENDENT living and/or improved behavior which impacts not only her life daily, but everyone she interacts with as well.

Норе

A chance for a life filled with less anxiety for all of us.

It could potentially save her life. Delaying the release of this medication by requiring further trials is a real disservice to so many who could benefit from this medication.

Peace

reduction in weight

Life

My daughter's life expectancy

Hopefully a better life! Could potentially be groundbreaking for the PWS community not only my son but many others. This could save lives. PWS is so scary we need all the treatment we can get!!

This approval would give us hope in a situation that can at times feel hopeless. The safety profile of this drug is very well understood and the risk of our loved ones trying the drug and having adverse reactions is so low. I don't understand the logic in denying it with the known safety profile of the drug. If the drug doesn't work then we as parents won't continue the use of the drug. Parents of loved ones with PWS face so many challenges and struggles and if one part of it can be eased then that is a huge win in our community. Something we have had very little of in the past, the ONLY approved treatment for PWS is growth hormone. To require another trial on this drug and delay it to our community is unacceptable. If you do this, you will be contributing to the mental health struggles of the parents and siblings of family members with PWS. This drug is the only hope currently for reducing hyperphagia and it can't be understated that delaying a drug with this safety profile would be a failure of the FDA in my opinion. We can't push this out any further our children need this NOW !!! Please reconsider your decision, our family can't wait any longer for this. You will never understand what it's like to have a child addicted to something that we can't deprive them of because food is something they need to live. My fear is that the cost of the trial will be so expensive that the company will not continue to pursue the drug. Please review this drug without another trial, you could be saving the life of a sibling who ends up with an eating disorder because of the damaging food habits, the marriage that could be destroyed because of PWS and the life of a child with PWS. PWS reaches so far beyond just the child it affects, it every aspect of our lives and our other children's lives.

Such a more positive and controlled life style.

Approval of DCCR would give our family and our loved one with PWS a safe and potentially powerful tool in combatting the hyperphagia that most people with PWS experience. There are so few options available for dealing with this life-threatening aspect of PWS.

It would give us the first medicine that addresses the issue of hyperphagia - a constant and intractable issue for persons with PWS. The need to control our son's access to food has impacted our whole family's way of life.

What would an approval of DCCR mean for your loved one and your family?

DCCR has the ability to put my daughter on a different life path. Currently without a drug like DCCR, my daughter faces a future that will be curtailed by hyperphagia, anxiety and other traits of Prader Willi Syndrome and prevent her living an independent life. DCCR will give my daughter the opportunity to live independently, and fulfill her potential without the shadow of hyperphagia hanging over her 24/7.

The opportunity to live her life free of constant hunger, obsession with food, and anxiety driven behaviors.

Possibly independence for our daughter.

Hope

It would help reduce the tremendous hunger drive and some of the behavior issues. It would potentially allow our son more freedom and reduce the stress on the family.

Hope. Hope for our daughter's health and future. Hope for a more inclusive, fulfilling life with possibilities. Today, we only strive for that hope. Soleno's DCCR can provide that incremental hope that is so needed.

This would mean hope for some "normal" in my little ones life. Normal is hard for our loved ones. Not only helping with hunger issues but also helps avoiding the other health conditions that come along with it.

A chance at an independent life.

A chance at living life to its fullest.

Hope for an effective treatment

Hope, better health, not feeling hungry. No on understands PWS as well as a parent. The toll this syndrome takes in on the entire family. We live in constant lock down of food, temper tantrums, doctors visits, constant supervision so she won't go steal food or take out if a garbage can. Yelling and screaming because she's hungry. Pain of clothes shopping to find clothes if tweens but she's overweight and can't wear those types of clothes. People don't want to be around her because she has no social skills and we don't as a family have friends nor do our family understand why she talks in a yelling tone. The list goes on and in. Please there is nothing out there to help people with PWS. This is the closest we have come to hope.

We have been participating in the trial and saw marked improvements in behavior and weight loss and reduced fat prior to Covid 19. Once all structure was taken away her hyperphagia went crazy. All the weight she had lost she put back on. We Need the opportunity to continue on this drug so our daughter can continue to live her best, healthiest life

Everything!! It means everything! This is a life changing drug for my son and our entire family!!

Hope and normalcy!

It would mean the world. Our community needs this drug. It's proven to be safe and effective. It's a chance for my child to live an independent life.

This drug would be life changing as it helps with one of the worst affects of PWS.

It would potentially be life changing due to the behaviors surrounding food seeking behaviors my son's life is very limited

It will be an extraordinary it approval.

It would mean the world to us as it would help manage one of the most debilitating symptoms of pws: insatiable hunger.

Opportunity for longevity

Any reduction in hyperphagia and behavioral difficulties would make life significantly easier for my daughter and her caregivers

This is the only life saving drug out there to help my loved one live a better and healthier life. It would mean the world to us and our child

It could potentially save a life

It would change his life and free us to enjoy life more.

Maybe some hope.

Hope for our children to live a life of not being hungry! And to not have this life threatening situation for our families our children would have a normal life and be happy!

This could potentially save lives!!!

Possibly being able to not lock our cabinets, fridge, and pantry. Living a life as close to a typical person as possible at least when it coming to food abs eating habits

It would greatly help her mental and physical well being

Hope for my grandson to have a more normal future with reduced risks from the effects of PWS

It would mean another tool in our arsenal to possible help our son in his life-long battle with PWS.

If effective in controlling hunger and hyperphagia it could result in a dramatic life change for my son and the entire family and social network. It would be hard to overestimate the impact.

Help so much with food seeking.

Everything

Hope

It would help my daughter can better control over life and would make her a healthier adult

A chance to minimize certain "symptoms" related to our child's diagnosis.

This approval means so much to my daughter and her future, and for us as her parents. Prader Willi Syndrome has so many symptoms the worst being hyperphagia, and if this drug can help my daughter to never have to feel that constant hunger, so that she can focus on learning, and growing. You cant focus on those things if you are always hungry. Jessa has 3 siblings that want her to grow up and do big things and affect lives and she needs this drug to do that. Please don't take that chance at a better life away from her.

a better life

Hope!

Our community needs this NOW, lives are depending on it.

That we could live life without the daily fear of losing our child to overeating which she cannot control.

Hope and less anxiety

Combat some of the most prolific health concerns for our son now and in the future.

We could combat some of the most prolific health concerns that face our son now and in his future.

A chance at a happier life for my son.

What would an approval of DCCR mean for your loved one and your family?

It would be life changing. My son would be able to live life without the constant hunger that plagues children with PWS. My son would be able to enjoy life.

At last there would be a drug to curb my son's insatiable appetite.

It would mean the world. We want our granddaughter to have a normal life.

It would give my lived one the ability to control her destructive behavior.

A chance for him to grow up and live a relatively healthy life.

Hope

To help to curb my daughters appetite would bring so much peace into our home! She deserves a chance to be more 'normal' and enjoy life, even if just a little. It is unbelievably difficult managing a PWS patient, and her limited understanding of the situation makes it even more challenging. PLEASE help make this drug available to our PWS family members, as soon as possible. We are willing to take the risk, so that our children may live a better, happier, and healthier life!

A step in the right direction to live a normalized lifestyle.

Freedom for our girl around food and typical anxieties that are bound to develop.

Much needed help

Our son does not experience severe hyperphagia, so at this time, this treatment is not needed for him. But for those who do struggle with severe hunger/appetite, there have been good results, and those individuals deserve the opportunity to be free from constant gnawing hunger.

Much needed help

Potential relief from debilitating symptoms caused by PWS

Improve his life quality

Less stress that my child will suffer.

My son is in high school so he is on the doorsteps of adulthood. He is a smart boy who has a ton of potential to be a productive member of society. Having a medication that helped him manage his PWS symptoms could be the difference between being able to take

college classes in person with peers and only studying at home online so that mom and dad can always keep an eye on him. When it is time for him to enter the workforce, an effective medication could the difference between being able to hold a job independently and only being able to work when closely supervised. When you also consider how many work programs for adults with disabilities focus on the food industry, the future work options for my son look really bleak without help from a medication like DCCR to help him manage his symptoms.

Life changing

A chance to function as a family.

Less stress better health

Freedom

Maybe a chance for a more normal life for my daughter and my entire family.

A more normal life!

A future without fear of starvation

Everything!

Could be lifesaving and definitely comfort providing for those who cannot quench the sensation of hunger due to PWS.

If it controls his hunger EVERYTHING

HOPE for a more normal future

The only form of medication that can help test and control what he has.

QUALITY OF LIFE

Approval would mean a chance at treating the most life-altering symptom of prader willi syndrome and giving my daughter her biggest chance at tackling her biggest future obstacle in life.

We are so hopeful that DCCR treatment would revolutionize therapy and medication options for PWS. My son's quality of life would greatly increase if he never had to struggle with insatiable hunger.

Approval of DCCR means our son will have a chance. A chance at an undeterred education. A chance to live independently. A chance at a successful career. A chance to live life FULL!!

Change, COVID vaccine provided in less than a year get this one done...

My son Markus is limited from living his full potential in life by hyperphagia. He is so blessed to have not been affected by any other life threatening symptoms or co-occurring disorders of PWS however just this one requires him to live in a group home, in order to keep him alive. My son has participated in two other FDA studies, we're trying SO hard to do all we can to help ourselves and others. This treatment could potentially save the life of all of our loved ones with PWS. It is critical to so many families to get this drug on the market as soon as possible!

Treatment for hunger pains and ability to better control weight and wellbeing for people with PWS

Living a better life

Life changing medication for those living with PWS

It would help my daughter deal with the struggle PWS is going to have on her

This treatment could potentially save the life of our loved one with pws.

Hope for a normal life

A chance of normal human life!

A quality of life worth living.

It will be very helpful in the future.

A sigh of relief for my baby

Freedom.

Help with behavior and eating disorder.

It gives our family hope that our daughter could have a normal life. That she would not have to struggle as much.

This drug would give our daughter a hope for a normal life.

Potential lifesaving and quality of life for my daughter.

This is the only viable treatment for the most life threatening symptom of our daughter's very complicated disorder. It could add years to her life.

What would an approval of DCCR mean for your loved one and your family?

Approval for the first treatment to for the most challenging symptoms of PWS would be life changing for my child and our whole community as we currently have no treatments.

Life changing

Hope

It can save my kids life.

A better life

Greatly improve his quality of life

Better care for my child.

A light forward for children that struggle to move through simple daily tasks, and time spent with loved ones, without the soulcrushing desire to eat. Why wait on "safe" and "effective" drugs if we can give even some of these children a chance to focus on things we take for granted.

A treatment for PWS would be life changing for my son. Currently, he tries to eat himself into a coma. With treatment, he could potentially live an actual life not revolving around food!

It would give a treatment for their constant hunger. There is currently nothing else on the market that does this.

It would be life changing. Our PWS kids and adults could live a fulfilling life. It's so very important for all.

This treatment could potentially save the life of

My little guy could Live Life FULL. It is my goal that he will never have to feel like he,Äôs starving. With DCCR, that would be possible.

The possibility of living life independently, as well as not having a permanent feeling of hunger

It might have helped her from becoming morbidly obese and eventually dying from the syndrome.

It would be life changing for our Milo

Living every day easier

A greater sense if normalcy

A better future for my child and family. The possibility of my child being freed from the

slavery of being obsessed with food. Hope that finally something could ease his daily struggle

It would be a life saving treatment for our loved one

Hopefully improved quality of life for my child and the family.

A healthy life

The chance at a normal life! The chance to live and love like the rest of us. The world is hard enough without having PWS, why would we continue to knowingly make it harder when there is a treatment like this available?

A better and fuller life without the damaging affects of pws

This would help him live a fuller life physically and his overall behavior.

It would give Paxton a chance at more typical childhood and life. There are no drugs available today to treat what we know is coming. As parents we want and need to at least have a drug available that we can choose to give him. Without the fda reconsidering their denial of the NDA, it takes from parents the opportunity to made that decision.

We would him to take it to help control his appetite as well as social development.

HOPE. Right now as a parent I have nothing to offer him. We have no choice but to wait to watch him struggle. Knowing this was working it's way down the pipeline is what offered us hope these past couple years.

This could be life changing for a person with PWS. This is the only drug addressing such a horrible part of the disease. Please approve this.

An approval of DCCR would give us the "security" to know that our son could live a decent life, full...This would include living a life as normal as possible when at home, attending school, going to family functions, etc. Without DCCR, we have nothing other than locks on cabinets and the unknowns of a rare disease that could kill our son.

A complete change of life style that would prevent premature death, allow for participation in society AND reduce the cost of care by hundreds of thousands.

Immense pain and suffering would be alleviated and quality of life would improve

independent good quality of life

Independent life and better quality of life

The ability to keep our child safe. Keep him at home instead of a group home and some stability in our family.

It could change the quality of life for many PWS individuals.

Greater opportunity, better life

It could potentially save the life of my son who has PWS. It is the only treatment for the major symptoms of this disorder. It could save his life so please get this drug in the market ASAP. I WOULD LOVE FOR HIM TO BE ABLE TO TAKE THE MED AT THE POSSIBILITY OF NOT HAVING CONSTNST FEELINGS. OF HUNGER

It would mean a chance at some sense of normalcy.

After 22 years of constantly battling feelings of hunger and spending her waking moments obsessing over food, our daughter could live a fuller, richer life. She could enjoy everyday activities without worrying about her next mealtime. She could stop feeling isolated as she does now, when she can't even do something as simple as eating out with friends.

Better Quality of life

Improvement in quality of life. Possible additional independence.

It would, quite literally, change the course of my daughter, Äôs entire hunger-driven life.

That I could leave him with others for periods of time.

It would be equity in access. My sister has PWS, and it is a challenging syndrome to live with, both for herself and those around her. Any opportunities to improve her wellbeing should be accessible.

Improved quality of life

Supports getting a drug to a patient with unmet medical need and supporting a foundation for additional research be supported to get better drugs to patients with PWS

After reading the study data I am confident this drug will significantly reduce his anxiety and compulsive aggressive behavior. It would improve the quality of life for him and our family

What would an approval of DCCR mean for your loved one and your family?

Better care and health

It would mean my daughter can have a "normal" life!! It would allow her to eventually live independently, manage her own health and keep her safe.

Hyperphagia is a devastating disorder that affects families and caregivers of PWS children.

It would mean a fuller and safer life for my daughter

A control of my daughter's anxiety. An ability for her to have more control over her actions. An opportunity for our family to come closer to being "normal". My other children not being embarrassed because my daughter with PWS gets upset or ruins a meal or an event or has an outburst in front of others. A chance for my daughter with PWS to not always feel like she has no control, but that she can control what is happening to her. An ability for my husband and I to have some semblance of sanity in our daily struggle with PWS.

Everything! Our daughter has much better behavior, much less anxiety, and the ability to do school because she is not consumed by anxiety and wanting food. We NEED this medication!

Our 33 year old son has lived every day with unrelenting hunger. Behavioral issues have disrupted his and our lives. DCCR presents the first chance ever to help these issues, and with a medicine that will not ham him. Please approve

Life changing. Our son has PWS, and has the constant hunger of PWS along with behavioral issues, at times becoming destructive, lashing out verbally or physically. There is no treatment. His mom has stage 4 breast cancer, and DCCR would give a chance for some peace for her and our family.

Possible independent future. FULLness, healthier future, feeling of content. Control over self, it would mean so much and is our biggest hope for him and others like him

It would mean a better path for my daughter, hope that she'll be able lead whichever life she chooses. Our PWS community needs it and the sooner our kids can begin treatment the greater the chances we have of getting ahead of hyperphagia.

A life less restricted.

DCCR addresses symptoms that no other medication covers. A medication that helps with hungry suppression vs having locks on all

the cabinets and fridge would be helpful for the PWS community!

life changing possibly

A more healthy child and less anxiety about his future.

It would ease the fear of my child may sneaking food and eating until her stomach ruptures. It would allow her a more peaceful day instead of worrying when her next snack is or her next meal. It would allow her more restful nights instead of wandering the halls, checking the fridge, the locks on the trash cans or the garage in search of food. It would allow her to function in a more normal capacity because the desire for food wouldn't be there. It would allow family peace to function as a more typical family instead of having to plan outings around snacks and meals because we have to prevent the tantrums and melt downs.

Freedom, hope, life changing opportunity to not have a child with anxiety and continued health complications.

Improved quality of life

Freedom in ALL ways

Help with the most significant issue our grandson deals with, insatiable hunger. Having treatment options available to deal with this will improve the likelihood of being able to exist on his own some day. We need options like this for PWS patients!

Healthier longer life

It could potentially save the life of my daughter. There is no other medication out there like it. It needs to be approved.

Total game change to have a child who wasn't hungry

A full life. Ability to life with out others to support him

Future options for treatment of the main symptom of PWS. To date, there is no approved treatment for the hyperphagia that is present and quality of life altering for those with PWS.

Норе

Greater freedom in life, navigating around food, and a decrease in unwanted behaviors triggered by food or a lack thereof.

Freedom!! Freedom to live!!

We would be happy.

I believe this treatment could help improve the lives of those with PWS. DCCR has been shown to be safe, effective, and is currently the only viable treatment for the most debilitating symptom of PWS. It is not an overstatement to say that DCCR can save lives! It is critical to this community to gain access to this drug as soon as possible!

Our daughter could potentially live life full! Our family wouldn't have to go through the struggles of her always being hungry and the guilt of having to tell her no when she doesn't understand why her body is different than ours. She could be healthy, happy and not experience some of the pains her disorder is known for!

Hope. Hope for a better quality of life for Logan.

I strictly monitor my daughters food in take. Having a drug that will help with the hyperphagia is a god send. It would mean that I will still have to worry but not as much.. It gives my child more freedom. It allows me to ease up a little. It means that I am not the mean one. It means that I am not "that parent" at the school who the teachers and admin despise because i hold all of them accountable every minute of every day that she is on campus. It means peace of mind for me to not have to be "that parent" and "that mean mom" who makes the rules and makes sure that they are always followed. PWS parents need a break too.

A new med which can be given to my "child" to improve his life!

Freedom from constant hunger and anxiety

It would be life-changing and potentially lifesaving.

Peace of mind, having my child present and not stuck with her perseveration, anxiety, etc.

Everything. Quality of life improvement for my child and an opportunity for one day to him to be independent.

It would mean the chance for a normal life. In many cases, patients on DCCR are finishing school, working, driving, and enjoying social events for the first time in their lives. The idea that the FDA may take away any chance of my son receiving this life-changing drug is infuriating to me.

Safety, piece of mind, and overall health. This is priceless.

What would an approval of DCCR mean for your loved one and your family?

Our daughter works very diligently to maintain a good weight. All the extra work studying she must do, leaves little time for rigorous exercise. She wants peers to feel she looks good and is like them

It could change our daily stress and anxiety over behavior. It could help us travel and actually leave our house. It could change how we participate in our community, neighborhood, and our other adult children.

Everything in the world. This drug is the next step closer to allowing to live a full independent life. This drug is needed for thousands of people right now. We do not have time for another trail.

This medication could be the future for us. It could potentially save my Child's and others with PWS lives. We want what's best for our children and if its a medication, then that's what we need! Please reconsider this drug!

Improve quality of life

a chance

Life changing for our son

Норе

DCCR is a life saving medication!

After suffering with Prader-Willi Syndrome for 41 years, this medication has the potential to greatly improve the health and quality of life for our daughter.

Improved body composition, reduced hunger and improved behavior

Not struggling with being hungry at all times and maybe being able to manage weight better

Everything to us

It would mean the absolute world to my family if DCCR was approved. I don't want my child with PWS to have to experience hyperphagia. Just imagine having to live hungry for the rest of your life.... Now, imagine being 8 years old and having a long life ahead of you. But you never feel full. A drug like this could help immensely!

To save her life! And to surpass this painful experience

Peace. Right now the seeking of food constantly comes with anxiety. That anxiety is turned into uncontrollable meltdowns. This drug could save

the lives of our loved ones. Along with the added benefit of peace within our family. Everything we do revolves around our child with PWS because they can not control their hunger. All comes down to the hypothalamus.

A chance for a normal life. Independence instead of lifelong dependence for my son. Freedom. Less anxiety, less aggression, less fear. A NORMAL LIFE

It would be life changing!! The approval of this drug would mean that our son would not feel as if he were always starving! It would also help relieve anxiety around food and other social situations. In full, this medication could mean the difference between a life of food seeking, obesity, anxiety and depression or not.

This drug has the potential to save my child's life from this cruel disease.

Another tool to help us deal with the many many affects on my son caused by this genetic condition.

More options for treatment for my son, treatment that could change our lives for the better.

Nic is a smart kind and loving little boy. He is in the 4th grand and struggles to keep up with his "typical" peers. He has many struggles that he is trying very hard to overcome such as: His constant hunger for food/ and food seeking, he has some outbursts that can cause damage to things and people around him, ect. His family and doctors believe that DCCR is one key that could unlock his future. Please reconsider their application and give PWS kids and their families this much needed medication.

Hope, peace, love, less worry

Our son will continue to live life feeling full and no more hunger with the ongoing treatment of DCCR

My son has PWS, and over the last year we have been seeing an increase in food seeking, and behaviors related to food. Because of this, our son is only able to think about food in instances where a typical child could focus on play, school, and social relationships. The approval of DCCR would mean that we could have a treatment for the food related behaviors so that our son could live free of the burden of hyperphagia and enjoy just being a child.

It could relieve some of the day to day suffering they experience of insatiable hunger

Everything!

A treatment option

John is a sweet little guy who loves to learn. By having access to DCCR, we believe it would significantly improve his quality of life and for the ones who he interacts with on daily basis. It will be difference between day and night. It will also help him to pursue his dreams by taking away some of the obstacles out of the way.

Potentially avoiding the unrelenting hunger and emotional trauma associated with hyperphagia--never feeling full.

A chance at a normal life

Life saving to this child

Good option

Behaviors would decrease and being able to live a more fuller life would increase.

An approval would give us great hope for our daughter. Hope that she can live a long, happy life. She was dealt a hand we cannot take away. However, with a treatment to lessen the symptoms of PWS, she wouldn't have as many obstacles to face each an every day. This approval would mean the world to us!

A longer healthier lifespan. More time to enjoy precious moments making memories

life changing.

It would mean I don't have to worry about how much pain he's in and restraint he needs to have at such a young age.

It would mean help with the worst effects of Prader-Willi Syndrome including aggressive and destructive behaviors. All children deserve a chance at a more normal future.

Hopefully would help in their behavior & reduce egocentric reactions constantly.

Peace of mind of managing hyperphagia

It would mean that he might never feel the affects of hyperphagia.

Since our son is not quite 3 years old, he does not experience hyperphagia yet. But he is already showing an increased interest in food compared to his neuro-typical peers, and it is only a couple of years until his appetite will become insatiable. We are terrified of this prospect and the challenges it will bring to him and our family. We are hopeful that DCCR will be available for use in PWS before our son

What would an approval of DCCR mean for your loved one and your family?

reaches the stage of hyperphagia - that he will never have to endure the unrelenting hunger or the extreme food-related anxiety that accompanies it. With DCCR, our son will have the ability to reach his full potential in life and won't be held back cognitively and socially by hyperphagia.

Complete and utter detriment to the life and success of one of my students and her family.

DCCR would give hope for my child with PWS as the hunger aspect of the disorder is the most challenging. We need DCCR for the best life for the PWS kids.

Some hope for an unknown future

a more normal life...locked fridge, pantry and all edibles are locked opening and closing each every time in AND OUT OF ANY FOOD SUBSTANCE location is critical.

An answer to our prayers. Our girl is the light of our loves and this therapy could give her an unprecedented chance at a real and free life.

Life without limits

It would be life changing of my daughter.
Provide her the opportunity to do as other kids
her age do both now and when she gets older.

A better quality of life for our son, Brock. Healthier, happier...

This treatment could potentially save the life of

A treatment, finally

Better future and quality of life for my son, treating the hunger and other effect of PWS would mean the world to us

Control of appetite and behavior

Piece of mind and healthier life

A life of independence for our child and the joy of seeing her living a normal life

An improved quality of life

This would mean so much to me and my family . It's has been a difficult Journey for us . My daughter was diagnosed at the age of 5 yrs old. She just started growth hormone treatment a yr ago April 2021 would be a full yr. she is 9 now and so full of life. That's just two-three pieces to our puzzle. So just imagine my daughter's Heath condition. To have approval would help not just my daughter but to many

families. It just Makes me so frustrated and sad knowing it's not enough PWS awareness. Numerous times I had to explain to Medical physicians (Dr. Nurses. Specialist .etc. what is PWS. We need HELP and it's needed. I want my daughter to live a full and healthy life . Please..

This could potentially save his life and others like him. It's imperative that this drug get approved and on the market ASAP.

A better life for my daughter. Can you imagine our poor children feeling hungry 24hours a day. Put yourself in there shoes. How do you feel when you super hungry and simply don't have time to eat, hangry, frustrating, pain. Now think of when you finally get that stratified feeling of being full. Think of our PWS kiddos that do not get to know what that satisfaction feels like. Please reconsider.

This will mean a better life for my baby girl. Anything that will help with the hunger feeling will be amazing. Can you imagine going 24hrs 365 feeling hungry.

Treatment option for a disease which has none

Extremely important

It is a hope for my child.

Better quality of life.

Live life o the fullest

For our loved one: Improved developmental outcomes (socially, academically, physically, psychologically, and emotionally) when not plagued by symptoms such as hyperphagia and obsessive compulsive disorder. Social acceptance from peers, a sense of belonging, a chance at a normal life and independence. For our family: Reduced emotional and financial stress, fears about health problems, morbidity, behavioral issues, and long-term care in our eventual passing. More time to enjoy family outings, gatherings with friends and family, and celebrating typical life milestones.

It would mean that my loved one can live an independent, successful and comfortable life like any other child/adult. It would mean that my loved one can live a life that is not overshadowed by additional anxiety, behavioral issues, stress and hunger. This would allow my loved one to live a better life and enjoy life experiences like any other kid/adult.

My daughter died at 20 from gastric rupture while in a hospital. Had she lived, and had access to this drug to treat the hyperphagia, she may still be alive.

The possibility our son can live a more independent life.

A potential cure to a life long struggle with PWS for my son.

Aide my son in future struggles with excessive hunger.

Less mood swings, her life wouldn't be in danger from over eating, her quality of life would change

We want to make sure that all of our PWS Warriors live a full and independent life!

It would potentially mean better sleep and less anxiety, less stomach pain for my 9yo son. We also lost a 6yo son with PWS last year. We had HIGH hopes for DCCR to help his anxiety and pervasiveness around food and in other areas of his life. We know MANY of his PWS peers have similar struggles. They deserve this chance now, not years from now.

Possible more normal life

A great deal

To live normal w/o judgement from others that don't understand this condition.

A safe and independent future for our only son.

Hope! Imagine your child never feeling full!

It would be life changing not only for my son but for all you care for him.

My son was just diagnosed yesterday. This would mean the world for his future.

Could be life changing. My child is constantly hungry and therefore forages uncontrollably. This makes it very difficult to keep her in our home. Can you imagine living your life in constant hunger?

It would greatly improve quality of life for our daughter. To always feel hungry is a real challenge in every moment of the day and night for her and her loved ones.

So many life changing solutions

The approval of DCCR would mean HOPE for my daughter's future. It would mean my daughter could avoid challenges and give her a shot at a normal life.

What would an approval of DCCR mean for your loved one and your family?

The world! Our individuals need to this to lead happier and healthy lives. As well as potentially cute them

Less stress and anxiety

This drug can help eliminate some of the obstacles in her way of that dream. Her family and her doctors believe that DCCR is one key that could unlock her future. Please reconsider their application and give PWS kids and their families this medication.

Help her decrease her eating habits, help her improve her behavior skills, and make her overall - have a happier more productive life!!!!

DCCR is the only viable treatment for the most major symptoms of PWS. It can save lives and is critical to get this drug on the market as soon as possible. This drug could significantly improve the wellbeing of my friend with PWS as well as their family. Please reconsider all of the benefits that DCCR can result in.

The hunger. The food seeking. The constant supervision and anxiety around food. Huge strives for weight loss instead of being focused around every meal.

It means a lot to control the symptoms of PWS patients. We truly need it to proceed and all PWS patients can benefit from it after commercialized. Thank you so much!

Help people with Prader Willi Syndrome

Quality of life for our son!

A better life!

Hope for a better and more independent living conditions.

This could save her life and so many others.

A chance to help our son live a more normal and safer life

The PWS community has been "hungry for a cure" since Prader-Willi syndrome was first discovered. Our daughter has a BMI of 43, yes, 43! She has completed 3 Clinical Trials,, walks 4-5 miles a day, is on a strict diet, and the FDA doesn't want to review data on a Stage 3 Clinical Trial that has been proven effective? We are asking you to PLEASE review the Stage 3 data, just as you would ANY OTHER DRUG's performance, and PLEASE approve it. We do NOT want our daughter to die from a syndrome that the FDA can help prevent with your approval.

Could save lives!

PEACE OF MIND...KNOWING THAT WE ARE A GROUP IN NEED OF GOVERNMENT SUPPORTIN ALL SHAPES AND FORMS "MONEY INCLUDED"

This would be life changing! Our girl would have relief from everyday agony of feeling like she's starving and many other negative issues.

This could be a life-saving treatment for my son and for all individuals with Prader-Willi Syndrome!

Hope for my child to live with a significant increase in quality of life and one day living independently.

A chance to live a normalized life

The possibility of help in my child's never ending hunger. This kid never stops thinking about and asking about when his next food is whether it's a snack or meal or a piece of gum it consumes his life and therefore for ours. If this works it could be absolutely life-changing in a super positive way for my amazing wonderful kid

Hope for an independent life and a more typical childhood with friends and activities without the constant supervision of a parent. DCCR gives hope that my child will be more similar to his peers and that he can be safe while outside of the watchful eye of a parent. DCCR provides hope that my son will not have so many additional symptoms/issues because of the fact he has PWS

Less stress, more hope and opportunity

HOPE and a quality of life that everyone should be entitled to.

A healthy future

Please take a moment to google the outcome of PWS when not controlled by family. Morbid obesity. Death. Give our child a chance.

Her future might be easier for her then we think it will be at the moment

That families have options in treatment

The ability to live a life with higher quality and independence.

It could save the life of my loved one with PWS!!!

A longer quality of life for the younger ones and their families

Quality of life

a possibility for a more normal life in a community and a chance to spend more time with family.

It would mean freedom from obsessing about food all the time and freedom to relax and enjoy life Instead of feeling hungry alway

Hope

The approval of DCCR would mean that there is a possibility that my daughter with P.W.S. could go to school and be able to focus on school without the hyperphagia. At home it could mean a relief of stress for her that the hyperphagia can cause.

more freedom in experiences outside of home where we currently manage food

It would mean potentially saving the life of my son!

Better quality of life.

It would mean a somewhat normal life for my son

A chance at a normal life. This diagnosis has crushed every dream we had for our new baby and this would give us this dream back. He deserves a chance at a life that he was sent here to live.

The approval would mean that when my daughter starts food seeking or has meltdowns over food restrictions I would have options to make her life and my family's life a little easier.

DCCR is the only medication with potential to be available to those that need it soon. Not having any option to potentially help treat hyperphagia is unthinkable, even if it only helps some or has some side effects which are less devastating than hyperphagia.

Our child and our family's life would be transformed for the better. The data coming out has give us out first real hope for our daughter since the diagnosis.

It would be life changing for him. He'd have struggles but this could help in so many. We'd have more hope and he'd be able to have a more normal life.

What would an approval of DCCR mean for your loved one and your family?

Possibly saving the life of my loved one or another child/person dealing with pad.

This drug would help improve my son's behavior and the possibility that he could live independently when he graduates high school. Without it, we have no hope of him living independently.

Over 14 years ago, we received a diagnosis for our son of rare syndrome unknown to us. It was clear from the start that we would need to be vigilant in learning the complexities of this syndrome in great detail to ensure his safety and development. What was also striking was the lack of treatment options which left us little hope for his future. Never to be ones to stand idly by, we committed to being a part of the solution to advocate, fundraise for research and most importantly, participate in clinical trials for solutions to the hallmark symptom of PWS that is so limiting, hyperphagia. To date, our son had participated in 2 natural history studies, 3 behavioral studies, 1 eye tracking study, 1 weight study, 1 dental pulp study, 1 PATH for PWS study, and 2 drug trials. We are committed to our doing our part in providing researchers a willing study subject knowing that everything we learn about PWS is a step towards the future of independence in his life and an unshackling from the chains that tie him to a life of constant hyperphagia and surveillance by adults who monitor his every move every hour of the day to ensure he doesn't consume a quantity of food that would kill him. To say we are tired would be a pathetic attempt to describe how one feels after running a marathon. To say we would like solutions is a paltry vision of the overriding desire to have even just one solution that makes life simpler and freer for our son and for our family. The solution may not be perfect, but meaningful improvements can allow us to let up off the gas just a bit and breathe a bit easier knowing the danger has lessened. A review of this drug is what we ask. Those that have been participating in the trial can attest to their staunch belief that this drug has made meaningful differences in their lives. We want the same chance to have this change in the life of our son. I urge you to consider review of the medication for him, for us, and for every single person touched by PWS. It is time and we need help.

My daughter has pws. It will be hard for her as she gets older to always feel hungry. This medication has the potential to help her to not have to feel hungry all of the time or to eat so much that it could end her life. What if it were you?

Better quality of life for all family members, reduced suffering with hunger and behaviors for our loved one with PWS.

What a tremendous difference it will be to help him feel better

It would help to reduce stress for everyone, anxiety, and frustration. It would also improve the health of our daughter

A major change

Life saving! It has been tested to be safe and effective!!

Many blessings

It would help relieve Brody from the constant hunger which leads to behavior issues. It would bring more joy and less stress to our family!

Possibly help in keeping a healthy weight

Life changing

a better daily life and furture

It would be essential to my loved one for a fair way of life

This medication has the potential to significantly improve the life our son and our entire family.

With this drug our sweet Quinn would never have to experience the most debilitating side effects of PWS. The PWS community had been loud and clear, we WANT this. We want our loved ones to live their lives comfortably and happy.

Jocelyn is an amazing 8 year old girl with many hopes and dreams. She wants to be a doctor when she grows up. This medication could make that possible.

The world!

Happiness

Hope, extended life expectancy, options

Less anxiety and mental health issues; significantly improved quality of life for all of our family.

This would be transformative and life saving for our daughter!

EVERYTHING.

less OCD

Significant improvement in daily living

Life changing meds for our daughter with PWS. We have several friends of ours who are in the trial and doing so well. One Of them is 22 and she can now go to the mall with friends without the risks of eating herself to death. Please reconsider. PWS is one of the cruelest syndromes out there. Please help us.

we can have a normal life again

It would mean my daughter Grace would potentially live free from hunger pains.

The approval of DCCR would give us the ONLY option of helping our daughter with the debilitating and life threatening symptom of hunger. There is nothing available to treat our loved ones most devastating symptom. Please help us.

The ability to reduce the insatiable appetite in my son would reduce his suffering and thus the suffering that I go through as his mother.

Improved functioning in general. Less distraction / outbursts over food. Fewer discussions about when/what food will be available.

A better quality of life

That he is not taking about food all the time and for him to feel full

Removing the stress of our child binging to death

It would mean that my sister wouldn't be starving anymore. It would also take a huge weight off of our family's shoulders so we wouldn't have to worry about her relationship with food every time it's in the room.

The chance to not worry that with one slip up on my part as caregiver, she could overeat and die. A chance for my daughter to live a more independent life.

A chance at a more normal, less stressed life!

To be able to live independently without staff around the clock.

Help for the hunger and behavior aspects of PWS

Everything

Freedom for her and the parents/caregivers

More normal life

What would an approval of DCCR mean for your loved one and your family?

They would be able to live more of a normal life.

Perhaps save his life

A life changer

It would be life changing. The hyperphagia that this drug addresses is a debilitating aspect of Prader Willi Syndrome.

Any reduction in the unrelenting hunger and drive for food, would ease a huge burden on us both. It would also allow for weight loss, which is a never ending struggle.

A better control of the syndrome and anxiety and behavior issues related to it and an optimum quality of life for loved ones.

The options for her future change dramatically.

It would be life-changing as it would give our daughter a chance at having a more normal life.

It Would it be awesome for the family and my son.

My son receiving help for the severe day-to-day struggles he faces due to PWS

Happiness

A normal lifestyle and longevity of life.

It is so incredibly disappointing to hear the denial of approval of DCCR for individuals with PWS. This decision could not only cost time, that many do not have but potentially create the loss of treatment if a further trial can't be funded. There is NO current treatment for this debilitating aspect of hyperphagia in individuals with pws. So many are suffering NOW, unable to live full lives. They need help now, THEY ARE WORTH IT! My son is a beautiful, happy 3 year old... I never want to see the day where he is continuously hungry and unable to have the same independence as his peers. He deserves A VERY FULL LIFE free from the shackles on continuous hunger!!!

Our child is three years old and we don't ever want to see the day where he has to go every hour of the day feeling hungry and unable to live his life to the fullest. This approval would be life changing for both our son Owen as well as all others with PWS. Incredibly disappointed at the news that the FDA is not going to approve DCCR for individuals with PWS now No. approval could cost these individuals years (that they don't have) or even worse could lead to not having the funding to conduct another trial and completely miss out on this

desperately needed treatment. Could also cost lives period. There is currently NO treatment for the debilitating effects of hyperphagia for individuals with PWS Many are suffering, unable to lead filling lives due to the constant hunger they feel. They need help NOW, we can't wait. Their lives are worth it This should be an easy decision and will literally save lives.

EVERYTHING!!! This treatment can save the life of my nephew. It is extremely important

Better quality of life for my son.

Treatment options, currently not available

Maybe we could start to try and live a more normal life and our child could enjoy life and thrive instead of so much focus and outbursts about food

Having a one year old it's impossible to not be in awe each day of the infinite potential of the human spirit. My daughter is amazing and resilient and I want her to have every opportunity to create the life she wants to lead. Any chance at supporting her to face less challenges, especially as unfathomable as constant hunger, is an opportunity she deserves.

Peace

She would not be on a constant hunt for food. She could build normal and healthier relations with people. Verses building a relationship with someone because of their lack of knowledge of her PWS in order to get food from them.

My child would be able to go throughout the day without the constant feeling of hunger. She would be able to focus in school, have some independence, feel less anxious. Our family will feel less stress and heartache. We will be able to live a "normal" life.

Hope

Independence for our child and the chance for him to feel full and less anxious

A chance to reduce life threatening symptoms of PWS. This is as important as it gets for helping this community.

While we are not currently experiencing the debilitating effects of hyperphagia we know this is a scary reality of our future that could change at any time. We need treatment options desperately yo allow our child the ability to live and independent and full life. This is only one aspect of PWS and unfortunately can be deadly for some. Having the ability to try

DCCR when the time comes would be invaluable. It was proven safe and effective for some - having this drug available will save lives.

It would save her life

She would be able, for the first time in her life, to go outside and play with her 5 siblings. She has not been clinically cleared to go out in public because of PWS, and this has caused a hardship on the entire family of not being able to do things most families take for granted.

Freedom from the type 2 diabetes she already has due to her hyperphagia. She can focus on things she wants to do instead of her hunger.

It could save the life of our little one. LIFE SAVED

Life saving

DCCR would be potentially life-saving for our daughter Ella as it is a safe treatment for dangerous symptoms such as hyperphagia and dangerous behaviors.

Improved health and overall quality of life

These individuals currently live in a structured group home together. This would dramatically change their daily living.

A better, more productive, happier life.

It could possibly save her life. She could possibly be able to live a normal life that she so desires.

It would mean that my daughter could live a closer to normal life. It would improve her quality of life as well as our family.

Would mean everything

This medication would provide hope for a better quality of life for my daughter and our family.

This is a life changing drug that would have a huge impact on my child's QUALITY OF LIFE!

A brighter future without the difficulties hyperphagia brings

We had such hope knowing DCCR might have been approved before we got to the hyperphagia phase. But, we are getting closer to it becoming our reality, and not having this medication means our daughter will know what it feels like to be constantly hungry. Our non verbal daughter will possible be screaming and

What would an approval of DCCR mean for your loved one and your family?

crying from this feeling. But, DCCR was our hope we needed, and we need it. Hyperphagia is life threatening. We need this medication now.

This treatment could change the life's of dose with PWS.DCCR has been shown to be safe, effective and is the only treatment for PWS.

This may save his life!!! Our son is only 8 and is just starting with some hunger issues. This scared me so much. He is already somewhat overweight, please help him.

It would give my daughter independence.

Treatment for the biggest concern for our daughter that would help the entire family. Me, my husband, and our 3 other children are always on watch for our daughter trying to protect her from acting on a basic instinct, hunger. It's heartbreaking to tell her she can't eat when she feels like she's starving. This could save her life. It could bring some normalcy to her in every aspect from home to school and give her a better quality of life. This is the treatment we've fundraisers for, prayed for, never knew was possible. This is a hope that we have and makes all the worried thoughts, sleepless nights, locked cabinets and refrigerators worth it. We've protected her the best we can but having this treatment to help her body react normally with food would be a dream come true for our entire family.

It could save my sons life and many others with pws.

Relief

A possible decrease in dangerous food seeking behaviors and aggressive behaviors. Increasing the quality of life for my special needs child and her siblings.

That my son would be able to lead a more normal life and be out in the community for a more normal job.

 $\label{eq:much less stress} \mbox{ In eating situations.}$

It has been shown to be safe and effective. It can save many lives so it should not be put off.

A lot less constant stress and worry about the food control. For my daughter personally a much better quality of life without constant 24/7 anxiety.

My son is diagnosed with a rare disease, that should not mean people with rare disease cannot aim to lead a normal life. Every human on the face of earth deserves a good healthy life irrespective of any disease. We cannot wait another long wait for more trials we need cure and we need the drugs to treat rare diseases. PWS affects 1 in 15000 births in USA and our kids deserve treatment.

It would help him live a more normal and fulfilling life

More independence. less stress, the possibility for an independent life

We need help with hyperphagia so that our Thomas, and others, can live life to their fullest and remain as healthy as possible.

Freedom

To give any chance possible to alleviate any pain by using dccr

Improved quality of life for him and for us

Independence. Less worry about PWS person dying or ending up in prison

This potentially lifesaving medication would become an integral component in the treatment and care of our son. One that could immeasurably change his quality of life by allowing him to thrive free of constant hunger.

Weight loss

Everything This can save and help my little love one and all the people with PWS

When behavior management is impossible, we need pharmaceutical options for treating the very challenging symptoms of PWS. Approval would mean one more option that might help improve the life of our son, and by extension our lives also.

DCCR would help control the constant drive for food my loved one experiences every day, all-day.

Better quality of life

It would mean a better quality of life and long life expectancy. It would mean potential independence for my son with PWS as he transitions into adulthood. It would give him the opportunity to pursue his dreams without the disruptions associated with his diagnosis.

The possibility of living a more independent and typical life--DCCR is the most promising chance to date to allow children with PWS to transition to a possibly independent life as they reach adulthood. Without it, they are undoubtedly

certainly required to live in a group home or at home indefinitely.

Hope!!

Happiness, improved family life with improved relationships, decreased supervision of child with PWS leading to increased independence and self-esteem.

Better chance of a longer life for our son

A better quality of life.

PWS was first diagnosed over 60 yrs ago. To date there is not a single treatment to help with the Hyperphagia that these poor children and adults deal with every day! It is absolutely appalling that there is a potential treatment that the FDA is halting for more testing when the testing has been done. If you had a child that was STARVING each and every day.......you would take the meds!! We have waited over 60 years! Don't make us wait any longer! Just because it's a rare syndrome these kids are worth receiving treatment! Please let them receive the help!!!!! Don't make them wait any longer.

A future

Better quality of life

DCCR needs to be FDA approved NOW. We do not need more trials, the research for DCCR has shown to be safe and effective treatment for debilitating symptoms of PWS. There are no ill effects for DCCR and it has shown to reduced Body fat and mass as well as reduce the uncontrollable hunger for PWS. This uncontrollable hunger can cause those with PWS to eat themselves to death. Cade (my 6 year old son with PWS) is currently not having any of these signs or symptoms, but it could happen at any day. It is not fair for him and others with PWS to live in fear of their hunger when it can be reduced and/or eliminated with DCCR. This is why it needs to be approved now with no other trials.

DCCR needs to be FDA approved NOW. We do not need more trials, the research for DCCR has shown to be safe and effective treatment for debilitating symptoms of PWS. There are no ill effects for DCCR and it has shown to reduced Body fat and mass as well as reduce the uncontrollable hunger for PWS. This uncontrollable hunger can cause those with PWS to eat themselves to death. Cade (my 6 year old son with PWS) is currently not having any of these signs or symptoms, but it could happen at any day. It is not fair for him and others with PWS to live in fear of their hunger when it can be reduced and/or eliminated with

What would an approval of DCCR mean for your loved one and your family?

DCCR. This is why it needs to be approved now with no other trials.

Approval of a treatment for hyperphagia would provide our son not only with relief from overwhelming anxiety associated with unrelenting hunger, but also relief from the tormenting impact his hunger-related behaviors have on his self-esteem and relationships with his parents and others.

A chance at improving his daily life

It would literally be life changing and life saving by addressing the two issues that threaten his health and emotional well-being.

It would mean a life without fear of my son's overeating. It would mean a possible future of independence.

The approval of this treatment would mean everything to our family and community. This treatment will give our daughter a chance at an independent life one day and could potentially save the life of our little girl with PWS.

This treatment is potentially lifesaving for our loved one with PWS!

Possibly EVERYTHING

Norah is a kind and caring girl. She loves dance and gymnastics. She asks why is she hungry all the time and why it's so hard. This drug can help eliminate some of her biggest obstacles. Her family and doctors believe that DCCR is one key that could unlock her future. Please, reconsider the application and give PWS kids and their families this medication.

This treatment could potentially save the life of our son with PWS! Approval of this drug means that Hudson and those in his PWS community will be able to lead a more normal life, without the most debilitating aspect of PWS--hyperphagia. It is the most promising treatment for the major symptom of his rare genetic disorder. This is a life-changing medication for those living with PWS and their families! It will give them the chance to live comfortably and increase their chances of living independently.

A changed life for our family and reducing suffering for Hudson (6 years old).

Relief

It would mean the world

It would give us hope that our son could experience more independence and a full life as he grows into adolescence and adulthood.

The world for her and us and hope for a safer happy life for her

Peace. Positivity. Being able to sleep at night, KNOWING how hard our community has fought for this, and continues to trailblaze for PWS & A Cure, not a proverbial band-aid!

Better quality of life for the whole family, no nore locks on the fridge.

absolutely life changing, without exaggeration. Hyperphagia is likely to be the ONLY thing that stops my daughter from living an independent life as an adult!

It would mean my daughter's future of independence and health possible.

It would mean she can feel something that all of us take for granted. It would mean she can focus on life rather than hunger. It would mean I can stop wondering what she could be capable of if she weren't crippled with hunger.

The treatment could potentially save the life of my daughter with Prader Willi Syndrome. It is the only vial treatment for the most major symptom of her disorder. It can save her life and others lives and is critical to get this drug on the market as soon as possible.

DCCR would give Kimber the chance to live an independent life free of hunger and able to accomplish the things she dreams of!

Everything. It's our only hope.

Hope for an independent, fulfilling future

DCCR is the only treatment of its kind to provide PWS families hope surrounding the combatting of hyperphagia. Approval for continued testing and distribution would be not only extremely beneficial, but even life altering/saving for those with PWS.

As close to a cure as we will probably ever get

I don't have any information on DCCR.

Everything

This might allow a more independent lifestyle for my son- one that has the potential to be more fulfilling. One he very much deserves if he were able to control his hunger.

potential for a better quality of life

A better chance for a healthy and longer life

Less suffering for my son. Improved mental health for who family due to reduction in daily stress.

Our child has avoided the debilitating symptom of excessive hunger in PWS. While this has been delayed with diligent control of food in our son we have seen 1st hand the devastating impact to families and individuals with PWS when they can no longer control their food intake. It impacts their ability to function, always hungry, it becomes a fight to survive, a most basic need they are trying to fulfill. We are hopeful that a treatment is approved to address this most critical item for the PWS community. Our son is progressing well academically. Once this phase of hunger hits he will take a turn and struggle to continue eclectically through education as he will be obsessed with food. We want to avoid this debilitating issue within our

Relief and peace of mind as a single parent.

Better quality of life

Freedom of having constant hunger.

With proper medication for increased appetite my daughter will be able to go to school without anxiety over food. She will be able to participate with her peers without the preoccupation of seeking food and will be able to lead a more independent life as she ages. If hyperplasia is under control, she has the chance of leading an independent life without constant supervision due to food seeking. The stress this brings on a family is exhausting. Medication is needed for the overall outcome of our entire family. Please allow dccr to be approved not just for my daughter but for her siblings and parents.

Happiness. My child is anxious and has trouble focusing bc of food related thoughts.

It was be dramatically life changing for us and the most important thing is it would give us the much needed hope we seek and need during this trying time.

He may lose more weight and feel better.

An opportunity to live a normal life.

Everything

The ability to live a more normal life. He could learn and play without always being disrupted by the never ending hunger. His focus and concentration are severely limited due to hyperplasia.

What would an approval of DCCR mean for your loved one and your family?

A better life.

Taylor is a smart and sassy 1st grader who loves to read, loves skiing and has so many goals and dreams. She wants to be a doctor when she grows up. This drug can help eliminate some of the obstacles in her way of that dream. Her family and her doctors believe that DCCR is one key that could unlock her future. Please reconsider their application and give PWS kids and their families this medication.

My daughter's life would be radically changed for the better. If she were free from the constant hunger she would be able to live a fairly independent life. And I would not have to live in constant vigilance about her being in danger near food

It would mean the chance at a normal life.

Simply put, any helping in reducing my daughter's hunger is enthusiastically welcome and immensely life changing.

It would be a miracle for him.

Everything! I want my son to live life full and be able to have a productive meaningful life. This medication would make that possible!

DCCR would allow my child to have a better quality of life, both physically and socially. Addressing the hallmark symptom of PWS, reducing it, even by a small margin results in huge gains of normalcy, lessened anxiety and a sense of independence. This would mean the world to my daughter and our entire tribe of family and friends.

Everything! It would greatly improve her quality of life.

A huge difference in his future

The ability to live a happier, healthier and more productive life.

This would be life altering for my child! We currently do not have any treatments for the insatiable hunger for our children. I know personally, families that have been able to get their kids into this trial, and ALL of them have had positive outcomes that have completely changed the lives of their child, thus the family as well. It would change the future for our children, with hope for independence! Please reconsider!

It would change their life to be independent and not be hungry for food. This is currently the only drug helping with our children's hunger and proven to be safe. Alleviation of a LARGE number of symptoms that make life a daily living hell.

Everything.

A miracle.

It be would mean a complete improvement in the quality of life and future of my daughter. For her to live a life similar to other kids her age and be able to grow up with them at the same level

Have better control on what she eats and the effects it causes on her future development.

It would mean having help with the daily struggle of my son,Äôs uncontrollable obsession of food. A return to some semblance of .Äúnormal life.

Increased quality of life

A chance to have a life that's a little bit easier on a daily basis

DCCR would remove or at least reduce the largest roadblock for Evan and kids like him being able to live happy independent lives. It would be life changing for him, our family and all PWS families. Please reconsider Soleno's application and give PWS kids a chance at a life with the brightest future possible.

A healthier relationship to food and future

After watching her struggle for 19 years with no treatment, having a tool to help her would be tremendous beyond words, not only for her but for us as family and caregivers. The amount of strain to all of us continues to mount with each passing day and the recent COVID restraints have further added to that strain. There are so many issues with this syndrome and we as caregivers have to be constantly attuned in order to pick up on subtle changes that can turn into devastating complications. We all want and have lofty goals for our children. With this tool, we have something to help her at least have hope that she can have a future and a reasonable life span. Having any treatment option that may help her is better than nothing, which is what we have now. Imagine being told at your child's birth that "their are many group homes available for her". As a mom, that's what I was told when she was 2 weeks old as she was diagnosed with this unforgiving syndrome. Since that time, I've devoted my life to fighting for her future - every day is a struggle - 24 hours a day, 7 days a week. Although I will continue to constantly fight to better her quality of life, I am reaching retirement age and it frightens me to know what will happen to her without some sort of

treatment option. Please reconsider approval of moving forward with this treatment option. There are risks with every aspect of our lives for the past 19 years due to PWS so risks are part of our lives. Taking a chance to help her in any way has never stopped us from trying - we are asking you to do the same.

Possibly helping her live a better life.

Loved one

Tremendous change in our lives. It will be a day and night shift in behaviors. Life Saver.

A decrease in traumatic stress for us all!!

Ability to have a better quality of life

A new lease on a longer more productive life, free from hunger

It is life changing for both my son and as a parent. The results are huge. This drug has positively affected many of the problems associated with PWS. This needs to be approved.

A miracle

A better future and way of living for my daughter

Better life

The potential chance he can have a healthier happier childhood

It would mean there is Hope

A life much closer to normal, a life without daily fear, a hope for my child to one day be independent.

This treatment could potentially save the life of

It would change our world. Provide a glimmer of hope that my daughter would have at least the possibility of reduction in the hunger feeling she has daily

It could save his life!!

Help them to live a typical life of no diabetes

The average age for life span for someone with PWS is 29.5. My son is 27. As you can imagine, time and important treatment is of the essence. My son deserves at least a fighting chance to live a longer and healthier life. He deserves to have a better mental health perspective without anxiety about food and he deserves to

What would an approval of DCCR mean for your loved one and your family?

live life full. Not only full and free from seeking food that is ever present in his mind all day every day. But free from it's handcuffs that hinder his life and has cut many of his friends lives short

A better future for her and for children with PWS. Less suffering, and an easier life.

It would have a life changing effect on my son. A step towards normalcy, if you will.

It means another option for them to reduce the urge to eat.

We hope that it would be as effective in treating our beautiful daughter's hyperphagia and anxiety as we have heard it has been for others. PWS children need accessibility to this medication! This is and will be life changing for many. If Paisley did not have insatiable hunger, it would change the entire outlook of her future. It means independence and freedom.

A near normal life with no more insatiable hunger.

It would mean we have some hope that our daughter's future won't be driven by hunger.

A better life with her family and cousins and sisters that love her so much!

A dramatically different and easier life. The medication helped my daughter so much

fewer food-related restrictions and more inclusion in the community!

Peace of mind for our son's future, independence and more freedom potential in his future.

Approval of DCCR would mean that my son would have an independent future without the fear of the PWS symptoms. He could be a typical person, not someone that is just a disabled person. Please reconsider this decision. It really harms my son's chance at a typical life if we have to wait longer for this drug to be prescribed to my son. I have seen the benefits this has provided for other people with PWS and I know it will benefit my son. Please reconsider. We need DCCR so badly.

It would mean peace of mind, it would mean hope for the future, and most importantly, it would mean my child would have more of a chance for an independent life.

Further advancement is help treating my child.

I'm desperate for my child to lose weight. She is trying so hard but the hyperphagia takes over. It is heartbreaking watching her try so hard but the scale doesn't move.

Ability to enjoy life

It would help so much and provide a future for my child

An approval means a future that does not revolve 24-7 around the management of hunger and food-seeking behaviors. It means my son being able to grow up without experiencing the hallmark symptom of PWS which means he can have a more independent future. It means our family can still live a fairly normal life when it comes to the foods we eat and have in the house. It means we don't have to live in fear of our son choking to death. It means he is less likely to have life-threatening obesity. It means ONE of his many challenges could be improved or erased. I pray you reconsider the approval of DCCR for the treatment of Prader-Willi Syndrome.

My son wouldn't have to feel extreme hunger. We will have peace of mind that he won't ever have to experience that.

A chance for our beautiful son to live a quality life.

An approval of DCCR would provide our son the ability to live a quality life. We all work to help our children overcome this condition.

Approving DCCR will provide allot of hope to PWS families.

A huge relief and help with never ending hunger! Also stabilize weight and behavior issues.

My daughter's hyperphagia rules her life. She is obsessed with food and can concentrate at times on nothing else. Controlling this so that she can focus on learning would be life changing for her.

One less thing to worry about and hopefully a better quality of life

My son could live more independently without all the food/drink in the house being behind lock and key and without a caregiver having to be with him in order to lock up and unlock the refrigerator and pantry. There would be decreased cost to the state and federal government for his in-home care. He would be more self-sufficient.

Everything

This approval could be life changing for my daughter and ultimately our family. Please give my innocent child a chance at a less challenging future.

Hope

Give my child the opportunity to have a happy and a normal life as possible. With less anxiety for food and the possibility to share with other children with less restrictions. THAT WOULD MEAN A LOT! to her development.

He will be able to live a better independent life!

It would change his world. To not always be starving, to not constantly have food on his mind and be able to live a carefree life.

Could change the future of my child,Äôs life. She could actually feel full for the first time in her life. Her future may not be limited to a group home as she ages, reducing costs.

the best that can do for her

The ability to be free from the burden of always being hungry. The ability to concentrate on other things other then food. The ability of not having anxiety related to food. The ability to be live. Everyday I wake up and ask myself is this the day she will get the unbeatable urge to eat. Is this the day she will pick on her skin until it bleeds uncontrollably. Is this the day I will loss my sweet loving child to the unbearable anxiety, anger and mental health issues. Is this the day I loss my baby?

The opportunity to live a full life. It would take away challenges that prevent individuals with PWS from reaching their full potential. Parents should be allowed to advocate for and pursue any viable option for treatment. This should be considered a humanitarian exemption to give relief to individuals with serious mental and physical challenges. As long as potential risks are understood by parent and patients, there should be no reason to deny.

The first real and viable treatment option for hyperphagia, the hallmark and most difficult aspect of PWS, and its related effects.

It would mean an independent, normal life for our daughter. She is exceeding all of our expectations in every area and would no doubt be able to lead a successful and fulfilling life but hyperphagia will stand in her way. With this drug we would hope she could still live a full and independent life.

It would be a life changer for not only my 6 year old child with PWS, but our whole family! Many behavior issues could be lessened with

What would an approval of DCCR mean for your loved one and your family?

this medicine and it would take stress off of the whole family!

Possible relief from the hunger

Nothing else is helping my daughter. She continues to gain weight and without a treatment, early death is likely.

Progress

It would mean possibly a cure for this horrible syndrome, it would mean Tommy would have a little bit of normalcy in his life and not be hungry all the time. It would mean more than words could possibly describe.

A treatment when we don't have any.

This treatment not only has the ability to improve the lives of people living with PWS but helping with debilitating hyperphagia but to actually save their lives by reducing destructive behaviors and lowering fat mass. People with PWS live through exhausting circumstances of which they have no control and they, like all people, deserve the opportunity to live a life free from as much suffering as possible.

It would give my daughter the opportunity to try a potentially life changing drug that could improve the quality of her life.

It could mean an improved quality of life for both my son and by extension, myself.

Life changing ability for a more normal life. Life affirming hope for better health and quality of fife. Reduced stress on me, on my son and the rest of the family.

Give the girls an opportunity to live within the norm we all take for granted. As the Mom to two girls with PWS I would need an afternoon to sit and share what benefits this would bring.

Hope for living a healthier and happier life.

To live

It would possibly allow my daughter to function in society without constant food cravings.

Stress relief

My son is in the DCCR clinical trial. He has experienced weight loss and a reduction in hunger since being on DCCR.

It would possibly make a huge difference in my daughter's quality of life.

A better and healthier quality of life. My 6 year old's life revolves around food and eating times. Every minute of every day is a battle to keep food away from her. PWS also causes metabolic issues so she is also overweight

A possibility of living a life with out the cruel consequence of PWS, living in hunger.

Help with independence, mood and food seeking tendencies.

A healthy more independent life

Help my son not be hungry and help his behavior when he doesn't get the food.

A treatment offering opportunity for a healthier future.

Hope

It would be incredibly liberating to alleviate the relentless hunger.

It would mean everything. PWS people deserve to be able to help themselves with one of their greatest struggles.

It could potentially save the life of my child . It is imperative that DCCR be placed on market now!

Hope for future

It would possibly help her live life as a regular person without having to worry about having life long threats

It would mean EVERYTHING!!! I would love for my child to be able to have a better life.

This treatment would give my child relief and the confidence to continue to fight for a healthy weight and independent life.

It would change her life dramatically.

A chance at life. We are desperate for something to help ease the daily struggle for our daughter. We want to believe she can live an independent life without constant starvation, destructive anxiety, life threatening side effects of hyperphagia. PLEASE HELP US!

It would relieve my daughter of the severe anxiety that she's carried her entire life. She has to take several medications for it.

The drug has the potential to decrease food seeking and behavioral outbursts. Also the BMI improvements are promising

A more normal life around food, less anxiety for my son, a better quality of life.

Life changing hope and independence for my

Life changing

Life saving for all PWS community

To help with appetite - to suppress the hunger these kids have. To control behavior and weight gain.

It would mean more to our family then I can explain.

It would mean the world!! More freedom, independence, self esteem, less depression, less anxiety

This would be a life changer for my family. It would mean my child could live a free life from having struggles around food. She would be able to live independently when she came of age and be self sufficient. This would mean the world to us to have to not constantly worry about the safety of our child.

DCCR has been proven to take away the hunger in PWS persons. It would turn our world around

EVERYTHING!!!!! We won't have to live in fear, our child and family will have a better quality of life, food won't be the enemy

Relief, hope

Approval would mean that my child with PWS would be able to live a life that could be somewhat normal, with the opportunity to not be in a life threatening situation with food, the possibility of not being at risk of being obese, it would be the opportunity to not have food be a life or death situation.

A hope for even a drop of normalcy for persons with PWS. These people struggle with Behavioral issues and often times severe obesity. Right now there is no cure for PWS, but we hold out hope for treatment to help minimize the deadly symptoms. Life changing is what treatment would be.

Greater independence, open up many doors for the future

DCCR has given my daughter her life back. Not only have we seen a significant decrease in her hyperphagia and over all food anxiety. We have also witnessed a significant decrease in over all behaviors and anxiety. We no longer have to lock our pantry and refrigerator. My daughter

What would an approval of DCCR mean for your loved one and your family?

can now attend holidays and birthday parties without the overwhelming anxiety about food that was present prior to DCCR. She is able to make it through her school days without emotional and aggressive behaviors. Which prior to DCCR was not possible. DCCR has shown to be safe and effective. There should be no reason for DCCR not to be approved for our PWS community!

It would mean my son could live a full life with happiness and great potential! No more starvation!

This medication would provide a treatment for when my daughters hyperphagia hits. It's imperative there are treatments available for our pws community to help with these devastating symptoms.

A more full lifestyle that isn't driven by PWS behavioral concerns and issues.

It would change her life. Don't hold back medications that could help a genetic disorder with so many complications.

Because DCCR affects more than just hyperphagia, it would mean relief for my son from some of the most severe parts of his disorder, and would ease the burden from all his caregivers knowing he would not feel as affected. It would open up his future to even greater avenues, possibly needing less assistance, or even the opportunity to live without an aid. It might mean fewer mental health struggles.

May change her entire life fir the better

Approval of DCCR would improve my daughters quality of life. Having your child constantly feeling hungry is not only heartbreaking but consumes their every waking moment. This medication could give my daughter the opportunity to go to college and be a contributing member to society and allow her to Pursue her dreams.

Freedom and the ability to live a more normal life

A New opportunity to have a better health condition and a better lifestyle.

it would help them with the needs that they have to have

Higher quality of life for my daughter.

Potentially save their life. Hyperphagia is a great health risk for individuals with Prader Willi syndrome

alleviate compulsive behaviors and stress

Ability to live an independent and full life.

She would have the opportunity to live somewhat independently and hold a job.

Hope, safety

Possibility of a life without so many restrictions and risks. Reduced anxiety due to food control and behavioral issues.

An approval of DCCR would transform the lives of our daughter (PWS) and the rest of our family. She is currently in the DCCR study and the progress directly related to her anxiety and food-seeking has been impressive and rewarding. Please reconsider.

Everything

I would mean room for more testing and potentially a cure for the most challenging and prominent issue for my child and those with PWS

Less anxiety, food safety, peace of mind, comfort.

Hope.

This treatment could save live of those with PWS.

Both these beautiful girls I have the pleasure of knowing are loving caring children but when I care for them their desire to eat is non-stop. their other physical disabilities are heart breaking. Lack of speech adds to their frustration and impedes learning. This treatment would save the lives of my beautiful adoptive girls I believe it is critical to get third rug on the Market was soon as possible.

Better quality of life

A chance to give him a better quality of life!!!

Hopefully help save her life!

My son is obese. This could help him return to a normal weight. He is currently type 2 diabetic. This medication could save his life.

Currently, our sons behavior issues are our biggest concern. Due to aggressive behavior, he is a danger to himself and others. There has been no medication that has been helpful to help alleviate this most disturbing symptom of PWS.

Life changing for her and our family! Everyone deserves a chance to live a long life that is healthy, happy and full!

This could forever change the trajectory of her life, our family and that of so many others with PWS!

It would mean a chance at a more normal life. It's a complete game-changer that can alleviate some of the most severe effects of PWS on my daughter's quality of life.

That it would treat the most challenging part of PWS which would give our child a chance for a normal life.

A more normal life for our son and us, his parents. Much less worry for his future.

an incredible improvement in all areas of life for the child as well as his caretakers

Hope to address something that I think about every day. This could mean greater freedom and a better life for my son and thousands like him.

It would be hope, it would be life changing. It would allow us to grow our son through childhood knowing the worst and most hallmark symptom of this awful syndrome could be met with an effective treatment. Maybe it will allow him to live independently. Simple put: It would be possibility.

Life changing

Help to live a normal life

Our son would be safe. Grow up healthy.

Decrease unrelentless hunger. My daughter thinks about food constantly, which is heart breaking. Persons without experience with PWS have no idea how this impacts every moment of everyday and how a person with PWS can never be left unsupervised.

Any treatment that could potentially make life for my son better is a no-brainer! Living in a world that is saturated with food and food images is torture for our kids. Holidays are a nightmare! Many times they must live in isolating and controlled environments to lessen exposure to food. If it can improve lives then please, please reconsider your decision and approve this treatment.

Comfort, happiness, satisfaction

Treatment option for hyperplasia first the PWS population

What would an approval of DCCR mean for your loved one and your family?

For all the residents I work with, it would give them more freedom

It might have saved the life of my son.

Safety, more job options, more freedom for involved.

Improved quality of life

Freedom from the constant anxiety and fear that our loved ones run the risk of dying as a result of their hyperphagia.

Everything

Everything. We've been praying and waiting for an effective treatment.

Everything

Hope for an independent future, free of pain and suffering from relentless hunger

Never being worried about my dear son hunting for food and preoccupying himself with food.

Hope and life

This treatment could potentially save the live of our loved ones

More control with the disease and life expectancy

Peace of mind and body to focus to a happy and healthy life

Freedom of fears around food in any setting. We've had to ensure our son is not left with free access to food for 13 years. A free times we've slipped up and he ate everything available. This is severely dangerous. Think about the last time you felt hungry for a long time... how did you function? No think about having that feeling every minute of every day... now think about your child feeling that... you can help our kids free from that prison by allowing this drug to be used for PWS immediately.

Hope. A better future.

It would not be an understatement to say we are desperate for any new treatments that will help our son have a better quality of life. Please, reconsider your decision, so my son can be helped now, not years from now when he has less time left to live a normal life.

It would mean a future with not so much pain and suffering for my child.

My daughter (21 years old) is currently participating in the drug trial for DCCR. It has been life changing for her and for our family. She suffers from intrusive thoughts of food which are distressing and severely limit her ability to participate in regular life activities. Before she started on DCCR she did no cooking because being in the kitchen where there is food was too stressful for her to manage. She could not tolerate gardening at all because she knows that some plants are food, and that made gardening increase her intrusive thoughts of food. Going for walks in the neighborhood or a park was not cognitively engaging enough to distract her from the intrusive thoughts of food, so going for a walk intensified her thoughts of food and hunger. (She is on a restricted calorie diet, so there's a tight limit on how much she can eat.) She needed to be engaged in activities that were sufficiently cognitively engaging that they distracted her from the intrusive thoughts through all waking hours. The intrusive thoughts made it difficult for her to think of activities that would be engaging enough, so that work fell to the rest of the family all day long, every day. that she is taking DCCR, the intrusive thoughts of food are more muted and more manageable. She is learning to cook. She can plan a meal. She enjoys gardening. She can think of activities to distract herself from the intrusive thoughts of food. Books are more reliably distracting (before, they were often not distracting enough to keep out the thoughts). This has dramatically decreased her stress and the stress of everyone in the household!

We need some sort of treatment for hyperphagia.

This would make my house run much smoother, less debates between my daughter and everyone.

chance to have drug to treat hyperphagia and behavioral issues

A chance to treat hyperphagia and behavioral issues. No alternative on the market. Due to rare nature of disease, the chance to have another trial is complicated and diminish chances to have a treatment for our son

Treatment for hyperphagia, behavioral issues

LIFE CHANGING! It is the one thing that can alleviate the pain and suffering that all of our children and their families have suffered for so long.

Having had our son on DCCR for the past year has transformed his life, saved him from

inevitable harm danger and costly future medical issues, and it has allowed our family to remain intact-we will be lost, hopeless and helpless without this medication!

Everything

I would like to share the story of our nearly four year old daughter. She is a sassy and adorable little girl who loves her big sisters, baby dolls, her school, family and friends. She also happens to have Prader-Willi Syndrome. This has affected her life from before birth and it will follow her until she takes her last breath. We can not take away her syndrome but there is a drug out there that is so promising at giving her a chance at a more normal life. That drug is DCCR. The hallmark symptom of PWS is hyperphagia. I had never heard of that word before her diagnosis. It is now the word that haunts my soul and makes me wake up in the morning with tears. It could start tomorrow or it could start in five years but one day my little girl will have a hunger so unrelentless, painful and all consuming that she may do unmentionable things to try to quiet it. She may even eat herself to death from stomach rupture, from choking, or obesity. The results from the recent DCCR trial gave promise of a much different future for Domi than the bleak one we were given along with her diagnosis. That is a future that no parent should have to watch unfold for their child. Especially when there help in the form of a safe and effective drug. DCCR is that drug and it is not being allowed to be used to help those most in need. My hope would be that the FDA will see that this safe and effective drug to treat Prader-Willi Syndrome be immediately put to market to help those affected from hyperphagia have a fighting chance at a full life. It is critical that it not be a requirement to redo the clinical trial because there are children, adults and families who need this drug now. There are NO other treatments available for hyperphagia. Waiting for another trial would be impossible and unjust. Rare disease does not get the attention, funding or advancements needed to help our loved ones. Please do not take this promise of hope from us.

It would be a game changer. We would have hope if our daughter being able to live a life without feeling hungry and h e the anxiety that comes along with it.

Availability of effective treatments for PWS would be a game-changer for my daughter, allowing her to live a more fulfilling life with the absence of the constant and disturbing hunger

It would be a life changing event for both our PWS effected child and our family, giving the chance to live a much more normal life

What would an approval of DCCR mean for your loved one and your family?

Could be life changing for our son in the future.

Hope

Hope for their future

So much! No need of public school person to watch him every minute when he is at school, we can address issues that we can't even begin to with constant starvation at the forefront.

Life changing

Life as most of the world knows it..... but because of the effects of Prader Willi Syndrome we don't and more importantly our son does not either

Treatment for when he can no longer control his appetite.

For my child to have a happy, healthy life. To be be able to enjoy life, instead of only being focused on food. To be able to be a well-rounded successful adult.

The constant hunger my grand daughter lives with us heart breaking. Approval and use would hopefully help curb the desire to eat while also affecting moods. How angry, grouchy are you when you are hungry? Imagine a kid feeling starving all the time? Heart breaking.

An easier life.

An opportunity to love a normal life.

It would mean she may be able to live independently.

Hope

Possibly freedom

It would be more independence and more options for my young adult with PWS. Currently my daughter lives at home but she is so restricted, even before COVID, it. Äôs almost like she is in an institution because of the fear of access to food outside of our supervision. The unrelenting hunger of PWS limits every activity for our loved ones with PWS. My daughter has food worries and overeating at work and social events. Having a medication to curb hunger would mean she could better work and participate in social activities without constant worry about food security and gaining weight if she does go off her diet as it seems the medication also helps with metabolism. I have seen with my daughter who has been in the trial, that she can eat more food without having the weight gain, actually she has lost weight and she has more flexibility with meals

(she can wait for snacks and meals - it is not an explosion if we eat at a different time, and she can even skip snacks some days). Meal time used to be a constant stress in our house with high anxiety, crying and sometimes tantrums. Now it is much more relaxed and she is cooperative. It's pretty amazing. Having a medication would be a huge deal!

Controlling her hyperphagia--and thereby her weight--could contribute hugely to the mental and physical well-being of my daughter.

This medicine could help my daughter and so many others feel full again. Help fight obesity in many PWS patients and maintain a healthy life that they all deserve.

Our daughter has participated in the Phase3 trial for the past 17 months and DCCR has been LIFE CHANGING for her and our entire family. Thanks to this drug, our daughter has had a SIGNIFICANT improvement in weight, BMI and a reduction in hunger and food seeking. We DESPERATELY want other children and adults with PWS to benefit the same way our daughter has benefited from DCCR. We cannot imagine having to take our daughter off this amazing medication because the FDA will not approve a drug that has proven both safe and effective while drastically improving our daughter's life. Thanks to DCCR, we are leaps and bounds closer to our daughter having independence and the ability to break the restrictive bonds of Prader-Willi Syndrome. PLEASE reconsider the Phase 3 trial of DCCR and approve this drug for use in the PWS community.

Help for my son!!!!

My son has been a food seeker from the time he could walk. There are times his weight has ballooned to over 250 pounds as an adolescent and young adult. We struggle with food challenges EVERY SINGLE DAY! if this drug shows any Hope ANY!!,Äô Of WORKING and no adverse effects have been noted it is only fair to let us use it at least on a trial basis. My sons entire life is balanced on the availability of any drug to help as there are NONE at present! I implore you to revisit your decision.

Better future for her and ourselves. Without help and a way to mitigate the hyperphagia; she will have extreme troubles in life which could lead to death. It seems this medicine it helping in this area which would be such a relief to have.

DCCR would allow my daughter a chance at a future. It will give her opportunities to live a normal, independent life. It will reduce the risk that she will die as a direct result of PWS. This

would be life changing and life saving for my family.

Better life for my son

I love my grandson and I pretty sure he deserved full and normal Human life

The rapid approval of DCCR is critical for my daughter and our family. There is no current treatments to help with the hallmark characteristic of PWS- hyperphagia. This drug has been proven safe and effective and is truly life saving. When I heard that the FDA was requiring an additional trial, I felt defeated. My greatest fear is that when my daughter needs DCCR, it won't be available for her. My biggest fear is that trials cost a lot of money and take time to do them. Who knows how long it could take to gather the funds? Who knows how long it could take to run a successful trial? What if another trial can't be run? Our community could lose out on a treatment that addresses one of the biggest challenges our loved ones face with PWS. The data presented has shown DCCR to be safe and effective and there isn't a drug like this on the market at this time. I want to make sure this gets to the market as fast as possible so that my daughter has access to it when she will need it and that those who need it now have access to it now! When my daughter was diagnosed, I promised her I would do everything possible for her to have a future where she could LIVE LIFE FULL. Helping to get DCCR to the market as fast as possible is one way I can fulfill that promise to her. I don't want to wait for the possibility of another trial. They are expensive and take time. We need DCCR now! We don't have time for another trial. My daughter has friends living with hyperphagia now and I want to make sure we do all we can to help them now and help my daughter in the future!

It could save my kids life.

Save her life

My daughter is on this drug now. We have noticed significant positive changes with this drug.

better life

Everything!!! Mostly a chance for life!

My daughter will have cure for suppressing hunger and will help with emotional/behavior issues.

A chance to bring him home from his residential school if his hyperphagia and behaviors could be controlled.

What would an approval of DCCR mean for your loved one and your family?

It would change our entire lives. It would mean a chance for a somewhat "normal" life for my son.

It would enable us to live without worry of some of the more challenging symptoms of PWS.

Life changing for my son.

The brightest future possible for my nephew. He has exceeds odds left and right but this would make more possible in the future. #caydenstrong

Tremendous decrease in food related tantrums/issues

Everything! This could potentially save the life of the beautiful loved one with PWS.

It could potentially mean a more normal life. It could mean possible independence, friendship, and hope.

Give my boy a chance at a full life. Independence. Opportunities. And SO MUCH MORE

Everything. Hope in life.

It would mean there is a medication available that could help my son when hyperphagia hits. Our biggest dream is for him to be able to live a full and independent life, especially as an adult. If there is not a medication to combat hyperphagia, we fear he will not have the ability to live independently as a young adult (going off to college, etc) and then as as an adult. We have friends with PWS children who have been in the trial for DCCR and tell us how amazing the medication has been for their children and their overall family's quality of life. Thank you for considering!!

Increased control toward normality for life. The changes would offer an opportunity to align more closely with those of his peers and is one less obstactle that is in front of him.

This medication has been life-changing for us and has given us our son back. He was consumed by hyperphagia, skin-picking, and anxiety and was miserable. The stress level of our entire house was so elevated. DCCR has changed him and really, all of us. Please let us continue this medication for our son.

It would mean everything. This is an amazingly promising drug that is giving our community tremendous hope for the future.

A real hyperphagia treatment option could change our son's & our lives.

Hope for a normal future, our only hope!

This would be life changing for my family and the future of all people living with PWS

An incredibly hopeful future for my child, one that could literally change our lives.

Stability

Even half an opportunity to know the freedom from hunger would be a measurable gain in the lives of those with Prader Willi Syndrome.

maybe a more independent normal life

Hope for better quality of life

A better life

Quality of life

He would be able to live a normal life. Wont have to worry about hyperphagia. We won't have to lock up our fridge. He would be healthier and would not have to worry about obesity in the future and all tjat goes along with it

many things will change for the better I hope it will be approved soon

Hope for an independent life one day.

a change of his whole life for good

Hope. I would like to see my son better and we need to try everything. This is very important for us

An approval of DCCR for our child would give her a better quality of life (as we have been experiencing through the clinical trial study). On the DCCR, she can actually get through the day without talking about food 90% of the time as prior. We need it!!!!

Hope of a better life for my son and so many others with PWS. No one understands the magnitude of PWS unless you have PWS, are a parent, sibling or loved one spending countless hours with him or all of the wonderful people working / helping PWS people such as the PWS foundation. DCCR could make a big difference in the quality of life for PWS. Just what everyone has been waiting for.

The ability to go to a restaurant (post-COVID!) without having to monitor my son's every move.

To not suffer as much

Independence

Potentially life saving benefits in the area of physical health and reduction in weight and BMI. Potentially life saving benefits to my sons mental health.

Improved overall functionality and life fir both parents and child with PWS

This treatment is the future of PWS and can save the lives of our loved ones younger.

Ability to work and not be in SSI Independence. His condition would not be life threatening anymore it could save his life

Our son suffers from violent outbursts due to his hyperplasia. This drug could help him reduce these behaviors. He would love to have a job to earn his own money but his extreme behaviors prevent him from doing so. This drug is critical for him to having and obtaining the dreams we all have.

We are hoping it would help our son with his extreme behaviors and allow him to experience a more normal life.

It would mean everything to us!!! This would help her lead a more normal life.

help in the care for my daughter.

An approval of this drug would help prevent my child from suffering from hyperphagia. It would improve my child's overall quality of life as well. Being allowed access to this drug would minimize chances of medical conditions such as obesity and diabetes caused from overeating.

Hope and confidence for our daughter's adult life.

A Better quality of life for all involved

Overall behavior management for constant need for food - be it the driving need, overall desire and ultimately food seeking. This will reduce anxiety on child and also the stresses this creates for the entire family incl siblings.

A different life for all of us for Lily.

That my little one doesn't feel starved

What would an approval of DCCR mean for your loved one and your family?

Hope for a better life. There are so few treatments for PWS that any new option important.

Hope for her future. We need therapy to address the many challenges of PWS. This is our best way to give them a shot at living an independent life and living up to their fullest potential.

Independence for my child. The ability to be around food without getting anxiety. Attend school and family gatherings without the worry of overeating and sneaking food.

It would mean everything. Our child to have a life without having to live in constant hungry.

My grandson is just beginning to seek food. This drug approval would mean he might not have to endure the agony of hyperphagia.

It could end the never ending feeling of starvation for my daughter.

Everywhere we go as a family we are confronted with stressful situations regarding food. I cannot imagine the positive impact not having to worry about where and when we are going to have would have on times spent with our family. There is contestant stress when our son is with us and constant guilt when we don't include him. I also cannot imagine how having a more normal appetite might improve my son's quality of life. Can you imagine what it would feel like to not be starving for the first time in your entire life?

A chance to hold a job and be out in society without constant supervision.

A chance! Able to navigate in society and have access to work & social life.

Options

It would mean that my daughter didn't have to suffer from things beyond her control. It would mean that she could potentially be able to be helped instead of have difficulties.

The possibility to live safely independent without the need for a constant caregiver.

Approval of DCCR would provide treatment, hope and another much-needed standard of care for people with PWS. It is imperative it be approved because our family is experiencing first hand the benefits of this medication in PWS. Our daughter's body composition has improved so much after being on DCCR, which is incredible for anyone living with PWS. I asked her this only and direct question

recently...how does DCCR help you? And she said without hesitation, 'It helps me feel full.' THIS is all we as a PWS community need to hear in order to know something is working and helping our kids. She said it plain and simple. And that's EVERY PWS parent's longing, desire, prayer, hope for their child...to feel FULL. This needs to be approved soon to help eliminate the challenges of PWS.

I would mean peace of mind for the future. Less worry about how hyperphagia will affect his quality of life and less worry about how our family will adapt.

An independent future.

my daughter is two and has accomplished things our doctors told us weren't possible. she is full of life love and spirit. she works hard for everything she does. we would be crushed if the worst of this syndrome ends up taking control of her life, of her freedom...the hunger has the potential to create an undying anxiety that could undo all she's worked toward. this drug is the hope we have all been searching for since hearing about this sick and cruel disease. it's so complex. imagine this was your child. what would you say then.

Please help us save our kids from such cruel symptoms of this syndrome.

Maybe she could have a good quality of life

Christina has been in the trial and DCCR has been life-changing for her. I am devastated to think of losing it! The benefits have been incredible - Christina is more vibrant, alive, compliant with food guidelines, less frustrated, and more engaged in life. DCCR has given her the opportunity to thrive.

It would mean that our daughter could live normally without fear of her overeating due to the disease and all of the issues that come along with over eating.

a better quality of life

this would mean one of the scariest parts of this diagnosis would be under control

It could relieve a lot of stress for our child and our family. It could allow her to have a more independent life.

A chance to live a full and independent life

It is the only treatment to help with hunger as well as other issues. It needs to be available asap. Would you want your loved one to feel

like they were literally starving 24 hours a day 7 days a week?

Saving my son's life!

Increased quality of life for our son and our whole family!

This treatment will save not only my babies life but so many peoples. This is a breakthrough treatment that will be available for pws. It will make patients with pws independent and so much more.

my sister has pws and has severe mood imbalances and behavioral disturbances that have made living with her and caring for her challenging. We are constantly being bullied by her mood swings and behaviors. If there was more research into medications that can help in these areas for individuals with pws would be one of the biggest benefits to those who suffer from these disorders

It is very hard to live with someone that wants to eat constantly. Has given me major anxiety the last couple years just trying to keep her from overeating.

Our entire family (mom, dad, younger sister, and older brother) is bound by the chains of her constant hunger. If there was treatment for PWS, we could have experiences like a typical family!

This treatment could potentially save the life of Hudson who lives with PWS! Approval of this drug means that Hudson and those in his PWS community will be able to lead a more normal life, without the most debilitating aspect of PWS--hyperphagia. It is the most promising treatment for the major symptom of his rare genetic disorder. This is a life-changing medication for those living with PWS and their families! It will give them the chance to live comfortably and increase their chances of living independently.

Could help so much!

Improved health; greater opportunity to manage behavioral problems arising from PWS.

Less hunger

Could mean a better quality of life

Anything than can help with my daughter's hyperphagia would be a Godsend.

great news

What would an approval of DCCR mean for your loved one and your family?

An opportunity to improve some of the symptoms that are associated with PWS. Considering there are currently no treatments for PWS, it would be nice to have the option to help my child if I can, rather than feeling helpless.

A blessing. We have severe outbursts at times.

Most importantly having this drug would pave a better way of living for everyone with pws. They suffer enough with so many obstacles in life that having a drug to help this large part of the struggle would be life altering. As a mom knowing there's a drug that could significantly change our loved ones lives but could get denied is excruciating to hear. Most of us moms hang on by a thread most days and having this part of the syndrome being helped would make all the difference for us and more importantly them

A happier and healthier life for my daughter

A decrease of fear, a hope that my perfect little boy won't have to go through life constantly feeling like he is starving.

Substantially better quality of life and more independence.

My son would never feel the overwhelming feeling of starvation that accompanies his diagnosis

It would offer us the option to provide our son with an potentially effective answer to his constant hunger.

It would mean everything to the PWS community. Our Megs was on another trial until pulled by FDA. Give our families choices for medical treatments even if experimental! Give our families fighting chances and hope of longer life spans!

Our daughter is a beautiful, hilarious, and loving 8 year old girl. She loves anyone and everyone ... and she sees beauty in all life throws her way. She is the epitome of a warrior!! She - and all her friends - DESERVE what most of us gain from the moment we're born ... the ability to live life FULLY. All humans already have so many things to stress over in life ... the last things these incredible PWS humans need is the NONSTOP, NEVER ENDING, CONSTANT stress over food. PLEASE reconsider your decision here. So many lives ... the PWS individual AND their family ... are at stake here. And we believe y'all will truly make the BEST decision for these families. Thank you so much for your time.

Avery is a hilarious, loving, joyful little girl. She adores her 5 brothers and sisters and anyone else with a heartbeat. PWS has confined Avery's life like one can't begin to imagine. This medication is something we have hoped and prayed for ... for years now. Please reconsider your decision and help these kids get the life nearly ALL of us already have as our birth right. The life of feeling full and actually living life.

Freedom to live their life.

Hope foremost. Improvement in daughter's health, decrease in her daily struggles with food.

A potentially better future and better quality of life.

To have him not sneaking or melting down around/because of food. To curb the obsession of food.

A chance at a longer healthier life.

A new life without the torture of unrelenting hunger

It means a possibility of an independent life. It will increase her and our families quality of life. Although she will not need it for a while, there are so many children that need it now! And although our community is small and PWS is rare, these kids deserve to have something to help.

healthier life

Life changing for their future

Possibility of a better, longer life for our child with PWS

Save pws life

A difference between life & death

This could make a life/death difference in my pws family member. It is critical to get this drug on the market as soon as possible so that lives may be saved.

This is the only drug out there that has the potential to address the debilitating symptom of uncontrollable hunger. It is so very important for it to get to these patients as soon as possible. It would be life-changing to them.

Less aggressive behavior better weight control better health and hopefully more independence

So much hope and life quality

It would mean a better quality of live for a child with pws or an adult. We have seen major changes for the better being apart of DCCR trial.

It would mean that our son would have many more options for living a meaningful life. It would open the door to a more normal life for him and for us.

It would give the family hope on a terrible situation and would give my niece a chance at a semi normal life

Another option that may contribute to helping my son have a safe and productive life. We have so few medication options for PWS.

It would mean an additional option to help my son. Medication and interventions for PWS are so limited.

He could focus on friends and relationships and not food!!

Guardians of the individuals I work with and the individuals themselves should have choices on their medications they could try if preliminary trials have been done and successful.

It would mean a less stressful days.

A chance at living an independent life in college with employment and earning potential.

Can treat a daughter who suffers from Prader-Willy's disease

The opportunity to live a more normal life.

This is the only drug available to help curve hyperphagia. This symptom is the biggest problem for PWS patients and leads to other issues. This will entirely change my child's life and offer him a better future. Why would we deny a drug to help with this when it can save lives and benefit those who need it? My son needs this drug to live a full independent life.

It would mean a longer, healthier life for our loved one that he is not guaranteed to have.

My daughter is a participant in the DCCR trial. The impact on her quality of life has been immense. As a direct result of the drug, my daughter had a significant reduction in anxiety, significant improvement focusing, significant increase in the ability to accept schedule changes, the ability to skip snacks and be late for meals with no issue at all, just to name a few. Especially during the pandemic, I can't

What would an approval of DCCR mean for your loved one and your family?

imagine how life would have been for her or our family without her being on this drug. Virtual learning has been a million times better than we could have ever imagined, again that is due solely to the positive impacts of the drug. For the first time in my daughters school career, this past Monday (first day of in-person learning in over a year) I put her on the bus and wasn't in tears with overwhelming worry, fear and anxiety. Fearful of my phone ringing because she snuck food or whatever other PWS related issue reared it's ugly head. Again, that is due solely to the positive impacts of this drug. Every day since my daughter was diagnosed, I prayed for a drug that would give her the best possible life. After seeing the changes in my daughter over the past year, I know that DCCR was the answer to my prayers. Not only my daughter, but the whole family. Although it, Äôs only one individual with the diagnosis, the whole family lives everyday with the unique and overwhelming stress of PWS. To think of my daughter not being on DCCR is unimaginable.

Critical help for the PWS symptoms he suffers with every day

Its like providing life for my child. We need treatment and cant wait for any more trails every second is crucial.

My son is currently enrolled in the trial and the changes we have seen have truly been life changing.

It would allow my son to not be hindered by the feeling of always being hungry. It will continue him to live as normal a life as possible and to be able to go to friends houses. If he is unable to take this medication, no one will allow him to their house because Of the fear of food seeking. In addition the anxiety that controls his, regarding food has drastically disappeared on DCCR.

This is a treatment that would save the life of my son who has PWS. We need to get this treatment on the market as soon as possible to help save everyone's lives with PWS.

A normal life for my grandchild. A life of not focusing on food and focusing on being a child

A better way of life

It would improve the quality of life of my stepson and our family

Independence, health, and possible save her life

Relief from difficulties endured by my son

A chance for an independent life living with PWS

A better life for my daughter!

hope

It would give our son the ability to not be afraid to go to social events or church where there my be food. It would allow our family to have a typical family gathering around birthdays or holidays or just because we like to get together. It would mean no trips to the emergency room to prevent a gastric rupture due to over consumption of food.

It could potentially save the life of a person with Prader-Willi syndrome

I am president of the Utah Prader-Willi Syndrome Association and helped start a medical clinic where we run studies like the one for DCCR. Many of our families in Utah participated in the DCCR study and reported life-changing results. A few years ago, my Kate was a student body officer, was in the school musical, and lived a full life. DCCR will help her to get back to this spot of having joy in her life as many symptoms of her syndrome would be alleviated by DCCR. She wants to be a dance teacher but it is very hard for her to make it 15 minutes in the class where she is an assistant teacher now. This drug would help eliminate some of the obstacles in her way of that dream. We and her doctors believe that DCCR is one key that could unlock her future. Please reconsider their application and give PWS kids and their families this medication. We will do anything to help make this happen.

increased quality of life with an opportunity to live life as an adult at home with family

Its potential to help my son live independently.

Hopefully controlling excessive hunger symptoms

Life changer

A chance at a normal life!

A piece of my mind that he can live a normal life without the scare of him continue to seek for food and potentially causing declining health issues and even death.

It would mean the reduction of suffering for my daughter. She is tormented by the hunger of PWS.

Nathan is a bright, ambitious young man who so wants to lead a normal life with a job and

the same prospects of his peers. DCCR would allow him to pursue so many of his goals without the restrictions placed on him due to the hyperphagia.

Less restrictive measures and more freedom for Grace to be herself instead of being dominated by her obsession with food. DCCR is the first option to treat these behaviors and we need this to help her be herself

As we plan for transition services we are confronted with the many challenges facing our daughter in adulthood. Managing the specific symptoms of PWS increases the difficulty exponentially. Effective medical management of PWS would greatly improve our daughter's ability to manage life as a more independent adult.

Life changing

It would help us with daily struggles and allow my son to live a full life.

It could be life changing for the family and her quality of life. We were hoping it got approved this year so she could start on it.

Not having the feeling of endless hunger. Can you imagine how heartbreaking that is going to be as a parent of a pws child.

She would not have the feeling of being hungry all of the time. Help provide her with some normalcy.

A second chance at living a productive life without barriers

Better quality of life

Less risk of morbid obesity better quality of life

Change the quality of life and so many symptoms that the symptoms causes

Anderson is a lovable, smiley little boy. With the approval of DCCR we think Anderson would be able to live life to his fullest potential and not have the effects of hyperphagia interfere with his life.

Less worry of tough to deal with behaviors related to hyperphagia and potentially other long term benefits such as building better eating habits and reduced risk of things like obesity or diabetes among other medical issues which could occur with trends of overeating.

Hope for the future. No more anxiety and panic attacks.

What would an approval of DCCR mean for your loved one and your family?

She may never have to experience hyperphagia due to having PWS.

A more normalized existence.

It would change his life plain and simple...it would be a game changer for him to be able to function better in society and life in general. I could go into a long list but it would be a life changer for him and help him lead a much better life.

Less hyperphagia and a healthier happier life

A better life.

Patients wouldn't have to suffer

Hope for a more productive and fulfilling life.

Give her a chance for happier and healthier life

DCCR has been life changing for our PWS child. She lives at a level of independence that I'm not sure she would be living at if not on DCCR.

It is a basic quality of life issue. Without it out child faces life threatening symptoms of PWS.

Having had 25 years in the PWS world, and seeing absolutely nothing be developed to help ease the symptoms of PWS, we are desperate to have any possible tool at our disposal to help our daughter create a healthy future. She has struggled with so many serious issues through the years and the thought that there is something so close to being available to us to help her is thrilling. You have to understand that thousands of families in the US and more worldwide live in a constant state of crisis. Repeat. We live in a constant state of crisis. One mistake on our part could cost us our children's lives. In our family, we are seniors and are the primary caregivers. Our stockpiles of adrenaline dried up long ago and we are running on empty with health issues of our own which have been accelerated due to 25 years of caregiving. The biggest task left for us, and one that we will devote the rest of our lives to, is doing everything we can to help our daughter have the future she deserves. Most parents have lofty goals for their children. Our goal is to keep her alive long enough for science to develop tools to support her continued health and happiness. Now, with DCCR, we have a tool that could help with that and it's being sidelined. There has been sufficient testing. Further testing is next to impossible because of CoVid restrictions. If the FDA is basing its decision on looking at a scenario where there is no risk of side effects, then they are not seeing our reality. A diagnosis of PWS brings more side effects than is even described in the literature. You would not know that if you

don't live your life under the curse of this diagnosis. Having a treatment option that might help is better than having nothing at all, which is what we have right now. Eliminating risk is a luxury we don't have. PWS took that away from us long ago. I support the approval by the FDA of DCCR as a tool for the possible alleviation of the symptoms of PWS with no further delay.

best possible life

Absolutely everything!!!! It would mean a better, longer, healthier life! We need this for our children!

Cora is a loving, intelligent, fun-loving, and determined 2 year old who deserves the best chance at a full life. This drug can help eliminate some of the major obstacles in her way. Her family and doctors believe that DCCR is one key that could unlock her future. Please reconsider their application and give PWS kids and their families this medication.

A happy and independent life

it brings hope to our family, that there is some kind of a medical help for our son

The hunger and constantly seeking food!!

A much more normal life for our entire family!

Improve quality of life.

It will alleviate our PWS loved one from the constant feeling of hunger which will also allow a more independent lifestyle.

Relief. Hope. Independence. Freedom. Friends.

For a valid and effective treatment for hyperphagia

My daughter could be relieved of this unending focus on and desire for food. And she would not have to be monitored 24 hours each day (yes, even in the middle of the night) to be sure she doesn't crave, seek and consume food at all hours of the day and night.

The opportunity to live life normally. Without worry. People with Prader Willi syndrome already have so many issues this would illuminate one of the scariest issues

It would help her lead a much more normal life.

It could save the life of our daughter who suffers from PWS. She has an extreme case

Significantly reducing excessive appetite (hyperphagia), which is the hallmark symptom of PWS

My daughter could live a more full life, with decreased hunger drive and more self-control around food.

Relief! And hope, for a happier future for my son.

Keep my son loving with me vs in residential living. His behaviors make it dangerous to stay home. I was hopeful he would out grow the aggressive behavior but it keeps escalating.

Everything!

This would give our family hope for a better future for my young child with PWS.

Independence!

A functional life

DCCR would change the quality of life we have as a family. It would give my daughter a chance to lead a somewhat normal life without some of the most challenging behaviors that PWS brings. It would also bring some much needed peace to her siblings and some rest for father and I.

It would provide treatment for a major symptom of pws that in all cases leads to other major medical issues. The access to this drug would prevent this and allow greater opportunity to a normal life.

Ensuring a better life for my child with this disorder

Life expectancy, quality of life, happiness, mental health for me and my family. This is a great drug that could bring so much to the challenges that my daughter is living. No one doesn't need to go living feeling hungry all time for all their life. My daughter needs this. She deserve all the options.

Caring for a child with PWS means constantly living in a highly stressful environment that affects the emotional, social, and physical well being of the entire family. As a parent of identical twins, both diagnosed with PWS, DCCR would be game changer. The hope alone it provides would improve the well-being of our entire family.

Break through to possibly have a more normal lifestyle and lessen the risk of health complications.

What would an approval of DCCR mean for your loved one and your family?

Hope for a better future and life

Hope. There is anything else that will help her to avoid hyperphagia at this time.

It would mean that they have the chance to live a normal life free hunger control issues.

Would mean the world to me knowing that there's something that can help.

The chance for her to live a life without feeling constant hunger, obsession with food and out of control anxiety.

It would give my daughter the opportunity to live a more independent life. She will not ever be able to live independently without a drug to help her control her hunger.

I support the FDA's decision that more data is needed. The FDA is doing its job of protecting us, ensuring that approved drugs are effective and safe. I reviewed the data from the initial release and was not impressed by the effectiveness. I want the FDA, not the study investigators or the drug company, to tell me that this drug's efficacy outweighs potential adverse effects before I want physicians prescribing this drug to my child.

Allow a more normal childhood and existence.

A chance at an independent life.

A chance for a more normal life.

Hope for this possible treatment and continued research for future treatments

PWS is a rare disease and doesn't have any treatment for symptoms. Dccr drug trial has shown positive results and gives hope to thousands of pws families. We can not wait more years for further trials.

Extremely improved quality of life.

Everything

It has the potential to give her a safe life without the debilitating and life-threatening insatiable hunger that comes with a Prader Willi Syndrome! Our families are desperate for DCCR as a treatment to help our children.

A better life for my baby boy

Everything

As a parent I want my child to love the best life as he can. With this drug it will improve his quality of life dramatically. .

maybe some improvement in her

It could mean independence and longevity for my son.

better quality of life

Some sort of normalcy

Allow for a treatment option to manage the most significant symptom of hyperphagia for the PWS population.

it saves life of Prader-Willi syndrome patients. We need it to be on market as soon as possible.

Better quality of life

We need approval and not waste time. PWS is debilitating not only to the person with PWS but to the whole family. Hyperphagia reduces concentration in school and activities, causes family and relational issues.

That my child and others with PWS would have a viable option to help mitigate the constant hunger as well as increase their metabolism and be able to have more calories in a day-commensurate with other young adults rather than significantly lower, without the constant worrying that she will gain weight.

When we got our son's diagnosis, we were told hyperphagia was both inevitable and uncontrollable. We were told that because of that, our son would have behavioral outbursts that would likely mean we'd need to find ways to protect our older daughter (his sibling) and ourselves, up to and including placing him in a residential home. We were told it would impede his ability to function at school, church. and social events without constant one-on-one supervision. We were told to purchase locks for cabinets and the fridge now, before hyperphagia set in. And we were told he'd likely never be able to hold down a job due to the uncontrollable, debilitating hunger of hyperphagia. It was a VERY bleak picture...and it was capped by being told that there was no treatment or cure...nothing we could do but hope. DCCR is the hope, not just of our family, but of all the PWS community. It has shown promise and proven itself to be both safe and effective in the Phase 3 clinical trials. With it, we have hope for a better future for our son. Without it, we are right back where we started on that awful day we got the Prader Willi Syndrome diagnosis: no treatment for one of the most debilitating, life-altering, and devastating symptoms of a rare syndrome.

We know you have the responsibility of making sure that all drugs you give approval to are both effective and safe. We feel that DCCR has proven it's effectiveness. Based on the results for the Soleno Phase 3 clinical trials, we also feel that it has proven to be safe. We would feel comfortable giving it to our son based on those results. And we do not make that decision lightly.

Charlie would not have to face the challenges caused by hyperphagia, likely enabling him to avoid having an emotional behavioral disorder that would devastate his home and school life, and save our family from a tremendous amount of stress in caring for him by turning our kitchen into a prison environment.

A chance for a fuller healthier life

Mackenna is 7 and loves life but not without struggle. Every year we are noticing little changes in our already complex lives. Things that should be easy become difficult. We are stuck to a schedule for eating. And moving from the schedule is often difficult. Having more treatment available is so important to help our little girl live the best life possible. By stalling this treatment, it puts a giant roadblock into her reaching that life.

The possibility of leading a normal life for our loved one.

It could potentially save the life of the patient. This is the only treatment that has seemed to work for her. This needs to be on the market ASAP to potentially save the lives of people with PWS

It could save the life of my niece and many others affected by pws.

It would change a little girl,Äôs world. How would you feel if you were hungry all the time. This is torture!

everything

Independence. Better life. Safety!!!!

Life altering behaviors

Hyperphagia is the scariest, saddest, hardest ongoing impact of this condition. To have an alternative that could lessen the impact on our daughter could literally change her life.

It would save the life of our daughter and allow her to live out her dreams just like any other child to live independently, get married and have a family. Without the medicine her hopes and wishes would be snuffed out.

What would an approval of DCCR mean for your loved one and your family?

It could give him the ability to function more normally in the real world. Without the constant drive to eat. To have a healthier life.

A chance to make my loved one's life better. There currently are no good options for treatment & we are asking for a chance.

A better life and more control over PWS.

So much more independence in his life.

Hope for her future.

Our daughter has PWS. This medication would mean treatment for one of the scariest, most life threatening aspects of this syndrome. It has the potential to save her life as well as many others that suffer from this devastating syndrome.

People with PWS suffer greatly, constantly. DCCR has a good chance to significantly reduce the pain that my daughter faces.

This is the treatment we have been waiting for. This drug gives our son the chance at having the childhood experience and the education that would allow for his independence as an adult, without it we are facing a much different outcome.

Improvement in quality of life for individuals living with Prader-Willi Syndrome.

An approval of DCCR would give us hope in the possibility of improving the quality of life of my child who is affected by this devastating disease.

Hope

This could save the lives of so many people with pws and help make their lives healthier

The opportunity to meet her potential and to pursue aspects of life that have been unavailable to her.

It could help her lead a happy healthy life, my child wouldn,Äôt have to struggle everyday feeling like she,Äôs starving and possibly eat herself to death in the future

For my loved one to have a chance to thrive at life and not experience hyperphagia and all the complications it leads to causing a negative impact in her quality of life.

My child could live a longer happier life.

Game changer

A sense of relief...at this time our child has to be monitored 24 hours a day or he will sneak something. My son suffers from anxiety that interferes with his day to day activities.

A chance for my child to have a life, a chance for my shield with PWS his siblings to know him and have memories and interact with him, he needs the self esteem that comes from taking this drug. This drug has been life changing. My child has gone from meltdowns and suspension at school to straight As and principals list this drug is worth it for my family and child

It would mean everything. To be able help my daughter live a life without the constant suffering of hunger would be amazing.

It would provide our family and daughter an opportunity to see her have a fulfilled life without fear and anxiety over food,

DCCR would give us a critical tool to help our daughter live a normal life, free from the behavioral, emotional and physical challenges with which she struggles every day. PWS is a cruel disease. Please grant approval to DCCR and help give all PWS kids the chance for a life with less suffering.

Hope that my kid doesn't feel hungry all the time

A chance for a better life.

Independence

A possibility of independence and living a life of giving back to our community with greater impact.

It will give my child to have a better quality of life and help her family enjoy her.

More independence for our son and to be able to have breaks from constant supervision regarding food. It would be easier for him to manage his health and less frustrating.

There is no cure for PWS but we would have the chance to try and mitigate some of its consequences.

Improved quality of life

it would mean a lifetime of not feeling like they are starving 24 hours a day for our son.

Hard to say at this point given the vagaries of a trial, but hope for a challenging disease on many levels.

The approval of DCCR would mean the world! Charlotte doesn't have hunger issues right now, but she definitely will in the future. Her anxiety is so high while she is around food. Having a treatment like this on the market would give our family a piece of mind while we are waiting for her hyperphagia switch to flip. Please reconsider. Our children need to feel some kind of normalcy. I,Äöve seen what this drug has done for some. This could be life saving.

It would mean that our 3 year old son, Hayden, might not ever have to experience the horrible effects of hyperphagia.

It would give me a little more peace of mind not constantly worrying that my daughter might get into food and hurt herself by over eating.

The approval of DCCR would be life altering. Every day I wake up with a pit in my stomach wondering if hyperphagia was going to effect us. Everyday I wonder and worry about every single encounter with food. My life is of constant panic. DCCR has the ability to ease some of that worry. DCCR gives my son the chance to live his best life. DCCR has the chance to change the course of history for our families.

Hope, freedom, a future, a chance for our favorite little guy.

A better life.

It is the only treatment available for hyperplasia. For us it is miracle drug that we have been waiting for

Our precious granddaughter would not have to suffer from always being hungry and over eating, leading to obesity and other health issues in top of what she already has.

This treatment could potentially save the life of my loved one with PWS. As far as I know, it's the only viable treatment for the major symptom associated with this rare disorder. It could save his life, and the lives of others! Please, let's get this drug on the market!

It would give me hope that my daughter will not suffer, live as normal a life as possible, and be independent.

It is the most viable treatment for insatiable hunger that our loved ones with PWS must live with. This drug must be made available to help Improve lives!

Our son's employment and community opportunities would greatly expand and no longer be restricted because f access to food.

What would an approval of DCCR mean for your loved one and your family?

This could help somebody I care about with Prader Willi's!

I am so disappointed at the news that the FDA is not going to approve DCCR for individuals with PWS now . This non approval could cost these individuals years (that they don't have) or even worse could lead to not having the funding to conduct another trial and completely miss out on this desperately needed treatment. Could also cost lives period . As you know, there is currently NO treatment for the debilitating effects of hyperphagia for individuals with PWS . So many are suffering,

unable to lead filling lives due to the constant hunger they feel. They need help NOW, we can't wait. Their lives are worth it

Life changing

A longer, healthier life.

We need more treatment options than growth hormones

It is our hope for my loved one

It will great increase chance to solve PWS

The relief of knowing that some of the lifealtering challenges my child faces will have treatment, that we are not alone in this struggle but have tools that can effectively treat him and enable him to live a more typical life

It would change the life of a loved one who has

What would an approval of DCCR mean for your loved one and your family?

Parents and Caregivers of Individuals Outside the US

As there is no treatment for pws having DCCR approved would be life changing.

There is no treatment for hyperphagia in prader willi syndrome, to have a safe treatment for this debilitating syndrome would be life changing

It would be an absolute life changing not just for her but for everyone

Everything! there is no treatment for this debilitating condition and this is a very safe drug that has showed very positive results

Another option for the treatment of symptoms of PWS

Another option in the treatment of PWS symptoms

Better life

No treatment currently exists for this debilitating condition and this trial has showed very positive results

It would mean so much to approve DCCR to help with this debilitating condition and has very promising results

Would change their life

The ability to have a somewhat normal life and stay alive

It could save a life and it's so necessary

It would be incredibly life changing and provide a glimmer of hope for this horrible disease

It would be totally life changing.

The approval of DCCR would for the first time give our family hope for a better and independent future for Alexander. He is a bright, happy boys whose potential will be severely limited by the impact of hyperphagia if no treatment is available.

quality of life

Better Life quality

Hope for better life for our little baby

Life

Chance to have quality of life

A hope for a life with autonomy and dignity.

Hope for a good life

It's very important.

Opportunity to have a better life

The world

everything

Live

Important to him

Very good

Quality of life

Very important for quality of life

Means his life

Possibility of a better life. Increase oir quality of life.

Improvement of life quality

Safe care

liberty

the right treatment

Anxiety control

Everything, hope...

better quality of life

Health and peace

Health

Quality of life

Save lives the ones that ele loved

Future and happiness

Very important and critical to save lives

It would offer better outcomes for my nephew including less suffering. This treatment to reduce pain and suffering is life changing.

Improvement in all areas of our little one's life!

A better and easier lifestyle

Saving their life

Save the lives of our Zakai and Kaleo

This treatment could save not only his life but many others as well. It is critical that this be made available

Extremely helpful to correct for symptoms like hunger

Better quality of life

No hunger

PWS is a rare disease and doesn't have any treatment for symptoms. Dccr drug trial has shown positive results and gives hope to thousands of pws families. We cannot wait more years for further trials.

Give them chance for a chance of better life and unnecessary procedures

A life full

Save the lives of our children

An opportunity to live healthy

Better quality of life, and more food choices so he doesn't get frustrated or feel different than any other child

A lot in terms of being able to be seen and treated as any normal person and have the medical treatments available.

Better quality of life

Freedom from suffering, support our family, a chance at a better outcome in life

What would an approval of DCCR mean for your loved one and your family?

It would make life for our twins easier and close to normal

Cure and a big help.

Hope

Opportunities for a better life, for the family and the persons with pws

Save lives

Hope!

PWS is a difficult disorder to live with on a daily basis. DCCR would help manage aggressive and rigid behaviors for my son, currently our biggest challenge. It would also help manage his hyperphagia. Just to give us a common an quiet life all together and a future for this little boy

A better life for my nephew because this treatment can help him manage his behaviour issues. Hence a better life for his parents and two brothers and extended family (ex: me).

The problem of food to be easier for children as well as for parents who care for children

Hope that a medication is available for our child before hyperphagia kicks in - this drug can help eliminate many obstacles and battles for many people with PWS. Doctors believe that DCCR can help in many ways, and I believe that, too. So, please reconsider their application and give PWS kids and their families this medication.

I hope that she will not experience the hyperphagia in the future other children/adults do experience at the moment, or at least to a smaller degree. Without hyperphagia or with less hyperphagia I hope that she and my family also will not experience such behavioral problems other families do experience at the moment. I want her to be happy and I think DCCR can contribute to that and make the life of my family a bit more normal.

I hope that my loved one will suffer less from constant hunger in the future and the effects, which come with it like anxiety, etc. This would make the life of my family easier and more enjoyable in the future.

A normal life

It would mean a lot

Life changing

Improvement in quality of life

Potential of a greater life for our loved ones

A greater chance to participate fully in schooling, social relationships, support and physical activities and have a better quality of life generally

Will improve quality of life measurably.

Survival and quality of life

This treatment could save the life of people with PWS

The chance to a normal life

Everything

An option to live a full life.

It would help enormously to mitigate the effects of the Prader-Wilii syndrome

An option of keep moving forward and get things done.

Could potentially save lives.

It could potentially save the life of a loved one with PWS.

Help with his future giving him the best possible future anything is everything.

Everything. It could save lives and I think it is critical to get this drug on the market ASAP to those who are living with PWS.

Quality of life

That we at least have one treatment that will work. That the stress around locking up food/hiding food and the affect it has on siblings is removed.

An easier progression through life

Everything for everyone involved.

Absolutely everything!

It means they can eat normally like any other child.

A better future

Hope

Hope of a better future and a independent life for my kid

The chance to reduce hunger, OCD about food, improve behaviors, and improve body composition.

maintain weight.

hope

It would change our and so many families lives for the future tremendously for the better. It is the only option available to treat the most horrible, devastating and debilitating symptom of PWS. It is absolutely critical that the drug is on the market now as so many people need it. There is no time to wait.

Hope for improvement.

Life saving!

A treatment option where none exists

If it eases the challenges associated with hyperphagia and behavior - it would be life changing and we are desperate for this to occur

For her to live a fulfilled life without out constant supervision, it would mean she could be independent as everyone deserves too.

Quality of life.

A longer healthier life for her. Being able to be around food without the fear of her eating until she dies. More freedom when she older as she won't need constant supervision due to food seeking.

The chance for a normal life for my PWS child but also my 2 non PWS children. Hyperphagia changes all our lives.

Managing hyperphagia in a completely controlled environment might not seem that difficult but the reality of managing this in daycare, school yards, birthday parties etc is a constant struggle and one of the most difficult parts of PWS. An effective means to treat this through DCCR would alleviate much of this burden and make a huge difference to the dayto-day lives of people with PWS and those in charge of their care.

Life changing for my daughter and our whole family. Hyperphagia is a debilitating and life threatening disease and there are zero treatments currently available. DCCR has proven to be effective and safe. By requiring

What would an approval of DCCR mean for your loved one and your family?

another trials this will mean many years before a treatment option is available.

it would change our future and take away the anxiety surrounding pws. the symptom of hyperphagia is by far the scariest and we are relying on this treatment for our son in the future. please don't deny us something that will help him immensely

It would change our future. We are so scared about what is to come and this would give us so much relief to know this is available. It would change our baby's life he wouldn't have to deal with the most debilitating symptom of pws

Live a normal life

Everything! Without any hope of treatment for hyperphagia we cannot even contemplate a semi-independent life for our son, which is devastating as parents. Knowing the potential path that lies ahead of him in the absence of any treatment causes immense distress and psychological trauma for us as parents and shapes the trajectory of not only our son's life but also of our entire family. The availability of any treatment would for the first time provide us with justifiable hope for a better future for our son.

Approval of DCCR would mean that my son would have the one and only therapeutic option available to him when he begins to show signs of hyperphagia which is so debilitating and as a parent to watch your loved one having to suffer the constant feeling of hunger is utterly heartbreaking.

Health and life

Being tormented her whole life by food and being hungry is not a life I want for my daughter.

There are no words to describe the possibility of her to live a life without feeling hungry. I still can't imagine what this must feel like, day in day out to never be satisfied, to have to live in a world where food and the temptation of food surrounds you. To give her a chance to learn without her brain being consumed by the thought of food or when her next meal may be. For her behavior not to be impacted negatively all because her body thinks it needs more food and she will do anything to get it.

Hopefully a chance at an independent lifestyle for my daughter

It will help them enjoy life without being hungry all the time. It will also reduce their risks of diabetes.

My child will never have to go hungry

Life changing! My child will never have to go hungry which means she won't have to suffer

A chance of independence for Thomas.

It would mean a normal and bright future for our babies. Life would not feel like we were living in a lottery system for years and years before we would know the true effects of PWS in our family. It would give jacks siblings a normal life. Not a life controlled by PWS. It would help our mental health and anxieties. It would take the unbearable discomfort away from our lack

It would mean happiness peace and independence for my child

Everything and hope for the future.

An absolute game changer. Less anxiety, a more normal household. A step closer to a better life.

Further Help with Medical Needs.

A chance to live happily

It would give my daughter a better chance in life.

Reducing the pain of continuous hunger for my daughter and our pain in a result. Making life easier for my loved one with PWS and my whole family as food restrictions will be less. Reducing anxiety that my daughter will live because of the excessive hunger. Having a medicine that helps with the most annoying aspect of this syndrome means a lot to us.

It will help them enjoy food as normal people and stop eating when they have enough food. It will have a great effect on their life style

Everything. It would completely change her life, our life and give her the opportunity to live an independent and meaningful existence with freedom from the most debilitating threat of the syndrome.

It would change her whole life. She could live a rich, happy independent life and fulfill her potential. This is truly a life altering drug that every person with PWS will benefit from

A reduction in restrictive practices, more choice and freedom for my son, increased inclusion in the community. This should then reduce behaviours of concern around food as well as the constantly heightened anxiety.

A life without worries, a normal life for my son.

My son can live a quality life after approval of this medicine. It's a relief for my family.

Improved options for treatment and continuing data and research to find effective measures for a rare syndrome, and corresponding information for wider use.

The possibility of living a normal life (as much as possible). Not only would it change the life of my son Nicholas, but the lives of many other children with PWS, and the lives of their families.

It would be life changing for my son and our family to have Hyperphagia under control

To assist in saving my sons life, to take away the the cruelest part of PWS which is his insatiable appetite and to enable him to potentially lead an independent life.

The benefits will be literally life changing.

Life changing

Health & life

Less restriction

another important treatment option

A chance at a full life without the debilitating impact that the desire to eat brings on.

This treatment could potentially save the life of our loved one with PWS

This treatment could potentially save the life of our loved one with PWS.

Our girl Will been funnier

Finally have an option to live life full.

A chance for a life without excessive hunger. Better quality of life for him, his brother, us, the parents, our extended family and community.

Improvement of life

Treatment and help

What would an approval of DCCR mean for your loved one and your family?

A good health
independence
Tudo, qualidade de vida, oportunidades.
Everything! This treatment could potentially

Everything! This treatment could potentially save the life of our loved one with PWS.

save the life of our loved one with PWS.

Everything Better quality of life

Quality of life, health, well-being.

A relief and a way of a better future with increased quality of life.

Hope to thrive

LIFE QUALITY

This treatment could potentially save the live the my daughter.

 $\label{thm:condition} \textbf{Everything! This treatment cloud potentially}$

Very important

The possibility to have an independent life!

Hope for a better quality of life.

Hope, the most important word in the whole World nowadays

Everything! For a very dear and loved child with PWS

Everything! Save the lives!!!

Family

Everything. This treatment could potentially save the life of our loved one with PWS.

Everything. This treatment could potentially save the life of our loved one with SPW

Save the life

For your curate

Survive

Hope and cure

Everything! This treatment could potentially save the life of our loved one with PWS.

Improvement in the quality of life of the loved one and his family

It could save the life of my grandson

Hope

Quality of life

A life of a child

Hope and quality of life

It means the hope of my daughter having a long and healthy life.

Everything! This treatment could potentially save the life of our loved one with PWS

Life

Important to him

Behavioral, hyperphagic and metabolic patterns improvement that would make all the difference for both social, psychological and mental development.

health

A possible salvation.

Important

Believe

New life for him. This treatment could be the difference in his life.

Life quality and new ways to live

The improvement of my son's general condition

This treatment can save his life.

respect, strength to try harder and a better life

This treatment could save the life of my parent

Qualidade de vida

hope for a better future.

This medicine is proved to controls the hyperphagia, the hallmark symptom of PWS, as

well as several other symptoms such as aggressive/destructive behaviors, fat mass and abnormal lipid profiles. With this medicine, we will be able to have hope that our beloved ones will have a better quality of life.

this treatment can give a lot of life.

an opportunity for a new quality life

Decreasing the risk of the child to become obese and having related health issues, besides it would help to live a fully independent life.

hope for a better quality of life!!!

Allow to relieve the intensity of the symptoms, to allow to live more and better.

Better life

Everything! This treatment could potentially save the life of our loved one with PWS.

More quality of life

A chance to avoid the hyperphagia

Better quality of life

Hope and quality of life.

Everything! This treatment could potentially saved the life of our loved one with PWS

Everything! This treatment cloud potentially save the liga of our loved one with PWS

it means a great victory and a great advance for my loved one! A life change

Everything. Better quality of line

He could enjoy life in a more normal and less stressful way

It would change everything. My son is very anxious, binge eating hv°s increased. This medication would mean more than hope is our chance to change our lives.

Mean a lot! Mean health and life

A better life.

it would mean the possibility of a better evolution in all areas of his life, as well as a possible independence of both him and his family

What would an approval of DCCR mean for your loved one and your family?

Hope to thrive.

It world increase some years of her Life, healthy life!

Hope in the gain of quality of life for my children.

Live, love, health

We would certainly provide a better quality of life, not only for my daughter, but for us, the parents. It is a disease of daily struggles!

Independence, life!

Her treatment and a good interaction with the family

It would be excellent for the health of our relative and also for the joy of the whole family.

Everything! This treatment could potentially save the life of our loved one with PWS

Important to him

Hope

drug on the market as soon as possible!

Relief

Very important

Provide a better quality of life for the patient

Improve quality of life

This treatment could save his life

Everything! this treatment would save my daughter's life. Obesity is serious.

Would be the chance for my daughter have evolution in Pws and my family have hoped to see this moment.

A better quality of life

Improvement of behavioral, hyperphagic and metabolic patterns that would make all the difference for social, psychological and mental development.

It can save lives

Everything! This treatment could potentially save the life of our loved one with PWS

Everything!! This could give them a better life!!

quality of life

It will help a lot in controlling the disease.

It would Change everything, his anxiety, hyperphagia, satiety, behavior and his cognitive

Would mean a chance for him to have a better life.

hope for the most normal quality of life possible.

Everything. Better quality of life

Probably a life saver

Better Life quality, better development chances, best treatment

It will change everything in her life, provide quality and prolong life to her

It would mean the possibility of choices in his life. In terms of where he can go to school, whether he can work and function independently.

Better quality of life for our daughter. Less anxiety for all parties involved

It would mean life saving opportunities and my daughter will actually have a full life.

Its life. Its giving my child a life to to be independent and live normally without feeling hunger every time. Give my child the strength physically and mentally to be stable and face the worldly challenges that we face in our daily life. Our kids challenges are additional to what we are able to normally.

Help my daughter focus on other aspects of life, not only food

miracle

A chance at normal life. A better quality of life my daughter.

A much improved quality of life, a healthier outcome and improved life expectancy. If this treatment helps the hyperphagia even by a modest margin it will be a vast improvement for our child

A potential treatment

A huge quality of life improvement for our whole family. An oral medication the combats so many of the debilitating symptoms of PWS would vastly improve the lives of our entire family. Most of all our son would be one step closer to a normal childhood.

Devastated is not a strong enough word to describe how I feel about the thought of my son growing up to live every hour of his life feeling constant insatiable hunger. It is a cruel and terrible way to live. Insatiable hunger is just one of many medical issues my son will face as he grows - others include extreme behavioral issues and mental health issues. Unfortunately there is currently no approved treatment for these extremely challenging aspects of Prader Willi Syndrome. DCCR is the hope that the Prader Willi community has been waiting for. It is proven to be a safe and effective treatment for the worst symptoms of Prader Willi Syndrome. It gives me hope that my son can live a life of fulfilment and quality. The thought of a treatment existing that he cannot have is upsetting to say the very least. Our family is feeling pretty defeated right now to be honest. Having access to DCCR would be life changing for my son and my family. I am begging, not asking, the FDA to please reconsider their decision to ask for an additional study and to approve DCCR as a treatment for Prader Willi Syndrome as quickly as possible. In a rare disease population, getting enough participants who have not already participated in a study is difficult as well as raising enough funds for the study. Further, it would be incredibly upsetting to see the people who are currently receiving DCCR from the trials and THRIVING need to stop taking what to them is life saving medication. Although Prader Willi Syndrome only affects 1 in 15,000 births, the lives of those who are affected and their families are often devastated by the symptoms of the condition. Please Please reconsider your decision and make DCCR available for the treatment of Prader Willi Syndrome as soon as possible.

Save the life of this baby and that in it self is worth it

It is in my child's best interest to have a drug to battle hyperphagia

Potential of hope to love a full life.

Hope for more quality of life

It would mean the world to us.

It would mean hope for a very uncertain and at times scary future. It would mean providing our child a chance of independence and our family

What would an approval of DCCR mean for your loved one and your family?

a chance of normalcy. It would be helping a population that so desperately needs options for treatments. It would be life changing!

This treatment could save lives

Approval of this drugs means Ludovic will live a better life and address one of the most debilitating effect of PWS - hyperphagia. This will give him a chance to live comfortably and increase his chance of living independently.

It would ultimately mean the world. A better life for them and a piece of mind for me as his mom

It would means that my loved one would stop to eat lots.

A chance for our child to live independently

Better quality of life. Save the life of my pws daughter.

It would save my child from suffering from years of feeling starving from hyperphagia and the associated behavioral effects it may cause, and increase not only his but our whole family's quality of life.

Currently, there are no treatments for hyperphagia. With the potential for this drug to address that life-threatening ailment, my daughter may be able to become independent one day.

Hope for twin babies living with PWS

It could mean a future with normalcy and opportunities for peace and enjoyment instead of constant upset. It would mean better health for our entire family.

A future for our child and those like her. Hyperphagia is one of the most debilitating aspects of this syndrome and prevents so many from living normal lives. Not only the person with PWS but those living around them.

It would mean hope to having a closer to normal life for the future and now. Not only for our daughter with PWS, but her sister who's day to day life is constantly impacted by her younger sister's needs and for us- as a peace of mind knowing that with that insatiable hunger controlled, our daughter can live her life to her fullest: hold a job, perhaps meet the love of her life and possibly even live on her own with minimal help. Her hunger is her one limiting factor, her big closed door to life... this drug is the key to open the door to her future.

This drug would be life-changing for my son and all PWS patients.

This would mean that Bennett had the opportunity to live life full without the constant feeling of hunger.

Hope

This treatment will change the life of my daughter. She is a high functioning charismatic little girl who could do amazing things in life, if it weren't for her constant struggle with food and the anxiety and obsessions it causes her. We need this drug.

A better life, possibly means life or death for my child or others. We NEED this medication. We cannot wait years

Progressive steps towards a better life and more options

A full life with possibilities

My daughter is 20 months old and has PWS. This drug cod be a game changer in helping her lead a normal and healthy life.

It would mean a lot. More chance for my child to get a normal life

A life.

A much better life, the potential for more independence like those of her peers.

Better relationship with our daughter, less disruption at every family occasion, and BETTER HEALTH FOR HER!

Less temper tantrum's, more active, possibility of weight control, getting him off anxiety medication, perhaps getting a small job in future.

Yes

A treatment option that doesn't currently exist. It means hope for our family.

An approve of DCCR would mean that our family could live without being on a constant and heightened guard to ensure food security around our child. We could relax a little and give our child some independence. Our anxiety and hers would be reduced and we wouldn't have to fear her gorging on food and potentially rupturing her stomach if she gained access to food. In short, a medication, this medication, that would reduce her hunger-drive, would be

life changing for our daughter and for our family.

He would mean everything. The possibility to live and thrive without the constant anxiety associated with hyperphagia

Life changing treatment to have a better outcome for my son.

It would mean the world. Imagine a diabetic not being able to get insulting to help control their blood sugar. Hyperphagia is THE most debilitating symptom of this complex genetic diagnosis my twin daughters are to face in the future. To be able to offer them this lifesaving drug would mean so much. Food is such a huge part of our society, as much as we can teach them coping strategies; this drug is another option we as parents would have to help deal with the every day challenges

A safer life, more control and peace of mind.

The possibility to upgrade the quality life.

That we get to support our daughter and potential help her with one of her biggest challenge

Improved quality of life.

My son won't get the chance to try this drug, but there are so many families that will benefit from it. This drug will be life changing for so many.

improved quality of life

Everything. it would make a tremendous different to Rebecca's quality of life and health

Hopeful help her to feel full. So we can live a more normal life. She's always hungry. She has been caught eating food in the garbage at school. Now she's working, she's been caught stealing other people's lunches. All our food is locked at home. She's been struggling with this for years. This has been affecting everyone in our family. I wish this drug would be available in Canada too.

Everything!!! This could save my daughter's life.

A treatment to live independently

It would mean a more peaceful life for my loved one and my family. The effect of this drug is so significant on managing PWS symptoms and it would cause a tremendous positive impact on the life of so many patients and families. Let's

What would an approval of DCCR mean for your loved one and your family?

reconsider this decision and act fast for the well-being of so many patients.

It would mean hope for her to live a fulfilling life without the devastating hunger associated with PWS.

A better future and possibility of living independently

A huge relief to help with the most debilitating effect, hyperphagia.

It would be life saving

An approval of DCCR would mean our beautiful daughter could have a future free of the torture of hyperphagia. A life of independence and joy. The thought that she can be robbed of this chance is heartbreaking to our family. We NEED this drug for our community.

Better quality of life ...improved mental health for pws youth and everyone in the family that deals daily with struggles of family member.

Better future

For my daughter to live fully

Hope

An approval of DCCR would mean a new treatment for my daughter's constant hyperphagia and some of the other behavioral challenges she faces due to her diagnosis of Prader Willi syndrome. In short, it would mean an step forward for her in being able to live a life free of some of the challenges of Prader Willi syndrome and having independence in her adulthood.

Hope that she won't be hungry, constantly distracted by hunger

This would make a huge impact on her life, her future and the people surrounded by her. This drug was such an exciting thing for her and our family.

Less stress about some of the issues with PWS

A more hopeful outlook for a normal life for my son. Less stress and worry and an opportunity for him to be a normal child.

Everything

Reduction of symptoms/effects or inevitable hyperphagia.

It would mean the world to us - my daughter can have the hope of a healthy life

An independent life with opportunities to live like any other human.

Life changing

Better life and independence

Hope for a new future for my son

A change at a life where an everyday thing like food isn't a constant threat.

The opportunity to live a life without fear, without crazy restrictions, without a helicopter parent. Just the opportunity to live.

Avoiding life, Äôs difficult due to hyperphagia

A treatment for a serious condition

The end of hypervigilance regarding food safety, and the fear of a premature death for my child

This is the only hopeful drug to manage the symptoms of PWS that limit my son,Äôs life.

This drug is a treatment for hyperphagia a potentially life-threatening disorder for my daughter. It also addresses other difficult symptoms of PWS such a as aggression.

A better life. And some weight loss.

There are currently no other drugs available to address hyperphagia in the PWS population. It is often the main reason that prevents independence. This drug could be a key player to offer my son the opportunity to live more independently.

I can't begin to say what a life altering opportunity this would be..

Approval of DCCR would mean that our son would have access to a drug that could help him manage the hyperphagia that plagues his life with the effects of never-ending hunger that could ultimately lead to his death. This would provide him the ability to live a better quality of life.

It would mean a better life for my son and out family.

A chance at a better life - so it would mean the world to us.

It would mean the world to us. Every day is a struggle and we need help.

A chance at an independent life. Health and happiness

A chance at a happy healthy life

Everything

Life

to have control on her eating and allow a healthy weight

It would be too important to control your food cravings

A better quality of life

Security and independence

Save their lives or at least minimize hyperphagia, main symptom of SPW

Basically, it could make a huge difference in his day-to-day quality of life. Hyperphagia is one of the great problems that you must face associated with anxiety, which makes him. dependent on that rare and bad condition. because it generates other behaviors due to anxiety such as uncontrolled impulse due to anxiety if this is approved and positive it means that God has answered our prayers.

change our lives for good

Improve his life and health.

improve her intelligence and decline her appetite for food

A potential improvement in symptoms that no other alternative can do at this moment.

life expectancy for my son

health, chances for a better life

It could potentially be a lifesaver, and would improve quality of life for my son and my family

A better quality of life for my daughter with PWS and our family.

The treatment could really help a lot of families. All members in a household is affected by the symptoms of PWS.

What would an approval of DCCR mean for your loved one and your family?

A safeguard

Long life no anxiety for any of those involved hope emotional stability

Its great

To have better life quality

A great change in life

Lifesaver

I think it will give my son a normal life

Mean healthy and normal life

Everything! I want my son to have life without hunger.

Hopefully it would become approved in worldwide use.

It would Mean that we can atleast ease everything that our loved one and us strugle for every day in life.

Hope for the future! A chance to make my daughters life easier with PWS

Possibly living an independent life as an adult as well as other positives too long to mention

More Harmonie in Family, less Crisis

It means much for our family

better live

More quality in life

Future perspective without fear and severe psychosocial distress

Health

Better live

Independence for her life, to live her own life

More independence for her life, own control, relief in everyday life

It would have the potential to our kids and our life much easier.

Hope that a medication is available for our child before hyperphagia kicks in - this drug can help

eliminate many obstacles and battles for many people with PWS. Doctors believe that DCCR can help in many ways, and I believe that, too. So, please reconsider their application and give PWS kids and their families this medication.

Hope that a medication is available for our child before hyperphagia kicks in - this drug can help eliminate many obstacles and battles for many people with PWS. Doctors believe that DCCR can help in many ways, and I believe that, too. So, please reconsider their application and give PWS kids and their families this medication.

A better life with less anger, fear and more quality

A big hope that a medication is available for our son before hyperphagia starts. DCCR can help eliminate many obstacles and battles for many people with PWS! Doctors believe that DCCR can help in many ways, and I believe that as well, as our son does not have yet the hunger and for a prevention, DCCR seems to work! Please, please, please reconsider the application and give PWS kids and families this medication.

Hope is given to reduce their suffering

Finally an option against one of the major PWS problems

Participation and normal life

Hope and safety

De-facto curation and switching-off this one main impact, the eternal appetite. Ir is like Insulin for Diabetis, yes you have to take it Evers day, but you can live a quality life in society.

Life changing quality of life and a possibility to live a more independent life.

Freedom

Hope for a better life, no hyperphagia, a better health state instead high fat mass with the consequence of morbidity of a just young person.

Life changing!! For my son to not be a danger for himself. A life threatening danger!

Life quality. Less mental stress. Self-sufficiency Participation normal life

Stop hyperphagia

Hope that the medication is available before hyperphagia kicks in

There is nothing on the market to help people with PWS with their hyperphagia and related symptoms like anxiety, behavioral problems, etc. DCCR has shown positive results and it would give me an option of treatment once my daughter starts developing hyperphagia. I am very scared of the future, especially because I know that there will be very little to help her, if DCCR is not approved. I have the hope that DCCR can reduce the physiological hunger and can prevent the development of the strong psychological desire to eat as a consequence. I believe that once this desire is established it becomes more and more difficult to treat in any way. Therefore, the time-scale of approval is very important.

As parents, there is nothing in this world that would make us happier at the moment that seeing DCCR being approved. The level of suffering due to hyperphagia and psychological challenges that are daughter will soon have to endure and the level of stress this will pose to us is unimaginable and there are no options on the market. In the area of rare diseases, we do not have 10 other companies waiting to fill the void and we do not have dozens of clinical trials in the pipeline. DCCR might well be the only shot at realistically changing the course of this condition for our children in this decade. We do not need perfect, we are desperate for options right now. DCCR is safe and has been proven effective, especially in severe hyperphagia. The results have been unprecedented in PWS, as hyperphagia seems extremely resistant to tackle. This drug is a game changer for us and can give our daughter and other children with PWS the much needed quality of life to the extent never seen before in PWS. Therefore, please reconsider your decision!

Living a normal life

it would change theirs and so many families lives for the future. It is the only option available to treat the most horrible, devastating and debilitating symptom of PWS. It is absolutely critical that the drug is on the market now as so many people need it. There is no time to wait!

Everything. We need help. My son need this help. His hunger and his behavior getting more worse with the time

Better life

A chance to freedom

Stop the suffering.

What would an approval of DCCR mean for your loved one and your family?

An independent and more fully life

Better quality of life

Very helpful

It will be very helpful to control hyperphagia and behavioral issues. With this drug will get some relief for my kid and family to lead normal life.

A new and independent life

Life changing

It would mean freedom from behaviour problems

It's is very much essential and will be life changing to our kids

Immediately

Dignity life

It means a lot .My child will be able to lead a life like other children.

It will mean a new life not only for my child but for my entire family

Access to the solution for life threatening issues in PWS children.

Improved life for my son.

This can change the life of our PWS and lot of hope behind this study.

It will be life saving drug for my child and I request you please clear this as soon as possible

It would be wonderful if a drug for hyperphagia gets developed before the onset of that phase

It would be really helpful ..if u can expedite the entire process of releasing this drug to the Market. this would be great help to us and many families like us.

A big change in my daughter's life and our life like a family

A big change in my daughter's life and my family

Everything

Life saving for family member with pws and life changing for rest of family.

A better quality of life for us all

It would mean less outbursts of anger, less aggression and not as much food seeking behaviour, it would save my sons siblings

A treatment option for the most challenging part of PWS

some degree of peace of mind that the anguish of hyperphagia might be reduced by the time my daughter is at risk

It would give improved quality of life. Help avoid obesity which will cause her an early death if this drug is not approved.

Hope. The opportunity for my daughter not to face excruciating hunger pains and seek food every single second of the day. This in turn will decrease anxiety, temper outbursts and depression. It would mean everything to us as it would be the only available drug to help people with PWS.

This could potentially save my child's life

Blessing

New life! Freedom!

It would change the life of our son and our whole family in profound ways and enable him to life a life free from the terrible effects of hyperphagia

Quality of life.

The world

It would mean the world to my family and most of all it would change my daughter's life it this drug was available to her.my daughter nos now 10 years old and she is realizing she is "different " to her peers and aswel it would improve the quality of her life if this drug cuts out her daily hunger and get rid of the urge to want to eat all the time.

Everything

It could save our loved ones

Hope and less pain & anguish for our daughter . Pws is cruel in so many ways and this would be life changing. It could mean the difference between aiming for a life of independent living and the possibility of living without constant supervision. Compared to the current expectation of living in a care home under constant supervision due to the consequences of life with hyperphagia. This drug could give Cora a chance at life.

A better healthier quality of life, not just for our child but the whole family. It will also improve mental health as stress levels around food will decrease.

Hope

This is vital, this drug works and my child cannot be without it. Please approve DCCR as this is life changing for my family and my child..

A chance at a more typical life, which would be life changing

it could mean the help my son needs to have a normal life, hyperphagia is one of the worst prader willi symptoms, which prevents both them and their families from enjoying life. Prader willi does not harm only those who suffer from it but also those around them. we need this urgently

Hyperphagia is our single biggest concern as parents. With no treatments for PWS Children surely they deserve a chance ??

It would mean hope after an absolutely devastating diagnosis- that threw our family into complete turmoil. And to think the only stand of care was growth hormone and nothing much else in the 20 years. I think if the people in the FDA would take another look and review trial 3 it would give all the carers of people with PWS a lift that they need to continue caring and a glimmer of hope that we are not being forgotten. Please don,Äôt leave people with PWS behind.

Improved quality of life

Life

The possibility of living a more normal life without hyperphagia.

Help to better her condition

It will give my loved one a chance for a better independent life

improves your life, advances!

What would an approval of DCCR mean for your loved one and your family?

hope that my daughter can have a life.

DCCR could provide the opportunity to decrease the intensity and/or frequency of the aggressive behavior, emotional outbreaks and food compulsion that dominates in our household. This would result in decreased stress and anxiety for the entire family, better results in school and work for the entire family (which would lead also to a more stable financial situation). In short - a higher quality of life for all.

It means a lot

It would be a huge help and motivation that our little girl someday will have an independent life. Now we have a fear that she and our family will not be able to live life full. Gabija is an amazing, positive, always smiling kid and we want that she would be always happy and able to reach her dreams.

This would mean that our family could live a normal life without hyperphagia

More hope for a devastated family.

It can save their life!

To improve the quality of life for my daughter, giving her a better future and potentially saving her life

It would be life changing. It would address one of the most difficult aspects of the condition.

Better living

this drug on the market as soon as possible

Hope and a better life quality.

Any medicament which can help alleviate the issues for PWS is a welcome move considering that as of now there is nothing which can be effectively help these kids.

This treatment will help our girl and many others with PWS to have a better life and without life threating problems.

Controling the eating is a game changer for a person with PWS. It will help us to focus on other aspects and improve the overall health.

Health for my daughter. Freedom in everything in our family.

That he could live without the constant hunger, and that we as family could breath a little more

and don't have to check his every move. It could also secure our future from aggressive behaviour.

Better future for living. Less worries. That my kid will be able to enjoy his life like others.

A much happier life

No words enough to express the feeling and happiness will bring to our lives.

Hope for our little girl to live a fuller life where she can participate more independently without her family and loved ones constantly worrying about her eating too much. It will reduce stress not only for her but for everyone around her. It might even make it possible for her to live independently one day, rather than stay with us (parents) her whole life or being forced into an institution to be monitored 24 hrs a day. Just a chance for more happiness in life

Everything. Releasing her from some of the anxiety and challenges associate with hyperphagia would be such a life changing situation

More options for treatment the better for all families helping young and old people with PWS

Remove/ reduce the negative effects of a significant obstacle (symptom) that could alter quality of life for our daughter and those around her. We fear the effects of one major symptom our daughter may get as she gets older and the implications this will have on her future and ours. If this drug can reduce the effects of this symptom, we very much want it to be available. For her freedom, well being and health. This has wider effects improving the quality of life of not only the patient but those who interact and care for them.

This would reduce our fears for a future life of misery and deprivation for our beloved son, that he will join the sad ranks of people with PWS who suffer from the wretched hardship of forever feeling hungry, the terrible risks of eating dangerous and toxic non-food items, and the social hardship of being unable to focus on social skills because of his unmanageable focus on food, as well as the health risks and social unkindness that come with obesity.

Everything!

Hope restored

A new life. More independence. Better focus on school, friends, hobbies.

The are all for us, new hope.

Hope for a better quality of life

It can change our lives, my dougter live quality can improve with this.

this can cater normal life for all of us

Great help

Our child could life like a normal child and in the future he could go to job and have family

Change of life, freedom for my child , independence.

Easier Life of whole family, friends, school etc.

Peaceful life for my Child

Changing the quality of life. Possibility of normality

Normal life

a better life and a better future my child could be independent

The approval of the DCRR drug for people with PWS is a great and the only chance for my family to at least eliminate hyperphagia in our child, which is the most difficult in PWS. The parent molecule, diazoxide, has been used for decades in thousands of patients (infants, children and adults) but has not been approved for use in PWS. In a phase 3 PWS trial, DCCR showed promise in the treatment of hyperphagia as well as several other symptoms such as aggressive / destructive behavior, in reducing fat mass and improving metabolic parameters. If the drug was approved, it would mean a chance for a better tomorrow for our family.

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What would an approval of DCCR mean for your loved one and your family?

mean a chance for a better tomorrow for our family.

Our life would be easier.

It would make our life much easier, especially for my son. He would be able to be more independent and do better in the future.

I believe that DCCR will help my daughter to live the normal life- go to the school without supporting teacher, give her an Opportunity to stay at home alone in the future, to live alone as an adult, to work as a normal, healthy person... and that all will make her happy and make her life longer..

A chance for a dignified life for the sick and the whole family

I am a single mother of 3 children, I have been struggling with my daughter's disease since I started. It would be very helpful not only to my daughter from PWS but also to our whole family

It would change the whole life, it means a chance to live "normally"

It would mean a great chance for better live for our baby and whole family.

That would mean a great chance for better life for our baby and whole family, greater independence for our child in the future and lack of fear for the rest of our lives

My Child has a chance for normal living

Better functioning of The son

Chance for a better life for us and our daughter

Our life would change for the better. We wouldn't have to hide with food. There would be peace.

The drug would change a lot of things. Among other things, I would not hide food at home, the child would not only talk about food all the time. Corka would have a chance for a normal life. You can still list so much ...

more healthy life

Hope for a better life

Change life for my child and my whole family

Almost normal life :)

Making place for new opportunities

Hope for future

It would mean better, more stable life. I wouldn't worry so much about the future consequences of obesity, behavioural problems.

freeing yourself from this damn disease and having a healthy baby

Even small reduction of hyperphagia would change the quality of my family's life. It breaks my heart when I see my small daughter suffering from hunger. It's so difficult with small children, because it's not possible to explain why they can't eat. They just don't understand the restrictions. It will mean the world to me and my family if our daughter with PWS could have even small chance for independent, slightly cos to normal life. I believe in safety of DCCR, but even with risk of some small side effects I would give it to my daughter. FDA I beg you to approve DCCR..

Would give us hope to for a normal happy life for the whole family.

Its Chance to our child whole Life for better

This would mean a return to normal life for Alex and his siblings, and a chance for some independence in his life.

In the end, we would experience normality, forget about the child's illness. The doughter would be calmer, happier. In turn, the younger, healthy daughter would experience sisterhood, which she dreams of.

Quality of live. Survival.

A much better life

The ability of having a life with quality not only for my baby but also for our Family and her brothers!

giving a life without torment to innocent souls

Health and place for my family.

Comfortable life and confidence in future

This medicine will mean a lot to my child. My child will be able to live like a normal child and not always go on diets.

Eliminating eternal hunger

This is a chance for my child to live a normal life

It is the only one cure to save life of our child and other people with PWS.

Hope for the future

The medicine will save my child from the constant search for food, tantrums and will allow him to develop intellectually, and not get hung up on food only. The family will be able to live in peace and not hide food.

calm state,

It's very important for my family

step to the normal life

This is the only chance to help my son in the fight against the main problem of Prader Willi syndrome

My daughter get a chance to live fulfilling life

Hope

Better life for my daughter

It would give my son at least option for brighter future. He is funny, happy, loving little guy,but bad days for him are about to come and DCCR could change that!

The world

Less stress around food and a better chance for a good life for my son

Improved quality of whole family.

To live "normal"

there is a chance my daughter may live a semi normal life. She is currently obese through very low metabolism and other pws conditions. Without it she is faces life threatening conditions in the future

I would mean the world to me not to worry so much as what the future holds for my little girl. I cant even imagine what it must be feeling like to actually feel like you are starving for the rest of your life. Currently, I am battling to get her to feed, and in a few months time, I would probably battle to get her to stop feeding, although I know that in her mind she would feel

What would an approval of DCCR mean for your loved one and your family?

like she hasn't eaten in days.... I cant even imagine what it must be like

It would significantly improve the Life quality of my child with PWS and our whole family, and we could have hope for a happy future

The possibility for my son to have a full and independent life

A better life

Hope, independence.

The possibility for her to live life fully

Because all the people with this PWS, will be happy, and independent person.

It would be a dream. My loved one could be live better, and his family same.

It is the only option we have.

Calidad de vida

This treatment will change the future of my son and all other children and adults affected by PWS. It will contribute to mitigate the most terrible effect of the disease, which is hyperphagia. Overcoming this challenge will definitively change the course of his life, and our family's. If there is a possibility of helping all the people affected by PWS, all the family and caregivers, please help us, think of what is right, and do not condemn them due to other interests. There is more than enough evidence that demonstrates the treatment is effective. We are real people, living real lives.

It necessary for the actually families

excellent, hopeful, great for counteracting the PW's symptoms

Peace of mind, tons of tranquility, my kid can do many things, puts lot of effort and can keep the pace with their peers, having a little help from a pill (not another injection!!) will have a great impact on his life as he will be able to live a normal independent life going forward (with lot of effort and goodwill compared to others but hey I take that chance!). DCCR will also have a great impact on the family, just imagine Christmas, friends or any other social event focused on food (almost ALL social events of adult life are focused on or surrounded by food) Currently there is no option, WE HAVE ZERO OPTIONS and the rest of the projects in the pipeline are maybe 10 years from being commercially available worldwide. Perhaps we

can find a cure through novel techniques in the future, but it will be in 10 years, and 10 years is a lot of time for so many people, you cannot decide this for the families and their kids, please, please take into account the impact you are having in so many lifes The medicine is safe and it works, if it can make a dent on the worst-case scenario (amazing), I can tell you, it works. You cannot take this decision to us while using warp-speed vaccines, please leave us the choice to use it

An independent future...

Hope

Live changing, hope

It Would be a game changer for my sons life! His future to be able to live independently, to not suffer, to live his life like any other person.

A better life

We need medication now for our children. We can't wait no longer. That will give our children a hell. Everyone needs a healthy life. This will help our children.

A life, that is the most important! Being under the craving and the threat of death is not what I wish for my daughter

It would mean a lot. So he could live a more normal life when he grow up

To live a more independent life as a family and to give our son a happy life without the severe hunger issue.

Everything

It will mean a great different for all off us.

It will mean a new life for my kid and my family

DCCR could give my son the opportunity to a more comfortable life in the everyday struggle he is fighting and this would increase his quality of life tremendously. This medicine would not only create a better life for my son but also for my older daughter if we don't have to put all our energy as parents to keep our son from eating. The medicine could give us all a more stable way of living. We wish nothing more then the best for our children and this drug cane really make a change for the better.

It would mean the ability for our daughter to live a fuller life. And it would mean everything for us as parents.

Means a lot

Everything!

Hope for the future

So that my daughter does not have to live with hyperphagia.

It will offer a brighter future for my son and offer hope to everyone who loves him

A chance of a normal life where our daughter and us can look at food as a positive thing and not a trigger for obesity, breakdowns and more.

It would mean that my child would be able to live more normal life than without dccr. It would mean that he will be able to have friends, to have his own job even maybe his own home and family. He will be able to Live Life Full. It would help alleviate stressors involved in managing PWS on a 24 hours basis.

you will save a child from torment, who can think of nothing but hunger

Extra support in her life!

New hope

The chance for my child to live independently, for us not to worry about what would happen if we weren't around any longer and for our other child to not have the pressure to have carer role as opposed to a standard sibling one.

Everything. It would be wonderful if I could take away the burden of hunger from my sons future

Everything

A change in life and hope

A life changing outcome and a better quality of life with less drain on NHS recourses

If it worked for my little boy it could make a dramatic impact on his life and our family's life. It brings hope to me as a parent if there is an option because it's worth the try if it means it could really help PWS.

Peace and happiness

Would help him live a happy and healthy life along with all the other pws families

What would an approval of DCCR mean for your loved one and your family?

A means to trying to enable our children to live happy, fulfilling lives and reach their full potentials.

Hope that she can live a happy, healthy and independent life.

It would help with with the biggest symptom of the syndrome and prolong my daughters life

Potentially, a route to increased independence for our loved one which would improve their quality of life, reduce the impact on family, and save government agencies money in the long

It would be life changing for my little girl and give her the best chance at a normal life

To know there is a drug out there that will help my daughter and others with PWS and stop their suffering would change everything

The world

A hope and bright future

Potentially life changing

With very limited options open to those with PWS the approval of DCCR by the FDA would represent a glimmer of hope of a more independent life for our loved ones. Personally for me having a baby son with PWS hearing that this application has been declined feels like a real kick in the teeth, as a family we worry for our baby boy as we know it will only be a matter of a couple of years until his hyperphagia begins and knowing that there is nothing currently available to help with this will be a growing anxiety as our son grows older. With growth hormones being the only available treatment for PWS sufferers in the last 20 years the approval of DCCR could potentially be a huge milestone for all of those affected and will be a source of comfort for their families.

Everything

She can live a free life without addicted by food which means she won't need 24 hours supervision on food.

DCCR will help my child's behavioural improvement, food seeking to lessen and body fat to lessen. This will have a massive impact on her quality of life for which striving for as close to normality should be a goal for any caring parent or medical organization.

A normal life. My daughter lives in residential school as I can't look after her.

Robyn can have the opportunity to lead a full and independent life free from the agony of hyperphagia.

It could be life changing. It would represent hope that our daughters future won't be blighted by constant hunger.

Freedom

It will significantly improve my daughter's life and potentially save her life

A chance of a brighter future

A happier and more relaxed child

Better life for my son.

Changes to weight which would help to encourage exercise and have less of an impact on health ie breathing sleep apnea osteoporosis. Influence destructive challenging behaviour for the better.

Quality of life

Everything! It's been proven to be safe and has the potential to improve the quality of life for people with pws; a drug worth having!

It would stop my baby being tortured everyday

A real childhood and a chance at a normal adult life with her own career and family

It could give my child the chance of a relatively normal life style, independence, health benefits and potentially save their life. The pain and suffering for the whole family would be massively reduced.

Chance to live an independent life.

Longer life

It could have a huge influence on the quality of life our daughter is air to have. Ultimately it could be a matter of life or death

It will give my son a better quality of life and hopefully extend it

Help and support

Control food behaviour and emotional compulsive aggressive behaviour

It would give Sami a better chance at an independent and fulfilling life and minimize the challenges he will face in later years

It would potentially transform her future and give her the chance for longer, healthier and more independent life.

Mean a lot

Hope for the future of my son and others like him who are staring at a future full of life threatening hunger.

Everything

Hope

It'd mean absolutely everything. It'd mean my boy wouldnt be as hungry 24/7 - can they just imagine what that must be like???

It could prevent premature death

It would be a life line

It would mean everything to my child and our whole family. We would have a chance at living a normal family life and my child may even be able to live an independent life one day.

DCCR is the only approved drug that contributes affectively to symptoms of PWS. We need this drug to be available ASAP.

Independence and longer life expectancy

It would mean everything to us and could save lives and be such a huge help for people with pws

It coupd potentially be life changing

A chance to improve quality of life

At 5, my boy already showing signs of hyperphagia. If food is around (at home and pretty much everywhere we go) he can,Äôt focus on anything else. He frequently gets upset and aggressive. We avoid so many places and situations. This is no future. If there is a chance of him not feeling like this then we have hope for a future and future for an independent life for him. Please don,Äôt put a ston to this

Life changing please go a head I beg you

So much suffering and anxiety would be eased for our daughter.

What would an approval of DCCR mean for your loved one and your family?

This treatment is the only option for our loved ones with PWS. It has been proven as safe and will increase quality of life for many. It is the only way to help reduce the societal pressures which face our PWS community. Please don't delay this drug our children need it!!!!

Everything! Increased normality, quality of life, reduction of societal pressures which are devastating to someone with PWS. It is shown to be safe. Get it out there!

Hope for a different future and potential independence for my child as she grows, the ability to be able to achieve things we never thought possible for her, happiness!

This treatment is the only option for our children with PWS. It has been proven safe and will increase quality of life my child and for so many others. It is the only way to help reduce the societal pressures which face our PWS community. Please don't delay this drug!!! My child/our children need it

A lifetime of less worry about our baby,Äôs future

Life

It would give us hope for a more independent future for our wee boy without the challenges and pain of hyperphagia This will save her life potentially and give us some hope for the future. Hyperphagia is miserable and life limitin. We need this ASAP

It will change the lives of our warriors with pws, it will improve our living and this treatment could potential safe the life of a loved one with pws

Hope for the future

Potentially save my daughters life from aggressive food seeking. Alone with all the other people with pws

COMMUNITY SIGNATURES

Parents and Caregivers of Individuals with PWS in the US

Signatures

Parents and Caregivers of Individuals with PWS in the US

Andrea A Basem A Renee Aalund Rachel Aazzerah Aaron Aazzerah Lina Abavineh **Bliss Abrantes** Jonathan Abshire Jennifer Abshire Priscilla Acevedo Stephane Adam Amie Adams Kelly Adams Lisa Adams Tina Adams Danielle Adamson Nichole Adamson Mary Adkins Sheila Afzali David Agarwal Janice Agarwal Chris Agnew Tracey Agnew Neha Agrawal Hugo Aguilar Jessica Aguilar Eric Ahlgren Arsine Akarakian Malka Akerman Elsa Alago Mary Alberg Shea Alexander Kaitlin Algeri Lynn Algeri Dean Allen Alisha Allour Sabah Alsamman Daniel Alsnauer Judy Alsnauer Celina Alvarez Dernitza Alverio Linda Aman Celia Ambriz Amillia Amick Aimee Anderson Erin Anderson **Graham Anderson** Jessica Anderson Kori Anderson Lisa Anderson Mervyn Anderson Susan Anderson Daniel Anderson **Grant Andrews** Hannah Andrews Jade Andrews

Jennifer Andrews

Jennifer Andrews

Maggie Andrews Suzan Andreww Thomas Ankney Jen Ankney Zayd Anwarzai Aaron Appelbaum Sasha Appelbaum Kellie Aragon Jason Archuleta Christina Archuleta-Tancik Christina Argo Julie Arias Chris Arias Yafa Arkin Wendy Armelin-Barron Stephanie Arnold Allison Arnold shifra aronoff Tanya Arrellin Gary Arstein-Kerslake Aracely Asencio Roxanne Ashby Tammy Ashley Arielle Askins Joan Asma Esther Atempa Jodie Atkinson Alvcia Atriano Carrie Austin Ed Austin Jessica Austin Amy Avart **Christopher Avart** Lori Avart Lori Avery T Avery Doreen B Shana Bachus **Brittany Bacon** Amy Badillo Amy Badillo Trenton Badillo Franny Baehr Jen Baffi Carrie Bagg Riad Baghdadi Rita Baghdasarian Kristin Joy Baguio Eric Bahr Traci Bair Ashley Baker Rusty Baker Becca Baldwin Gabrielle Baldwin Erin Bale

Cinda Ball

Curt Ball

Jeremy Ball Chelsea Balumas **Bruce Banks** Nikita Banks Brook Barker Elizabeth Barnes Yvette Barnett Linsey Barone Mike Barone Paul Barrett Ashley Barthold Christopher Barthold Stephanie bartlett Laurie Baskin C. J. Bastian Dana Bastien Chris Batcheller Katie Batcheller Amanda Bauet Kathryn Baughmsn Chelsea Baumann Taylor Baze Melanie Baze Anna Beasley Bailey Beasley **Houston Beasley** Lvnn Becker Shandra Beer Jav Behnken Nancy Behringer **Emily Beitel** Carrie Bell Lvnne Bell Molly Bellacosa Sherri Bellacosa Cari Benn Greg Benn Janine Bennett Jen Bensaid Morgan Benson Shantel Bergantinos Kathy Bergen Sarah Bernas Alicia Bernstein Megan Best Brittany Betrus Christie Bevacqua Katie Bev Sarah Beyer Samir Bham Urvi Bham JOSEPH Biagianti Sara Biggs Amanda Bill Jason Billingsley Deborah Bingham Charlotte Binkley

Ponder Bishop Delray Blanchard James Blastos Jana Blastos Lacie Blattner Julie Bleecker Jessica Blom John Bloom Sheila Blythe Darlene Bohannon Consuelo Bohorquez Julie Bollig Sherie Bombardier Paul Bombardier Traci Bonali Victor Bone-Allende Jesusa Bonner Abigail Book Rebecca Borgen Elizabeth Borzecki Crystal Boser Jill & John Boughton Kilma Bournigal Kilma Bournigal Marinus Bouwman Carolyn Bowden Laura Bower Marnie Boyd Matthew Boyd Stuart Boyd Theodore Boyer Joseph Bozzelli Mary Bracht Anissa Bradley Randy Bradshaw Laurie Bragg Gigi Brainard Chanah Brandt Peyton Branham Carol Braunschweiger Blake Brenneman Natalie Brenneman Beverly Briggs Nikki Briggs **Emily Brimhall** Neal Brock Jennifer Brock Rena Broderick Steve Broderick **CYNTHIA BROOKS** Melissa Brooks Melissa Brooks Shawn Brooks Allison Brown Ashley Brown **Bridget Brown** Dawn Brown

Lee Ann Brown

Sean Brown Tina Brown Amanda Browning Katie Brundige Dianne Bryden Brett Bryner Leigh Bryner Kyra Buch Jenny Buchanan Ann Buckley Diana Buckner Nancy Burch Christina Burgstaler Meghan Burke Amy Burke Valerie Burningham JAMIE BURNS Jamie Burns Julie Burns Michael Burns Jo Burnside Clayton Burton Doreen Busfield Laci Bush Paul Bushong Angelo Bustamante Valeria Bustillos Danielle Butler Steven Buttie Adelheid Buzzzerio **Denise Byers** Erica Byram Sara C de Baca Jennifer Cabell Rosa Calderon Celika Caldwell Tina Caligiuri Amber Callaway David Campbell Yurith Cancino Erica Canlas **Ashley Canty** Laura Capone Marc Capone Pam Capouch **Brooke Carillo** Reagin Carney Christine Carpenter Deborah Carpenter Axel Carranza Maria Carrillo Roberto Carrillo **VIVIAN CARRILLO** becky carroll Dan Carter Daniel Carter Erin Carter

Rose Marie Brown

John Bird

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Maelinda Case Julie Casey Sharon CASTER Sydney Castile Megan Catalfamo Arianne Catano Jimmie Catano Jason Caul Megan Caul Suzanne Ceppos **Katy Chambers Sydney Chambers Betty Chamness** Debasis Chanda Judy Chapmam Vida Chapman Jeannette Chapnick Stacy Chapnick Ramona Chappell Carol Charles Adam Chase Sharon Chen Jennifer Cheney Rachel Cherry John Cheshier Rochelle Chilcote Veronica Child Joseph Childress Tatvana Childress Amanda Childs Samantha Childs Samantha CHIPETZ Cera Choi Magnus Chow Barbara Christensen Tarvn Christensen Kami Christianson **Betsy Churas** Kara Chymbor Valerie Cirino Glory Clark Rachel Cleary Matthew Clough Erin Cogan Franki Cohen SYBIL COHEN Fran Collins Sujeiri Colon Debbie Colozzi Elizabeth Combs Patrick Condon Jennifer Connelly Katherine Connolly Will Connolly **Tobey Connor** Debra Constanza **David Conway** She Coo Calvin Cooper Rachel Cooper Franca Copeland Larry Copeland **Richard Cornnell** Valeria Corral Nicole Cory ginger coss Christine Costa

Johanna Costello Jessica Cote Carolyn Counihan Jason Counihan Tonya Coupaud Jennifer Court Joan Couture Joan Couture Carleen Covington Masani Covington Jamke Cox Michelle Cox Ryan Cox Sara Cox Angella Coyle Stephanie Craig Jane Cramer Ben Craner Marsha Cresmen Nichole Crespa Paul Crespo Sandra Crews **Ashley Crist** Cory Crist Colin Croshaw Lori Croshaw Ashleigh Cross Kayla Cross Shannon Crothers Dan Crowell Nicholle Crowther Stephanie Cude Lisa Culp Laura Currey Terri Cwgle Sierra Cypert Aimee D'Onofrio Helene Dahan Henry Daly Nithya Das Rachel David Ivan Davila Terry Davis Jeanne Davito Kayla Day Emanuely De Oliveira Barbara Dedona Lara DeForge William DeForge Lisa Dehner **Robert Deines** Jeannine Del Monte Dominique Deleage **Beverly DeLemos** Elena Delemos Laura Della Porta Andrew Demand Melissa Demand **Iillian Demaray** Marilynn Demaray Malea DeNatale-Bonk Patricia Dennette Olsen Susie DePianto William Derby Katie Deshotel

Elizabeth DeSimone

Brieann Desjardin

Charlene Devine Monique Dewarrat Imelda Dewi Terrie Diaz Emily Dicicco Paula Dickey Sandra Dickey Duane DiCola Lori DiCola Charles DiCosimo Geraldine DiCosimo Joseph Dighton Samantha Dighton Elena Dillard Amber Dillon Lucille DiMarco Felicia DiMuccio John DiMuccio Christina Ding-Diep Amanda DiPascale Sam Dirani Josie Dixon Chris Doerr Michelle Doherty **Emily Dohlman** Aimee Dollar Lindsay Donahoe Jenny Donaldson Michelle Donaldson Helen Donnelly Pamela Donor Kim Dooher Barb Dorn Pia Dorson Kelsey Dossa Katie Dotie Teri Douglas RaeAnne Dove Amanda Drewry Jaclyn Drinkwater Kevin Drinkwater Olive DuBose Daniela Dudas Charles Dudley **Kelly Dueitt** Destiny Dueitt Jessica Duff **Emily Dufner** Lilia Duhart Dana Dunfee David Dunfee Cherise Dunham Anna Dunigan Patrick Dunigan Amanda Dunn William Dunn Sarah Dunton Rebecca Duquesnoy Tina Duran-Hall Destany Durazo Tyler Duscha Cheyanna Dyson Rochelle Dyson John Ebling Julie Echevarria Nina Eduardo Allen Edwards

Candace Edwards Renee Edwards Erin Edwards Nicole Egbert Kirsten Ehresmann Phillip Ehresmann Rachel Elder Bianca Eleazar Jesse Elizalde Cassie Elliott Liam Elliott Olivia Elliott Larry Emark Jordana Emerson Angela Enderby Svetlana Epshteyn Steven Epstein Austin Escobar Jennifer Escudero Sosen Eshetu Morganna Espinoza Cassandra Estrada David Estrada Kelly Estrada Melissa Estrada Êμ∑Ëéπ Êú± Crystal Evans Wendy Everhart Taylor Everson Erin F Debbie Fabio Steven Faivre Carina Falk John Falk XINYANG FAN Paulette Farmer Barb Farmer LaShanna Farnum Saheed Farnum Mary Faughnan Janet Favorite Becky Fehrman heather feig Sarah Fellers **Emily Felt** Aj Fernandez Alain Fernandez Jillian Fernandez Rebecca Fernandez Eulalia Ferrer Lisa Ferrer Stephen Fetsko **Beth Fields** Joanne Fields JACQUELINE FINCHER Cameron findlay Lelia Finkel June Finnerty Flaine Fisher Maureen Fiske Terry Fistner Rhonda Flagler Kenny Fleming Kerri Fleming Erin Flintoff Madaline Fluhr

Kathleen Flynn

Julie Foge Carol Foley **Peggy Forbes** SARA FORMSLAG Donna Forster Janice Forthman Nickie Fotopoulos Andrew fox Chris Fox Renaee Fox Shea Francis Megan Francy Travis Francy Tabitha Frantl Brian Franz Kim Frederick Chelsea Fredrick **Charles French Emily French** Halley French John French Tom French Julie Frey Alicia Frick David Frick Jill Frick Alli Friss Samantha Fritcher Renee Frontiera Corey Fuller Elisabeth Fuller Leslie Fuller McKenzie Fuller Kristen Furtado Greta G. Marie Gabert Anarosa Galaviz Diana Galey MaryBeth Galey Letisia Gallegos Mariella Galvan Sandra Gannon Adileny Garcia Duff Gardner Joan and James Gardner Kerry Gardner YuneJa Gardner **Christy Gardner** Liz Garoutte **Taylor Garoutte** Suzette Garrett Lvnn Garrick Vicki Gartin Michelle Garvin Arpine Gasparyan Rosa Gastelum Silvia Gastelum Denise Gatz Ashley Gearhart Mike Gearhart Patrick Gearhart Ben Gebo Sydney Gebo Brittany Geglein Zachary Geglein

Celine George

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Sally George Andrew Geraci Christine Geraci **Bryan Gerdes** Susan Gerdes Marivett Gerena Nanci Gerhard Susan Gershenhorn Roseann Giafaglione Lucas Gibson Tigfany Gibson Cherisse Gilchrist Brian Gill Karen Gill Sandra Ginn Beverly Ginyard Amy Girling **Kevin Girling** Trevor Girling Jackie Glascock Sara Glashagel Andrea Glass Charles Glazier Melanie Glazier Meghan Goeglein Jessica Gomez Wanda Gonzalez Madeline Gonzalez Kellie Goode **Donald Goranson** David Gordon Jonathan Gordon Sarah Gordon Somys Gore Diana Gough Abby Gould Michael Gould Susan Grace **Russ Graff** Caitlin Graham **Chasity Grandberry** Penni Grant Kathy Grant **Estelle Graves** Stephanie Gray William Gray Lisa Graziano TJ Graziano Agnes Evette Green Lisa Greer Angeka Gregg Bets Gregsen Elizabeth Greskovics Robin Grey Kimberly Griffin Monique Griffin Stefan Griffin Amanda Griffith Atkins Chris Grimmer Ellie Grimmer Joan Groce Stephen Groot Sarah Grover Janice Grygla Michelle Guidry Alexis Guillory

Kellen Guillory

Kelly Guillou Ann Gurney Sabrina Hadro Judi Hager Amber Haggard Gabriel and Sarah Hahn **Elaine Hamilton** Tamie Hamilton Megan Hammer Kristen Hammill Myko Hammond Jada Hampel Jennifer Hancock Liz Handy Stephanie Hane **Butt Hannon** Heather Hanson Pamela Hanson Norman Harding Gina Hargis Nahla Harik-Williams Nancy Harkcom Courtney Harless Robert Harless Will Harmon Teresa Harnden Annie Harner Adelaide Harp hobbi harrigan **Denise Harrington Amy Harris** Felecia Harris Tate Harris Jess Harris **Robert Harrison** Genevieve Hart Jennifer Hart Linda Hartigan Kerry Hartzell Lvnn Harvev Ian Hassan Tarek Hassanein Amy Hathcox Samantha Hauk Tanya Hauptman Jeff Hauth Carol Hearn **Timothy Hearn** Claire Heasman Linda Hebert Matthew Heckler Toni Heckler Esther Hedrick Susan Hedstrom Daniel Hedstrom Janalee Heinemann **Bruce Henderson** Jill Henderson Kathryn Henderson Cathy Hennig Amiee Hennigan Susan Henoch Stacy Henrichs Tim Henrichs Jessica Henson Ryan Henson

Loraine Hernv°ndez

Elizabeth Hernandez Joanne Hernandez Luis Hernandez Luis Hernandez Adriana Hernandez Mercedes Hernandez John Hernandez-Storr Laurie Herne Barb Herrig charlotte herrmann nancy herzog Pamela Hesch Carrie Hess Cathryn Hester Clark Hester Darrell Hester **7ach Hester** John Heybach S it e Heybach Jen Hid Francisco Hidalgo Diane Higginbotham Chris Higgins Drew Higgins Trish Higgins WENDY HIGGINS Brian Hill Jennifer Hill Amy Hillanbrand Margaret Hinojosa Kay Hiott Denise Hipes John Hipes Michael Hirabayashi Kathryn Hirabayashi Mary Hirzel Kathy Hitchinson La Donna Hodges Jill Hoffman Jeff Hoggins Laura Hollatz Elizabeth Holley **David Holmes** Ginny Holmes Frederick Holstein Tammy Hopkins Vickie Hopson Nathan Hort Yang Hou Elizabeth Howard Jessica Howard Mary Howard Robin Howard Neil Hubberth agnes hughes Thomas Hughes Reva Hulzebos Caryn Hunt Jane Hunt Shannon Hunt Sheri Hunter Nancy Hupperich Aida Huseinbasic Catherine Hussey Colby Huth Ramona Huth

ROBIN ISBELL David Ishimaru Matthew Ivan Stephanie Ivan Sonja Jack Amanda Jackson Imani Jackson Sherry Jackson Richard Jacobson **Amber Jacomine** Betsy James George Jandl Harold Jandola Michelle Jandola Adrienn Janosi Allyson Jeans **Brittany Jencik** Jennifer Jenkins Megan Jenkins Brandon Jenkins Carol Jenkins-Gaye Kathryn Jensen Mark Jensen Mark Jensen Ronda Jensen Jennifer Jergens Maddie Jewell MARK JIMENEZ Joyse John Cindy Johns Cindy Johns Marie Johns Matthew Johnson Rachel Johnson Samantha Johnson Susan Johnson Heather Johnson Susan Johnson Miranda Johnzon Alicia Jones Ashley Jones **Bonnie Jones** Brittany Iones **Deborah Jones** Derek Jones Marina Jones Jennifer Jones-Miller Kelly Joniec Anna Jovanovic Mary Julian Katie K Justin Kabe Angie Kalasek Brian Kalasek Patrick Kalasek Samantha Kalasek Grace Kalt Tanya Kaminski Steve Kaminski pooiitha kammari James Kane Jane Karras Sarah Kasaby Sarah Kasaby pamela katsiris David Kaugher

Linda Kaugher Diane Kavrells Jenay Kayode Avgustina Kazikhanova Shaun Keefe Erin Keen Lauren Keenan Megan Kefauver Elizabeth Keffer Barbara Kehoe Charlotte Kellar Melanie Keller Robin Kellerman Alina Kelley Ian Kelly Jack Kelly Michael Kelly Sean Kelly Susan Kelly Susan Kelly Donna Kelso Amanda Kemp Laura Kemp Chloe Kemp Jessica Kempa April Kercheville Brent Kercheville Barbara Kerrigan Bill Kerrigan Amanda Kersey Cat Kershaw Michael Kershaw Lindi Kessinger Jennifer Ketcham Atif Khan Martha Khanna **Heather Kimmel** Ashley King Carolyn King Davna King Doug King Earlie King Tammi King Teresa King Renee King Torres JENNIFER Kinn Cathy Kirk Mary Kisaka Kim Kleinstuber Danielle Knoper Ken Knox Sharon Koay Melissa Koe Rebecca Koren Jacquelyn Kotar Chris Kowalczyk Lori Koyama Sheri Kraemer **Bonnie Kraft** Angela Krambeer Cheryl Kramell Stacy Kramer Jon Krasnoff Lisa Krasnoff Beth Krause Jill Kreacic Megan Kroff

Sara Irvine

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Juliette Krovi Waylon Krumvieda Steph Krumvieda Rebecca Krylow Jennifer Kryzak Karen Kubes Jean Kuklewski Lori Kuna Carrie LaBarge Patricia LaBella Maria Ladelfa Samantha Lakev Lisa Lamb Sara Lamica Sarah Lander Kelly Lane Stacy Lange Candice Lankhaar Dorothea Lantz Jaelle Laplante Michael Laplante Sarah Larkin Elizabeth Larsen **ERIC LARSEN** Greg Larsen Julia Larsen Tina Larsen Katie Larson Lindsey Larson Michael Larson Stephanie Lasher Danielle Lassen Angela Latchney John D Latchney Nicolette Lathan Hartman Laupati Melanie Laur **Heather Lawless** Erica Lawrence iames lazarus Lauren Leak Jennifer Leamer Sharon LeBlanc Ariana Lecai Erika lecodet Allyson Lee Amanda Lee Janet Lee Jarrod Lee Jennifer Lee Margaret Lee Matt Lee Matthew Lee Natalya Lee Tymna Lee Jamie LeFebvre Darla Legan Kati Leigh Craig Leis Lori Leis June Leitheim Sheila Lemcke **Amy Lemmons** Jennifer Lennon Jamie Lentz Phil Lentz

Katherine Leon

Theresa Leutik Sarah Levendoski David Levin Sasha Levine Joshua Levy Melinda Lewis Lissette Leyba Anna Leyva Yves Leyva lanet Li Jennifer Li Peiwen Liao Rhonda Lier Ashlev Liford Pawel Lijewski Jacob Lile kelli lile Yarong Lin Sandra Linden-Juncosa Casey Lindine Carol Lininger Abigail Littrell Amber Livingston Jennifer Lloyd Thomas Llovd Tricia Lobaugh David Locklair Kallie Locklair Jack Lockwood Mike Loconte Janina Locraft Judy Loewen AnnaMaria Lognion Carolyn Loker Tracey Lombardi Nicole Lomeli William Longworth Bonnie Longworth Amethyst Lopez Jessica Lonez Chelsee Loucks Rebecca Loupe Renee Lovern Renee Lovern Molly Lowery Nevra Lozano Yingying Lu Angela Lucero Kathryn Lucero Alison Luis Carlos Luis Heather Luna Steve Lundh ABIONA LUNSFORD Edan Luschei Ben Lye BARNEY LYKINS Marla Lynch Cherie Lyons Kelly Ma Keely MacIntyre Nathaniel Mack Andrew Macleod Cathryn Maczko Christine Maddock

Lorraine Magarian

Ray Magliano

Charlotte Maher John Maher Nikol Maher Peter Maher **Dorothy Maillet** Kaylea Main Jackie Mallow susanne malmstrom Julie Malwitz Megan Manfredonia Concetta Maniaci Mary Mankowski Anne Manning Theodosia Mantas Dominic Marci Clint Marcy JennaLee Marcy Lindy Marich Marissa Marinan Gary Markham Trisha Martin Andres Martinez **Brial Martinez** Hernan Martinez Patricia Martinez Chris Martiniak Larisa Martiniak Mikayla Martins Megan Mason Melissa Matejek Elisabeth Mates Lisa Matesevac Holly Mathie Wendy Mathre Lindsay Mattingly Dalia Matus Shelly Maxwell Al May Julie Mayberry Nicole Maver Jennifer Maynard Jonathan Maynard Kourtney Mays Michael McAndrew Jeremy Mccabe Marsha McCabe James Mccart Matt McCleery Rachel McClellan ReBecca McClelland Katie Mccollun Brittanie McCown Davlon Mccov Carol McDaniel Laura McDonald Melanie McDonald Nicole McElfresh Jade McGaff John McGhee Kathryn McGhee thomas mcgrady Adam McInerney Courtney McInerney Deborah McKissick Beth McLean Martin McLean Ann McLellan

Aris McMahon Elizabeth McMahon Gibson McMahon Richard McManus Joanne McMaster Elisabeth McMillan Carolyn McNamara Christa McNamara Patricia McRae Karry McWhorter Rebecca McWilliams Rav Mears Lori Medeiros Marco Mederos-Deppe Melbs Medina Randall Meek Randeep Mehroke Minesh Mehta Nisha Mehta Juan Mendez Colleen Mendoza Raquel Menjivar Danielle Menne Erin Mercadante Gary Mercadante Cara Mercadante Maria Merk Colleen Merkel Melinda Merren Lindsay Mesa Sandy Metcalfe Kim Mewhirter H Meyer Jim Miesle Laura Miesle David Mihalik Heidi Mihalik Charles Millard Abby Miller Casey Miller Cheryl Miller Denise Miller Gary Miller Lindy Miller Lisa Miller Reann Miller Susan Miller Tina Miller Tyler Miller Christopher Millner Jolleen Millner Jeremy Mills Sheri Mills Danijel Milovanovic Jav Minnifield Lisa Minor Malanka Misilo Gina Mitchell Jessica Mitchell Joanna Mitchell Kyle Mitchell Tiffany Mitchell TERRY MLECZEWSKI Debra Mleczewski **Brandy Modrow** Cory Moffat

Sameem Mohammed

John Mole Lorianne Moline Lorin Moncrief Gabriel Montano Nancy Montecinos Ryan Montililyahno Jp Montillier Sara Montillier Kirk Moore Meriio Moore Maureen Morales Eva Moresco James Moresco Kimberlee Morgan **Bridget Morris** Kim Morris Yosef Morris Cathleen Morrison Diane Morse Francis Morton Terri Morton Kristine Mosca Cindy Moscoso Fran Moss Katie Moureau Paul Moureau Sierra Muck Judy Mulder Marissa Muller-Reaves Danny Murphy Lori Murphy Pamela Murphy Tucker Amanda Murray Rosie Muth Becky Myers Rebekah Nafziger Tim Nafziger Ronda Nagel Jonathan Nash Drew Navolio Margaret Navolio Janae Nebel Ashley Neely Rahel Negeri Chelsea NegrV≥n Lyle Negron Billie Nelson Sara Nelson Francis Newell Maggi Newell Johnna Newton Yinna Ng Madelon Nichols Alyssa Nielsen **Hector Nieves** Janeth Nieves Spencer Noble Shannon Noe Alcinere Nogueira Renee Nohelty Paricia Noland Suzanne Norfleet Lanette Norgan Kathleen Novotny Holly Nov Lisa O'Leary

Charles O,ÄôNeil

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Dawn Romine

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Jan Gui

Sergio Guijarro Eliana GuimarV£es Milani Diane Guimont Monica Gutiv@rrez Verena Gutmann Laura H√§nninen Feng Haiyan Susan Hallmark Paul Hamilton-Brown Doris Hamilton-Brown MAHMOUD Hammad Ivana Hanv°kovv° Samantha Hanvey Jonathan Hanvey Samuel Harding Jenny Hardy Paul Harsch Anna Harsch Sally Hart Antoinette Hartnett Mandy Hayward Kinga Haziak Nicola Healey Mette Hebel Florence Hennerick Marcio Henrique Frances Herbert Maria Herdicka Svorad Herdicky Tanya Hernandez Antonia Hernandez Laura Herrera Brittany Herygers Thomas Hettman Jessica Hettman Javier Higuera Javier Higuera Christoffer Hillbom Jessica Hillhom Laura Hinojosa Rachael Hodge Stephanie Hodge Ian Holmes LUCAS HONORIO Andrew Hoover Ana Laura Hopper Garcia Diogo Hora Lisa Hoszko Sarah Howard-Jones Terry Hsu Junius Hsu Leo Hsu hu hu yunke huang chih chung huang David Hume Trista Humfries Natalie Hummel Ching-Chung Hung Yifen Hung Mel Hunt James Hynes Conor Hynes Mohamed Ibrahim Marilene Iensen

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Rhys Nasir Maria Regina Nassif Barbosa Ariel Navarrete-PV@rez C√°ssia NAVAS-CASTRO Bernadette Neiland LARISSA NEIVA COSTA Greetje Nentjes Gabrielli Neponuceno K√°tia Nery FILOMENA Nery Flv°via Nerv Felipe Nery Natalie Neto Silvana Neuls Daniele Nicolucci Medeiros Martin Niegl Joabe Nito Sirlei Nito Greg Niven Nicola Noble Ana Maria Nogueira Vergínia Nonato Luís Nonato **Dawid Nowak** Lydia Ntagara RAPHAEL NUNES **BELCHIOR** Erika O Sandra O'Brien LYNDA O'CONNELL Aisling O'Donovan Margie O,ÄôConnell Sinead O, ÄôReilly Shamiran Odesho ΕœÖœÜœÅŒøœÉœç νŒΣ ΣœÄŒ±ŒΩŒ≠Œ± Sera Oh Elina Oksa victor olate Gavrilova Olesva -û-ª-å-≥-∞ OLGA Natalia Oliveira Warlley Oliveira Bruna Oliveira Karina Oliveira Raquel Oliveira Henrique Oliveira Viviane Oliveira Renata Oliveira Daiana Oliveira Solange Oliveira Ana Oliveira Cleonice Oliveira Cruz Sandra Oliveira Schulz Anna Olsson Gabrielle Opolenski Marina Orban Beatriz Oreja

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Maisa Prado

Sandra Powell

Dannielle Prado Jaime Prado **GIOVANE PRATES** Oli Batista Prates Ana Prates Tain√° Prates Tain√° Prates Violeta Luciana Prieto Granada Jalene Primmer Carolina Proenca Anna Pugh Yael Putney Hadeel Qais Michelle Queiroz Pedro Queiroz Mohamad Raheia Bertrando Rabelo Inga Raic Furkan Raine Farha Raine Deepashwini Rajenahalli Jayadevappa Raienahalli Jayadevappa Neil Ramage Helen Ramage Ian Ramage Dayana Ramirez Valeria Ramirez Estrada Carolina Rangel GABRIELA Ratke Maiara Rebeschini Tracey Rees Cibele Claudia Reis Juliana Reis Giovanna Reis Ponce Angie Remuska Debbie Renac Walter Renato Anil Renghe Simone Resende Laura Retsos Laura Retsos Anna-Marie Reuter Carla Reyes Cheri Rhys-Jones Ana Claudia Ribas Pedro Ribas Adriana Ribeiro Mariana Ribeiro Manoelito Ribeiro Claudia Ribeiro Thiago Ribeiro Bruna Ribeiro Joana Ribeiro Cl√°udia Ribeiro Vanessa Ribeiro Silvia Rinaldi B√°rbara Rizzo Jov£o Angelo Rizzo Anna Robak Giovanna Roberti Michelle Robinson jose manuel Rocha

Yvonne Rochford Luis Rodríguez Liliana Rodríguez Panesso Lisiane Rodrigues Daiane Rodrigues Daiana Rodrigues Jaqueline Rodrigues Elyana Rodrigues Fernanda Rodrigues Rafael Rodrigues Franer Rodrigues Jéssica Rodrigues Fernanda Rodrigues Silvanete Rodrigues Andrea Rodrigues Ramos Padoim Aimara Rodriguez Ricardo Rodriguez Kajsa Rohdin Francisca Roias Merino edison alberto romero chirinos Garcia Ronderos Aracelis Rosario Lara Bernardo GuimarV£es Milani Rosimere oliveira santos Sumit Roy Maria Rozmus Celina Ruelas Jeison Ruge Cristina Ruiz Agnes Rup Eric Ruschin Tracev Ruschin Lenka Ruston Michelle Ryan Akhil S MIRJI Jennifer SV°nchez Eman Said yosif Ivanna Salehudin Maritonia Sales Flv°via Sales Miguel Gonvßalves Zejna Salihbegovic Danielle Sallatt Amanda Sampaio Eirini Samtanidou Jaclyn San Antonio Thelma San Antonio Ramon San Antonio Thelma San Antonio Jeanne San Antonio jose mauricio sanchez paez Sueli Sandre Luis Sandrini Juan Sanin Brenda Santana Gisselle Santana Santi Santi Licia Santiago

Savio Santimano de

Luciana Santos

Fabio Santos

Souza

Giovanna Santos Vinícius SANTOS Clarissa Santos JV¥natas Santos Rebeca Santos Alice Queiroz Dos Santos Santos Hélio Teruo Hashziume Santos Sandra Santos Thâmela Thaís Santos Santos Geovana santos altamir santos filho Nicole Sassaki **Zoe Saunders** Inez Saurin Ivana Savevski Savita Saxena Victoria Saywry Larysa Schenk **Ines Schipperges** Andressa Schmidt Elke Schmidt Leandro Schneider Melanie Schneider Karen Schwenken Christian Schwenken Conrad Schwenken Marianna Schwenken Ney Paulo Sene Jose Sepulveda Marina Shah su shan Jennifer Sharman Maria Sharman Kim Shaw Catherine Shaw mi she Julia Shevcheek Sharon Shiao Emma Shiels Deepti Shrivastava Sahar Sikandar Sahar Sikandar Gabriella Silva Alana Silva Jenifer Silva Adriele Silva Mariana Silva kerolav silva Joana Silva Cibele Silva Rosana Silva Lucelena SILVA ERICA CRISTINA SILVA Marcus Silva Renato Silva Thiago Silva Fernanda Silva Adriana Silva **RONIVALDO SANTOS** SILVA Roseane Silva Henrique Silva Laila Silva

Jorge Silva

medina

Parents and Caregivers of Individuals with PWS Outside the US

NATHALIE SILVA AI VARF7 Patricia Aparecida Silva Cortez Vinícius Silva de Araujo Claudete Silva leite dos santos Brasil Silvania só. Traz Machado Maria de FV°tima Silveira Antonio Carlos Silveira iunior Leda Agnes SimVµes de Melo Debra Sinclair Christie Sinden Sadhia Sindhu Khushboo Singh Prabhjot Singh ROMIRA SINISTERRA **ROSANA** Siqueira Wilson Siqueira Paulo Siqueira Joao Vitor Sisueira Simon Skogh Sinead Sloane Tania Smith Sam Smith Jodie Smith Marcia Soares Garcia Aparecida Soares Lourenv₈o Guilherme Soares Silva Cosma Sobral Federico Soledad Mauricio Solis Fernanda Solorzano Catherine Somerville Katharina Sonnen Antonette Soriano Andrea Sotelo

Catalina Soto Catalina Soto Cassemira sousa Andrea Souza vera spinelli Maja Sreckovic Harsha Sri Rebecca Standley Agnfó Stankevifçienfó Alda Staprans-Mednis Jasmin Steffek **Ines Steinert** Ksenia Stepanyants Michael Sterbal Sarah Stevens Janice Stevenson Yael Striet **David Studley** KATIE STUDLEY Ana lucia SuV°rez sanchez Miguel Suarez Angv©lica Suarez Zaki Suhaimi smita Sukale Jenny Sundqvist Maha Surani Joy Suttle Daniel Svedberg Jenny Svedberg Thiago Sversuti Susan Swayne **Gabriel Swerts** Susanne Szabomacdonald Marzena Szczawinska Andrzej Szczawinski Leandro Taminato Andrea Tassi ileana taus Diana Tavares Gemma Taylor Gleyson Telis

Therese Tembituze Susanna ten Wolde MERIELE TERUEL Helen Thirlby Richard Thomas Stephanie Thomas Dianne Thompson Cindy Thomson Madelaine Thurston Rory Tierney **Emma Tierney** Kash Tobiian Karen Todd Rômulo Toledo Diego Tomillo Morate Ana paula Toniolo de souza Camila Torbey Valeria Torres Eliana Torres Torres Lvdia Toson Ben Towell Armando Travaglia Natalia Travain dos Santos Natacha Tremarin Camila Treuenfels LO Trista Lucie Troianova Wendy Tshishimbi Irene Tsimeri Pedro Tura Lee Turner James Tyree Michelle Tyree Mankevich Udodova AndrV@s UsV°n Rhea Utley Xiomara Valencia Fahiane Da Silva Valente Fabiane Valente Maria ValiV±o

Luisa Fernanda Valle Ruiz Joakim Valsinger Louise Valsinger Pamela van Meeteren Shawn Vanneer Lucia Helena Vaz Ray Velestuk MIRELLE VELOSO Marina Verbivskaya Helma Verkerk Juliana Verona Cristina Vicente Bruno Vieira Bruna Vieira Elsa Vinha Cacilda Vinha Capiau Violette Tung Viwa Shekar VN Chere Volk Aswathi Vs Louise Wallace Cindy Walter Rebecca Walton rose wang li wang xiuxia Wang juan wang Malaika Watanabe Morgan Waters Darren Watson Lori Watson Laura Weavis Heidi Webb Daniela Weber Analu Weiss Medeiros Maciej WfÖsowicz Imogen Wheeler Amber White Jennifer White Todd Whitley Elliott Whyte

Deirdre Whyte Janice Williams Thomas peter Williamson Sally Williamson Sally Williamson Lisa Wixon Nina Wojciechowska Gloria Woloshyn TS Wong Nat Wooldridge Lisa Wooldridge David Woon nannan wu bao Wu Aleksandra Wysoczańska Rachel Wyszynski Giovanna Xavier ZuLin Xiao Vanessa Yamamoto Jougi Yamashita Mônica Yang Julia Yastremskaya Annie Yellin chen yiyi Hui-Shan Yu cong yu Recai Yuksel Gidiyatova Madina Yusuf Bruno Zabeu Tatiane Zago Tatiane Zago FELIPE ZANUZZO Angelica Zarichny taotao Zhang Joy Zhang FLavie Zhou amv zhu Sirlei Zonta Tamara Zvereff

Individuals with Prader-Willi Syndrome

Individuals with PWS in the US

To maintain the privacy of our loved ones with PWS, they are represented by their first name and last initial.

Myrna A. Raquel A. Bonnie A. Caesar A. Avery B. Daniel B. Felicia B. Trina B. Pete B. Regan B. Sarah B. Linda B Don B. Sharon B. Connie B. Keneshia B. Haley B. Tom B. Mesha C. Jane C. Kelly C. Teresa C. Avery C. Gina C. Sandra C. Danielle C. Adriana C Bridget C. Natalie C. Yadira D. Whitney D. Ashley D. Pam D. Marion D. Dante D. Lynn D. Cerridwyn D. Peggy D. Daniel D. Brenda D.

John E. Colette E. Sarah E. Courtney E. Mona E. Mike E. Karen E. Katie F. Emily F. Mark F. Mike F. Emily F. Emma Rose F. Beth F. Jean F. Patricia G. David G. Stephanie G. Thelma G. Mary G. Taylor G. Emily G. Sheila H. Ave H. Chantelle H. Conor H. Courtney H. Susan H. Jayden H. Erin H. Paula H. Claire H. Bonnie H. Melissa H. Jennifer I. Roxanne I. Kathleen J. Tracy J. Julia J.

Debra J. Abby J. Debbie K. Karen K. Joey L. Chris L. James L. Braygan L. Andrea L. Dominic L. Angelo L. Kasev L. Hugh L. Christine M. Deb M. James M. Margaret M. Patty M. Denise M. Kimberly M. Jeff M. Karen M. Katie M. Sarah M. Derek M. Lincoln M. Kettie M. Abbey M. AnnMarie M. Elizabeth M. Amanda N. Dorothy N. Cindy N. Bonnie N. Ann N. Catherine N. Emma N. Carson O. Jana 0. Maggie O. Melanir O.

Jean P. Kim P. Archit P. Jaden P. Denise P. Roxanne P. Kelly P. I.P. James P. Sheila P. Jason P. Eric R. Randy R. Diana R. Mary R. Ann R. Kelly R. Kristina R. Karen R. Melissa R. Doug R. Julie R. John R. Helen R. Cindy R. Jeffrey R. Alex R. Hope R. Jolee R. Jenny S. Jamie S. Donna S Karr8e S. Stacie S. Tina S. Tracv S. Kimberly S. Arabia S. Nikki S. Krystil S.

Diane P.

Lauren S. Michele S. Brenna S. Steffanie S. Jadyn S. Adam S. Andrea S. Betsy S. Dennis S. John S. Billie S. Roberson S. Judy S. Savannah S. Amy S. Barb S. Misty T. Ana T. Jennifer T. Amber T. Kaci T. Andrea T. Tvanna T. Joseph T. Lindsay U. Patricia V. Adriane W. Barbara W. Alicia W. Karen W. Carol W. Nicole W. Sadie Kav W. Gavin W. Christina W. TW. Antoinette W. Aaron W. Cheryl W. Amanda Y.

Individuals with PWS Outside the US

Edith S.
Anna S.
Josephine B.
Cristina B.
Maria Elizabeth M.
Francielli R.
Tassiani V.
Fab C.
Melinda F.
Aline G.
Wendy G.

Lorrie D.

Allira S.

Chad L.
Alvin L.
Grace M.
Guilene N.
Ashley P.
Shannon P.
Nordia T.
Josiane U.
Tina E.
Zhang H.
Jairo A.
Thomas T.

Amanda J.

Kristin J.

Lucy B.
Sonja O.
Charandeep B.
Yvonne O.
Colv≠osa B.
Carmel C.
Lorna H.
Ruth H.
Paula H.
Anne K.
Sharon K.
Tara M.

vÅine M.
Caitlin O.
Roisin S.
Laura T.
Eddy P.
Jessica C.
Rocio B.
Marv≠a B.
Marta C.
Diana I.
Ismael L.
Miguel L.

Lisa A.
Debbie B.
Amand B.
Imogen H.
Luke H.
Shauna H.
Morven R.
Neil S.
Sophie S.
Ace S.
Eva W.

Julie Y.

Researchers, Scientists, and Healthcare Providers Inside and Outside the US

Researchers and Scientists

Telma Almeida Jessica Ammon Adriana Arezes Betsy Barton JENNIFER BERTEN Jocelyn Bischof Sarah Bischoff Nathalie Bonafe Allan Brownlie Elaine Cafferty Olga Cain Carolina Cardenas Sandra Castille Daniel Chan Melissa Cobb

Steven Coonradt
Anastasia Dimitropoulos
Ana Diniz
Sudharsan Dwaraknath
Ruth Franco
Whitney Franklin
Karin Frazier
M L Hinojosa
Karen Israel
Julia Khrisanfova
tina LaFonte
Amanda Leskovar
Christopher Madden
Des Madden

Tatiana Collese

Caroline Matlock
Virginia Mattis
John Means
Robert Nicholls
Ellen Niemeier
Holli Palmer
Laren Reynolds
Ana SofV≠a Ribeiro
Maria Roallos
Sady RodrV≠guez PV©rez
Daniela Rubin

Ann Salm
Patricia Scott
Suzanne Simba
Sarah Zastrow

Healthcare Providers

Daniela Bittar Micheal Aaron Sandra Abril Jessica Adams Ionell Adams Jeanne Ahmed MG ALBANO Felicia Alberto Hailey Allen Katie Allen Elina Almy@n Amy Altizer Josephine Amato Stephanie Andersen Irina Anderson Jessica Anderson Jonas Andersson Denise Ann Lem Antoniou David Arena Ttisha Armstrong Ana Assuncao Mary Ater Jeb Atkins Jennifer Austin Sherry Austin Kristie Averill Emily B **Brittney Bacon** Kaila Baer **Amber Bailey** Jessica Bainter Jaya Baker Susan Baldwin Arielle Ball Margaret Ball Karalee Barch Hannah Bargman Sarah Barrick Jenica Barringer

Emily Bartha

Amber Bartling

Michele Beach **Bethany Beals** Ali Bean Lynn Beck Tina Beck Nancy Becker Josie Belle Amber Benson Hillary Benson **Ingrid Bentley** Adriana Berardi Zoie Berman **Brittany Bernard** Keri Bernardin Andrew Bernstein Johanna Bishop Paula black Terri Blackwell Santana Blanca Regina Blanchette Beth Boone Laura Boose Teagan Booth Victor Borges MaryAnn Bourgeois Casey Bowen Michele Brams Jessica Branham Stephanie Braud Ryan Breaud Shelly Breech Stella Breil meghan brindley Katelyn Bronder Yvette Brooks Olivia Brown Selma Brown Milynn Bruneau Sarah Bruntrager **Robert Buch** Valerie Bucior

Maria Bueno Rios

Anita Bullock-Morley Elizabeth Burchard Ashley Burchell Tif Burg Kandi Burlingame Julie Bye Asia Byrd Myra Cain Katelyn Cappotelli Gómez Carmen Kristin Caronna Casey Carrier Cambridge Carruth Joana Carvalho Beth Case Marissa Case Jeri Casley Crystal Casmirri Mindy Catalano Stephanie Cater Carrie Cerise Mirna Chagas Penny Chavez Madeline Chiardio Colleen Clark less Clifford Toni Coffee Stephanie Cohen Meagan Compton Ashley Conley Cindy Connellan Katie Connolly Margaret Conroy Danielle Constantine **TOBEY Coody** Janice Copeland Danielle Corff Alvaro Coronado V Craig Ryane Criswell August Culp Laura Czerwinski

Michelle D Stefanie Dahm Annette David Jazma Davis Marcy Davis Zach Davis Nicole Davis Laura Dean Patricia Dennette Olsen Beth DeSimone Jane Diamond Shanna DiCarlo Dana Dignard Rachel Dillon Dorothy DiMeglio Stacey Dirksen Lynsey Divilley Sandra Dobbs Ash Dodson Andra Dolton Annie Donaway Nicholette Donoghue Catherine Donohoe Jen Dressler **Bridget Duffy** Paula Duignan Terro Dupper knoper Twrri Dupper Inoper Meagan Dyer Wands Eaton Barbara Edgar Kelly Ehrnschwender Linda Elli Lindsey Ellis **Brittany Elrod** Ann Eskew Haweya Farah Megan Fardon

Jennifer Farnham

Melissa Fenger

Taylor Fennessey

Morgan Figurelle Beth Finke Rachel Fiorentino Bonnie Fiske Brittany Fitzgerald N Fitzpatrick Joann Fleckenstein Eric Fleming Janessa Fletcher Kaley Flip **Emily Fontaine** Delilah Forbes Lauren Fortier Sandra Fournier Cate Fox Krista Foxworth Michele Franzella Carah Frazier Sarah Fredriksen Karoline Freire Ioni Freitas Jessica Frenzen Janece Fretwell Sara Fulton Kate Funke Ashley Fyfe lisa g Liz Galetz Danielle Gallagher Lorraine Galligan Chloe Galvin Shari Galway Laura Gann Andre Garcia Rodriguez Amanda Gardner **Emily Garrissw** Yaritza Gautier Dvlan Gawinski Stern Priscilla Gennari Joanna Georgakas

Jaclyn Giafaglione

Sónia Fernandes

Researchers, Scientists, and Healthcare Providers Inside and Outside the US

Emily Gifford Perri Gilbert Bonnie Gilbertson Danielle Gillam Dianne Giordano Melanie Giroux Karen Good Marcia Gowdak Gracie Grant Heike Grav Katie Grayson Sarah Greear Mary Griffin Betty Grover Rachel Gugel Katie Gullquist Robyn Gurney Valerie Gutierrez Shannon Gyles Cara H Kim H Adam Hadro Tresses Haffner kika hajistathi Ginger Hall Lauren Hall Kathleen Harder Rachel Hare Lydia Harms Laura Harris Alejandra Hartle Zachery Hawes Robyn Haynes Ashton Hedger Mia Heidecker Angela Heinzelman Tania Hernandez Angela Herring Valerie Hibbert Heidi Hicks Penny Hicks Jennifer Highbarger Leigh Hileman-Steele Kate Hill Michelle Hill Shayli Hill Linda Hoban Darby Hoffman Jennifer Holland Colleen Holt Jillian Honevcutt Megan Hopkins Jess Horan Julie Horton Denise Houriet Cindy Howard Kaitlyn Huber Miranda Huffman Mariorie Hunt Megan Hursman Stephanie Husk Darcie Ikeler **Eleanor Ingram**

Aiesha Insingo

Marie Jackson

Jenn Jackson

Akasha Jackson-Williams Tammy Janssen Amy Jansuk Elisabeth Jelleryd Erica Jester **Angus Jones** Deanna Jones Erin Jones Christina Iones Emily Jordan **Brittany Joyce** Erika Juarez Kolby Kail Karolina Kaluza Bridget Kaminski Tabourne Nikki Katz Kristin Kelley Janelle Kendrick Audra Kent **Ruby Kershaw** Christy Kessler Kristin Kim Abby King Emma Kingham Sophia Kirchhoff Marta Klein Kathy Klein Heather Koenig Keri Koraleski, мот, отк/L Michelle Koval Roger Kruse Sarah Krzemien Ana Landaverde Jennifer Langley Eunice Larcena Amanda Laslie Michelle Lastovka bruna laub Megan Laurent Tammy Lauzier Derek Le Vicky Ledet Kay Lee Angelina Lee James Lentini Geraldine Leonard Erin Leone Lauren Lerew Mary Lou Lescarbeau Carrie Lewis Allie Ley Anita Lilja-Stenholm Brigit Lim Jennifer Lin-Nguyen Kristin Little Kay LoBello Liz Locke Michelle Logsdon Linda Long Jan Loper Shawna Lord

Moira Loring

Sarah Loupe

Erin Losh

Carly Love Sara lovelette Amanda Lovercheck Monique Lowery Nicole Lynch Edy Lynn Cristina Méndez Brittany Madison Cierra Maloney Laurie Marcosa Amy Marrapese Amanda Martin Lisa Martin Megan Martin Priscilla Martinez Katie Masterson Ashlev Mathias Melissa Mathiowetz Kateri McBride Amanda Mccaul Erica McCov Andrea McCusker Nanette McDevitt Kelsey McDonald Terri McFall Jen McHatton Bridget McIlwee Nicole Mckee Cynthia Mckeehan Kathryn McKissick Angela McMillan Lindsev Medhurst Ashish Mehta Marierose Mendiola Valerie Mettz-**Rommarito** Jennifer Metz Nazeeha Micciche Cindy Miller Shavna Miller Payton Miller Susan Millner Maria Mitchell Sarah Mitchell Megan Monier Kellee Moore Lorraine Moore Autumn Morales Jaclyn Morris Brittany Morrison Ariel Morrow Catherine Murray Katie Na **Beverly Navarrette** Andrew Nevett KellyRose Nichols Krystn Nickolaus Tiffany Nicoll Amanda Nolan Megan Notdheim Lara Nothwehr Patrice Nottingham Shannon O'Brien Emma O'Connor Lindsay O, ÄôKeefe Amy O,ÄôMalley

Kyley Ogard Dawn Olivier Elizabeth Ortiz Janet Osei Brittany P Kaylea P Rachel P Julia Packer Sarah Palay Analyn Pancho Jacqueline Pape Robin Parrish Kimberly Parrish Elizabeth Parry Jessica Parsons Samuel Paschall Norah Paschen Tara Paulauskas Alexis Pavey Michelle Pawelski Amy Payne Michele Pelley Julianna Peplinski Alexis Perrier Janine Peters Kayla Petrie Liz Petropoulos Lawrence Pierce Jessyca Pierre Amy Pike Patricia Plata West Plata West Jennifer Pope Sheila Poteshman Dan Powell Devi Power Lori Powers Meeta Prakasb **Roxie Pratt** Suzanne Pratt Lindsay Prebish Amy Preble Jennifer Price Elizabeth Pritchard Jessica Punzon Christine Rabenort Stephanie Ramos Jenna Reeder Erin Reese Andrea Rego Jessica Rehmann Mackenzie Reimer **Brittany Reineck** Amy Repko Jaclyn Replogle **RL Restrivera** Celeste Reynolds Courtney Rice Patricia Richev Kim Ricketts Laura Ridgeway Rebecca Ritter **Courtney Roberts Kelsey Roberts** Alexandra Robin Barbara Robinson

Michelle Rochman Jennifer Rodgers Alissa Roe Angela Rorick Meg Rose Christine Rosenthal Jennifer Rowzee Kristen Ruby Molly Rusin Lauren Saeger Megan Sales Amanda Salter Marie Sanchez Tammy Sandillo Renata Santos Melanie Sanvi Samantha Savio Nikki Schank Kelly Schiller Leslie Schreiber Keelin Schultheis Haley Scism Cheryl Scott Jill Scott Tami Scotto Michelle Seright Holly Shadden Elaine Shanaghy Ashley Shapero Rebecca Sharoian Catherine Sharp Jessica Sheldon **Ashley Shields** Heather Shipley **Kris Sietins** Melissa Sikoscow Elaine Simon Llewellyn Simon Mikala Simon Erica Singleton MaryBeth Sisco Stacey Sjoberg Allyson Smith Emi Smith Jen Smith Jennifer Smith Molly Smith Orla Smith **Emily Snyder** Cristina Souza Débora Souza **Emily Spain** Daphne Spohn Megan Spradley Joni Stalder Lauren Stalte Dori Stanley **Kasey Stansberry** Karen Stanleton Diana Starace Thomas Staton Shannon Stemler Nicole Stepneski Kim Steuber Alicia Stevens

Melissa Stiles

Researchers, Scientists, and Healthcare Providers Inside and Outside the US

Amber Stribling Ileana Sugawara **Karen Summers** Erika Summers Thea T Aileen Tai Chris Tak Nicolas Tan Aeryn Tau Loretta Taylor Fernanda Teixeira Marcus Tellez Leigh Terry Mary Tershak Jacqui Tessena Jennifer Thomas Maureen Thomas Jacobi Thomas

Lily Thomas Connie Thome Dawn Thompson Katherine Thompson Annemarie Tomczak Susan Tomko sydney topfer Ileana Toro **Emily Tracey** Carley Trina Tjarda Tromp Jackolyn Troncoso Candace Tucker Jean Tully Deirdre Tully andrea turnipseed Ali Tyra Janel Uelk

Katie Uhl Marie Ulrich **Betty Ulsas** Chris Uty Nolan V Harold van Bosse Kali Vasalofsky Viviana Velez astudillo Brooke Vesico Lucas Villalta Santos Amanda Vinson Asia Virella Craig Volcovici Cecilia Wagnon Brenda Wake Alicia Wales, PT, DPT Allison Walker Carol Waller

Leigh Walls Miranda Wang Megan Ward Jennifer Warren Madison Watkins Leslie Weaver Cindy Webb Jessica Weeks Michelle Weingarten Mara Welch Miller Megan Weller Melissa Wells Taylor Wengerski Jayne Werner Brenna Westover Kari Willett **Amy Wilmes** Kristin Wilson

Cherish Wilson Donna Wilson Katy Wingard Lisa Winschel Tish Withers Ryan Wolok Mandy Woods Molly Wright Aimee Wunsch **Becky Yates** Elisa Yeung Karen Young Katie Youngman Elizabeth Zeller Ying Zhang Christine Zoucha

Friends, Family and Other Supporters of Individuals with PWS

Other Supporters

Mariano Álvarez Karen Angel Akos A Catherine A Justin A Lynn A Maria A Sabrina A Stephanie A Anna A evedo Dina A-Hameed Kesh A. Kate Aanestad Susan Aarhus Melissa Aaron Madeline Aaronson Susana Abad Carlota Abad Casas Rowena Abadiotakis Zhanna Abaeva Mandi Abate Mary Abbatiello Tamunoipirinye Abbey Allison bbott Catherine Abbott Colton Abel Dana Abel Amy Abell Lydia Abell Maria Abernathy Stevie Abila Angele Abington Kristen bles Miranda Ableson Brooke Abola Nada Aboshawish Paulette Abourjaily Erik G. Abrahamson Rogerio Abrantes Kim Abreu Andrea Abshire Diane Abshire Thomas Abshire Ingrid Abu Ata Joy Abuhl Pamela Acasuso Laurelin Accardo Gina Acee Lucy Acerno Gustavo Acevedo Amanda Achacon Caresse Acheuler Michele Acker Marnie Ackerman Kendall Ackner Erika Acosta Ingrid Acosta Michelle Acosta Hannah Acton Linda Acton connie acuna Erick Acuna Jane Acuta Sandy Adamietz

Colleen Adamo

Alesia Adams Ben Adams Bryan Adams Carol Adams Cassandra Adams Debbie Adams Elizabeth Adams **Emily Adams** Jeanne Adams Jennifer Adams Jennifer Adams Katie Adams Kurt Adams laurie adams Laurie Adams Lorna Adams Mary Adams Megan Adams Mikayla Adams Patricia Adams Rebecca Adams Sarah Adams Sharon Adams Tammy Adams Tanja Adams Tara Adams Tom Adams Antonia Adams Cheryl Adams Stacey Adams Brenda Adams-Turk Sam Adamson Jessica Adamson **Emily Adaway** Janelle Aday Serena Addington Lindsey Addis Danielle Addison Lorie Addison Sophia Addison Stefanie Adjami Carol Adkins Dawn Adkins Loretta Adkins Megan Adkison Patricia Adler Andrea Adolph Silkia Adrovet Fernanda Afonso de Almeida Aakriti Ag Jennifer Agamenon Samantha Agan Catherine Aganon Natasha Agathangelou Sarah Aggarwala Margaret Agley Shelly Agnes Taylor Agnes Tiffany Agnese Dana Agrest Diego Agudelo Dejaik Aguiar Marlom Aguiar

Nicole Aguiar

candie aguilar Madelyn Aguilar Marcela Aguilar Maryann Aguinaldo Brittany Aguirre Camilla Aguirre Kerri Ahern Ann Marie Ahern Kris Ahl Pete Ahlquist Emma Ahmed Syed Ahmed Stacie Aho Stephanie Aholt Lori Ahrens Mary Aiello-Jones Shawna Aipia Leah Aiwohi Debra Aker Elisabeth Akers Stacey Akey Lanta Akiewa Kave Akins Tamara Akiona Taylor Akridge Melinda Akridge Erin Al-Nakeeb Jody Al-Saigh Alaina Alaina Cristiana Alaniz Beatris Alba Sandra Alba Kim Albanese Trinity Albarado Mary Albaugh Brandi Albea Jesdica Alber Elizabeth Albers Katie Albers jan albert Maria Albert Courtney Albertelli Blayne Albertson Kristy Alblas Linda Albrecht Karen Albright Mike Albright Anton Alcantara Jennifer Alcorn Kathy Alcos Leyani Alcos Meredith Alden Annette Aldergren Alyssa Alderman Carolin Aldinger Leslie Aldrich Sara Aldrich Pam Aldridge Irene Ale Gabriel Aledo-Rentas Thomas Aleksiewicz Joan Aleman Stephanie Alepoudakis

Bambi Alexander Barb Alexander Fiona Alexander Jeanne Alexander Lisa Alexander Scott Alexander Alisha Alexander Anetka Alexander Brit Alexander Donna Alexander Enda Alexander Michelle Alexander Sarah Alexander Sherrie Alexander »òireag Alexandra Haley Alexis Cynthia Alfama Michelle Alfano Jessica Alfasi Pam Alfieri Jenny Alfonso Maria Alfonzo Kelly Alford Maggie Alford Ray Alford Wyley Alford Brooke Alfred Shiela Alger Omar Alghamdi Marina Algien Rebecca Alina Shannon Alivado Debbie Allan Kimberly Allan Elyse Allard Jessie Alleman Alaina Allen Anne Allen Cassie Allen Dean Allen Jason Allen Jen Allen Jill Allen Julie Allen Karen Allen Katie Allen Kelly Allen Laura Allen Linda Allen Liz Allen Marge Allen Melaina Allen Nikki Allen Pamela Allen Pearl Allen Peggy Allen Rhian Allen Shela Allen Stephany Allen Susan Allen Angela Allen Debra Allen Jessica Allen Leslie Allen Pamela Allen

Virginia Allen

Nicole Alley Tamara Alleyne Marie Allgood Lauren Allingham Avse Allison Madeleine Allison Ann Allman Ashley Allman Sally Allpress Sydnee Allred Haleigh Alm Rosalie Almén Melanie Almanza Ana María Almeida Claudia Almeida Juliana Almeida Marcia Almeida Patrícia Almeida Jo√£o Vitor Almeida Ferreira Sven Almen Jennifer Almodovar Helen Almond Sunni Almond N Almonte Brandy Alonso Taylor Alonso Angela Alonso Gomez Jessica Alphonse Karem Alsaman Ahmad Alsamman Kayla Altendorf Heather Altenhofen Kathrin Altenhoff Ann Altherr Sue Althiser Rebecca Altier Lara Altieri Flaquer Alex Altimas Sarah Altman Eliud Alvarez Garcia Alvarez Joanna Alvarez Robin Alvarez Shyanne Alvarez Anna Alvarez Jeanette Alvau Giovani Alves Maryellen Alves Vivianne Alves Alex Alves Gomes da Silva Ashley Alwert Diane Alwxao Fatima Alzarbi Maggie Amadeo CRAIG AMAN Lynn Aman Pompolin Amanda Cristina Amy Amanti Carlos Amaral Giselda Amarante Larissa Amato

Marie Amato

Aleiza Alerta

Becky Alessi

Friends, Family and Other Supporters of Individuals with PWS

Rosa Amaya Elisabeth Amedee Stephanie Amedee Guilherme Amelio Jamke Amelio Mary Ameln Jennifer Amento Thomas Ameringer Connie Amerson Ashley Ames Alessandra Ameztoy Jaina Amin Lisa Amlung **Bethany Ammons** Caroline Amonson Kara Amore Jennifer Amos Roxzanne Amos Theresa Amos Angela Amundsen Lonnie Amundson Jessica Anaya Stef Anderko Deanna Anders Rachel Anders Alaina Andersen Alicia Andersen Ashleigh Andersen Heather Andersen Julie Andersen Amanda Anderson Amie Anderson Angela Anderson Angie Anderson Ashlev Anderson Bayle Anderson Bengt Anderson Bobbi Anderson Bria Anderson Carlye Anderson Darylene(Dee) Anderson Elaina Anderson **Emily Anderson** Emma Anderson Erin Anderson Henry Anderson Hope Anderson Janna Anderson Jeanette Anderson Jennica Anderson Julia Anderson Katelyn Anderson Kim Ánderson Kimberly Anderson Lesley Anderson Linda Anderson Lisa Anderson Margaret Anderson Matt Anderson Maya Anderson Natasha Anderson Natasha Anderson Nicole Anderson Rebekah Anderson Robynn Anderson Runa Anderson Ryan Anderson Samantha Anderson Sarah Anderson

Sheena Anderson Svdna Anderson Tara Anderson Tina Anderson Kathleen Anderson Kaye Anderson Korinne Anderson Sara Anderson Lars-Olof Andersson Lena Andersson Pia Andersson Gunilla Andersson Mikaela Andersson Nancy Anderton Susan Andetson Diane Anding Carrie Andrade Fl√°via Andrade Macey Andrade Rafael Andrade Scott Andrade Fl√°via Andraus Troyano Kassia Andre July Andrea Dominick Andreacchio Lori Andreen Javier Andres Shannon Andresen karla andrew Deann Andrewlevich Beth Andrews Elaine Andrews **Evelvn Andrews** George Andrews Janell Andrews Kathleen Andrews Lisa Andrews Mardi Andrews Mary Andrews Megan Andrews Peter Andrews Susan Andrews Zeddie Andrews Alison Andrews Kristi Andrews Patrice Andriske Joe Andriske Holly Andrus Jane Andrus Karina Andrus Sean Andrus Stacy Andrus Thomas Andrus Libby Andrusis Melissa Anesin Heather Anest Patricia Anest Kellie Anfosso Anthony Ang Melissa Angandeh Raymond Angeles Michelle Angell Anita Angelo Betty Angelo Lisa Angle Hilary Anglin Nicole Anglum

Christina Angotti

Drew Angotti Laura Angotti Megan Angotti Stephani Angulo Juliana Anhelli Leandro Anhelli Ana Anjos Jennifer Ankerberg Megan Anonick Someone Anonymous Claula Mariko Anraku Clelia Anraku Lilian Ansari Erin Ansell Raquel Antón Harvey Antczak Sarah Anteliz Kris Anth Becky Antholz Allison Anthony Jaqui Anthony Patricia Anthony Leo Anthony Amy Anticoli Kati Antill Kaye Antoni Angela Antonio Antria Antoniou Chryso Antoniou Maria Antoniou Ernie Antoniw Julia Antoniw Peter Antoniw Elizabeth Anttonen Alma Anzaldua Tash Aol Ineide Aparecida Ferreira Souza KALI APESLAND Leigh Anne Apke Lynn Apolinaro Lisa Apostolopoulos Whitney Appleby Cindy Appleton Lynn Aprill Lizette Aquino Loy Aquino Marie Aquino Karen Aradine Bruna Aragin Israel Aragon Kristy Arakawa Diana Arango Mary Aranyos Luciane Araujo Amanda Araya Jennifer Araya Alex Araya Luisa Arboleda François Arcand Ilima Arcangel-Witt David Arcaro Luciana Arcaro Annette Arce Geri Archer Wendy Archer Eilidh Archibald Dawn Archibald

Margie Ardelean Oana Ardeleanu Melissa Arden Sophie Ardern . Natallia Ardynskaya Inca Arechiga Ashley Arellano Michelle Arends Stephanie Arenholz Steven Arenholz Gilbert Arevalo Gillian Arganetto Debbie Argentina Alexa Argentina Carmen Argeo Jenna Argo Julianna Arita Marly Arita neli tie Arita grom Neth Arkanoff Catherine Arki Michele Armand Tracy Armbrust Yolanda Armelin G Armer Sharon Armiger Tina Armijo Jav Armitage Debbie Armstrong Jeanne Armstrong Lisa Armstrong Sara Armstrong April Armstrong Brett Armstrong Carrie Armstrong Christopher Armstrong Elizabeth Armstrong Julie Armstrong Niyani Armstrong Pamela Armstrong Jean Arndt Ashley Arnett Leah Arnett Angela Arney Bethany Arnold Lynn Arnold Mary Arnold Maureen Arnold Melissa Arnold Michelle Arnold Miriam Arnold Natasha Arnold Breanne Arnold Emily Arnold Eri Arnold Stefanie Arnold Martha Arnoldy Ines Arnopoulos Laura Arquero Amaya Arr Ruth Arranz Juan Arredondo Maryann Arrichiello Lolo Arrieta Carol Arritola Grace Arrowsmith Carrie Arsenault Leslie Arsenault

Jill Arsenault

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Cassie Nixon Jovan Nixon Patience Nkamba Elisabeth Nliss No No No No No comment No comment Kelly Nobay Cindi Noble Jennifer Noble Lacy Noble Susan Noble Jamie Noblit Malia Nobriga Alexis Noceda Catherine Nock Abigail Noel Rushmie Nofsinger Joyce Nogan Juan Carlo Nogoy Stephane Nogueira mary nohelty Amanda Nolan Gillian Nolan Janice Nolan Molly Nolan Patricia Nolan Samantha Nolan Andrea Nolasco Ashley Nolen Maggie Nolfi Jennifer Noll Maria Nolli Maggie Noojin Cathy Noonan Liz Noonan Karen Noone Coreen Nootchtai Marissa Norbert Debbi Nord Ronnie Nordberg Tommi Nordenger Erin Nordman Alison Nordquist Janet Nordrum Lisa Nordstrom Lori Nordvke Christy Norman Maureen Norman Simone Norman Jasmine Normoyle Stacy Norrell Jessica Norris Kirsta Norris Wli Norsworthy Pam Northey Claire Norton Dan Norton **David Norton Garrett Norton** Tom Norton Ashley Norville Valerie Norville Michele Nosko Kyler Not Afraid Samantha Not comfortable sharing Kris Notch Alice Nothacker

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Sarah Smith

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