
ANNUAL REPORT

2014

The Time Is Now!



THE FOUNDATION FOR PRADER-WILLI RESEARCH 2014: THE YEAR IN NUMBERS



11,890 DONORS

provided financial support for FPWR, helping us to advance Prader-Willi research

FPWR awarded more than

\$1.2 MILLION

to accelerate

high-
impact
PWS
research



FPWR Supported scientific collaboration with the TOP PWS researchers around the world through our annual

RESEARCH CONFERENCE & CLINICAL TRIALS DAY



Through our world class grants program,



20 PWS PROJECTS & INITIATIVES

were supported in 5 countries around the world.

Findings from
FPWR funded
studies were
published in



23 SCIENTIFIC PUBLICATIONS

OVER 8,000 PEOPLE

attended a
One SMALL Step
event to support
Prader-Willi research



FPWR Research Program: The Time is NOW!

FPWR continues to energize the field of Prader-Willi research and with the support of our dedicated families and donors, FPWR has become the largest PWS Research funding source in the world.

This past year FPWR was able to support 20 research projects and initiatives - a new record for our small organization! Thanks to the keen guidance of our scientific advisory board and volunteer review panel, our portfolio of grants represent the best ideas in the world and will advance the science of PWS as well as work towards the development of novel therapies for those impacted by the disorder. You can visit our [website](#) at any time for the latest information on our current projects.

FPWR HAS FUNDED
NEARLY
100
RESEARCH GRANTS
SINCE 2003

Several PWS clinical trials are currently underway in the U.S. and FPWR is working closely with these studies to educate families and facilitate trial recruitment. This year FPWR hosted PWS Clinical Trials Day - a day dedicated to educating our community on clinical trial opportunities. Trial representatives provided an overview of their studies, served on a Q&A panel and were available one-on-one for parents to ask questions. This powerful opportunity allowed families to compare trials and decide if trial participation was right for their family.

FPWR continues to be the driving force in PWS research because of YOU. On behalf of our staff, the board of directors and our children living with PWS, we thank you for your incredible commitment this year.

For a summary of our 2014 accomplishments, view our short end of year [video](#).



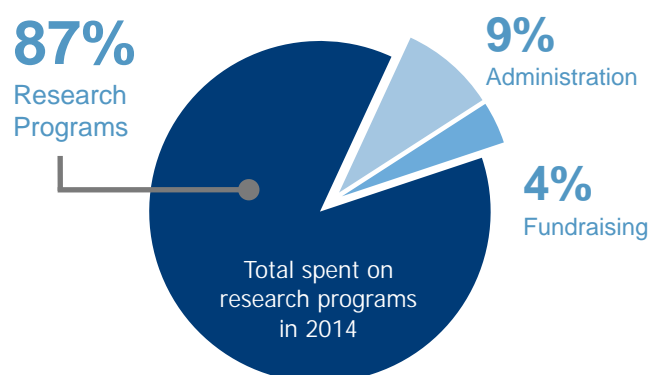
2014 IMPACT STATEMENT

While it is difficult to fully describe the accomplishments of an entire year, here are a few highlights we are particularly proud of:

- FPWR funded three new clinical trials to test novel therapeutics for PWS. Preliminary results from these trials are expected in 2015.
- FPWR investigators Dr. Bouret and Dr. Stuber have advanced the understanding of the normal brain circuits that control hunger and satiety. They are currently investigating how these circuits are disrupted in animal models of PWS.
- FPWR has developed key resources (new animal models, cellular models, bioinformatics) which have been adopted throughout the scientific community – these resources are critical for efficiently advancing future investigations.
- FPWR investigator, Dr. Leibel (Columbia University), produced the world's first human hypothalamic neurons in a dish which will allow for a deeper understanding of these critical brain neurons. This breakthrough will allow Dr. Leibel's lab to directly examine the function of these neurons in comparison to those from individuals with PWS and will provide critical insights into why the hypothalamus doesn't function appropriately in PWS.
- FPWR mobilized collaborative relationships with pharma, key advocacy groups, academia, regulatory agencies, other non-profit organizations, and patients/caretakers in the PWS community to accelerate clinical trials.
- FPWR joined the National Organization for Rare Diseases (NORD) and was invited to join the Clinical Trials Transformation Initiative where we participated in the CTTI Expert Meeting on Best Practices for Effective Engagement with Patient Groups around Clinical Trials.

Maximizing Your Investment

FPWR maximizes donor contributions. In 2014, 87% of every donation was used to directly fund research programs. In partnership with the NIH, academic institutions and private pharmaceutical companies, FPWR ensures that your dollars are used to effectively accelerate research and advance potential therapies to treat the many challenges of PWS.



2014 Funded Projects

FPWR proudly funded 17 general grants in 2014 exceeding \$1,228,000 in funds. Supported projects covered a broad range of research questions as diverse as the many aspects of PWS, from basic molecular and genetic studies to clinical interventions.

EVALUATION OF AUTISM-LIKE BEHAVIORS IN MICE DEFICIENT FOR *Magel2*. Christian Schaaf, M.D, Ph.D. Baylor College of Medicine (\$65,921). Dr. Schaaf and co-workers recently identified mutations of the *MAGEL2* gene in individuals showing many features of PWS, including autism. Here he will study the *Magel2* deficient mice to see if they reflect the behavioral changes seen in humans. This study will provide the foundation for evaluating therapy to alleviate autism behaviors in those with PWS and/or *MAGEL2* mutations.

ROLE OF THE LIPID-DERIVED SATIETY FACTOR, OLEOYLETHANOLAMIDE, IN PRADER-WILLI SYNDROME. Daniele Piomelli, Ph.D. University of California, Irvine (\$75,600). Oleoylethanolamide (OEA) is a hunger-reducing signal generated by the body. This study will examine the presence and function of OEA in a PWS mouse model and in people with PWS.

THE ROLE OF PREPL IN THE PATHOPHYSIOLOGY OF PWS: EVALUATION OF A NOVEL THERAPEUTIC APPROACH FOR THE TREATMENT OF HYPOTONIA. John Creemers, Ph.D., University of Leuven, Belgium (\$75,600). Dr. Creemers' group has identified deficiency in the enzyme PREPL as a possible contributing factor to hypotonia in PWS. This study will test whether treatment with the antibiotic sulfamethoxazole will improve neuromuscular transmission and muscle function in a mouse model of PWS and in infants with PWS.

GENOME-WIDE SURVEY OF DNA METHYLATION IN PWS. Soo-Jeong Kim, M.D., Seattle Children's Research Institute (\$75,600). Methylation patterns of an individual's entire genome have a profound impact on overall gene expression and, in turn, the function of every body system. Dr. Kim's group will explore whether the genetic and epigenetic alterations in the PWS region also impact the overall global genomic DNA methylation patterns in other, non-PWS, areas of the genome.

***HOW DOES OXYTOCIN CURE EARLY FEEDING AND ADULT SOCIAL BEHAVIOR ALTERATIONS IN MAGEL2 DEFICIENT MICE, A MODEL FOR THE PWS?** Francoise Muscatelli, Ph.D., Mediterranean Institute of Neurobiology, INMED (\$75,000). Dr. Muscatelli's group has shown that administering a single dose of oxytocin to the *Magel2* deficient mouse model of PWS at birth can restore suckling activity as pups and improve social behavior as adults. The group will now examine the mechanisms behind this effect to help define the relationship between *Magel2* and the oxytocin system. Results from this work could impact the development of oxytocin therapeutic strategies for PWS. ***Funded in collaboration with Prader-Willi France.**

UNRAVELING THE DEVELOPMENTAL NEUROBIOLOGY OF PWS: A CROSS-SECTIONAL BRAIN-IMAGING STUDY (Year 2). Anita Hokken-Koelega, MD, Erasmus University (\$73,007). These researchers will use advanced brain imaging techniques in combination with clinical data to better understand psychiatric problems in PWS. The goal is to identify markers for early detection of mental health problems to allow more timely and effective intervention.

TRAINING TASK SWITCHING TO DECREASE TEMPER OUTBURSTS IN PEOPLE WITH PWS. Kate Anne Woodcock, Ph.D., University of Birmingham, United Kingdom (\$75,479). Individuals with PWS have a strong preference for routine and predictability, with changes or "task-switching" often being a major trigger for temper outbursts. This project aims to develop a software prototype directed at teaching and improving task switching in PWS. If successful, this could be the first step in developing a valuable tool that would improve the quality of life for those with PWS and their families/caregivers. ***Funded in collaboration with FPWR-UK.**

***SMALL MOLECULES AND THERAPEUTIC POTENTIAL FOR PWS (Year 2).** Yong-Hui Jiang, M.D., Ph.D., Duke University (\$75,600). All individuals with PWS have a set of normal genes on their maternally-derived chromosome, but the genes in the PWS regions are 'silent'. Dr. Jiang will screen a library of 10,000 small molecules to identify candidate drugs that can reactivate the PWS region genes on the maternal chromosome 15, specifically SNRPN and snoRNAs. Promising candidate molecules will be tested for efficacy in PWS models, with the goal of ultimately evaluating their effects in patients. *Puzzle project

INJECTABLE PROTEIN BASED GENE ACTIVATION THERAPY FOR PWS (Year 2). David Segal, Ph.D., University of California, Davis (\$75,360). Building on efforts to reactivate the maternal chromosome 15, Dr. Segal's group is designing injectable proteins targeted at turning on the maternal *SNORD116* cluster and *Magel2* gene. These funds will help test the effectiveness of the proteins in a mouse model of PWS. A rat model of PWS will also be developed.

INHIBITORY CIRCUITS AND TRANSMISSION IN THE HYPOTHALAMUS IN A MOUSE MODEL OF PWS. Garret Stuber, Ph.D., University of North Carolina, Chapel Hill (\$75,600). Using advanced neurobiology techniques and the *Magel2* knockout mouse model of PWS, Dr. Stuber's group will be characterizing the distribution of *Magel2* throughout regions of the brain and the role of *Magel2* in neurotransmissions related to hyperphagia. These studies will help map the neurocircuitry in the PWS brain, a critical foundation for the development of future targeted therapies.

DEVELOPMENT OF APPETITE-RELATED NEURAL CIRCUITS IN A MOUSE MODEL FOR PWS (Year 2). Sebastien Bouret, PhD, Children's Hospital Los Angeles (\$75,600). Dr. Bouret's group has previously shown that abnormally elevated levels of the gut-hormone ghrelin and loss of *Magel2* can both impact normal development of hypothalamic neurons. This impacts key

physiological processes including appetite regulation. In year 2, his group will explore the mechanism behind this impaired development. They hypothesize that stress to a specific part of the cell (endoplasmic reticulum, ER) may be a main contributing factor and could be targeted with inhibitors of ER stress.

COMPREHENSIVE BEHAVIORAL INFORMATICS APPROACH TO CNS FUNCTION IN PWS MOUSE MODELS. Laurence Tecott, MD, University of California, San Francisco (\$75,600). In recent years, several new mouse models for PWS research have been developed. These PWS mice are valuable tools for testing potential therapeutics on PWS-related behaviors. To efficiently evaluate therapies in these animals, standardized assessments of behavior are needed. Dr. Tecott's group has expertise in automated monitoring systems for animals, and will perform a detailed behavioral study of two different mouse models of PWS.

GUT MICROBIOME IN INDIVIDUALS WITH PWS. Robert Shulman, MD, Baylor College of Medicine (\$54,000). We each carry a large and diverse population of bacteria in our gut, collectively called the "gut microbiome". These bacteria vary among individuals, are critical to normal gastrointestinal function, and can be manipulated by diet and supplements. There is an emerging field of research exploring how changes in the composition and activity of the gut microbiome may contribute to a variety of health issues, diseases, and disorders. This is the first study to compare the gut microbiome between PWS and non-PWS individuals to explore its potential contribution to hyperphagia and weight in PWS.

NUTRITIONAL ASPECTS OF PWS AND CHILDHOOD OBESITY: A METABOLOMICS APPROACH. Daniel Driscoll, MD, PhD, University of Florida (\$54,000). Hyperphagia and food related behaviors in PWS have been classified into six distinct nutritional phases. However, the mechanism(s) underlying these phases and what triggers the transition from one phase to another remains poorly understood. Dr. Driscoll's group will use analyze differences in specific metabolites ("metabolomics") among individuals in the six different nutritional phases. This study will provide insight into the biochemistry underlying each phase and the shifts between phases, providing potential targets for therapeutic development.

THE ROLE OF SNORD116 IN PRADER-WILLI SYNDROME Rudy Leibel, MD, Columbia University (\$75,600). This project is a continuation of a study examining the consequences of loss of the SNORD116 genes in iPSC neurons derived from PWS microdeletion patients and unaffected individuals. The research team will explore the downstream effects of SNORD116 loss on cellular function.

A DOSE TITRATION STUDY OF DIAZOXIDE CHOLINE CONTROLLED-RELEASE TABLET (DCCR) IN PATIENTS WITH PWS WITH A DOUBLE-BLIND, PLACEBOCONTROLLED RANDOMIZED WITHDRAWAL EXTENSION Neil Cowen, Essentialis Inc, (\$75,600). Diazoxide is an FDA approved drug that has effects on energy expenditure and appetite. It has not yet been studied in PWS. We will partner with the company Essentialis to support the evaluation of this drug in children and young adults with PWS, to determine the drugs effects on hyperphagia and energy expenditure.

TRANSCRANIAL DIRECT CURRENT STIMULATION, STARTLE MODULATION AND EVENT-RELATED POTENTIAL OF THE BRAIN TO EVALUATE HYPERPHAGIA IN PWS. Merlin Butler, MD, PhD (\$75,600) Dr. Butler's group has done a preliminary study suggesting that a weak, noninvasive form of brain stimulation, transcranial direct current stimulation (tDCS), may offer a new approach to reduce food cravings and overeating in PWS. Here, the research team will evaluate tDCS in 20 adults with PWS, measuring the effects of the approach on food drive, behavior, food intake and weight.

Special Projects

Global PWS Registry (\$50,000)

The Global PWS Registry will enhance the understanding of PWS by describing the full spectrum of PWS characteristics. The Registry will facilitate the completion of clinical trials and other research studies in the field of PWS. The registry is open to all individuals with PWS and can be completed by a parent /guardian, or by the person with PWS, if s/he is able. Patient data collection is set to begin May 2015 with the goal of enrolling 1000 patients with PWS in 2015.

SNORD116 Rat Model

MAGEL2 Rat Model (\$41,608)

Two key genes in the PWS region, MAGEL2 and SNORD116, underlie many of the major features of PWS. Thanks to a generous contribution, FPWR was able to create new SNORD116 and MAGEL2 rat models, each with a disruption of a critical gene in the PWS region. The full characterization of these new rat models and their use in drug development promises to bring a host of new opportunities to understand and treat PWS.

Advocate Reviewers Ensure Project Relevance

The grant selection process at FPWR is based on a collaborative approach, with scientists and parent advocates both playing critical roles. Scientific reviewers are chosen to review grant applications based on their expertise in the area of research. Their role is to determine if the work proposed in the application is scientifically sound, feasible, and will significantly advance the field.

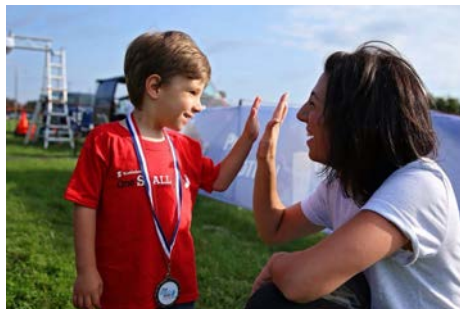
Advocate reviewers are charged with reviewing the project to determine its importance to the PWS community. After all, a proposed research project might be terrific science, but if it isn't relevant to what people with PWS and their families feel is important, then it's not our project to fund.

We want to fund the best science with the highest degree of relevance to our community. A thoughtful advocate review is key to using our limited resources wisely, and funding the best science with the highest likelihood of positively impacting those with PWS.

2014 Advocate Reviewers

Tina Adams
Mark Brosso
Monica Converse
Martin Geffin
Janet Gulley
Diane Guimont
Hunter Hammill
Jack Jones
Blair McWilliams
Laura and Jim Miesle
Adrian Pulkrabek
Tammy Renwick
Edwin Schauble
Alice Shapley
Jennifer Sharman-Koh
Ali Shenk
Rhea Utley

"I've completed advocate reviews for several rounds of grants, and each time, I'm reminded that there are brilliant and dedicated researchers devoted to OUR kids, to breaking through the barriers of PWS that our kids face. By helping make the decisions about which grants get funded, I get a sneak peek into the direction in which research is headed and I feel like, in some way, I'm taking back control of my son's future. It also reminds me of the importance of raising money so that no possibly groundbreaking study is left on the table unfunded. I recommend others give advocate reviewing a try!" -- Ali Shenk



Encouraging Collaboration: FPWR Sponsors 1st Clinical Trials Day in conjunction with Annual Research Conference

Over 180 parents, researchers and care providers were in attendance at our 2014 FPWR Research Conference, *The Time Is NOW*. Participants mingled with families and shared stories and laughter while learning the latest in PWS Research during this two day event.

The conference began Friday evening with a special gathering of FPWR Leadership Circle members and presentations by Dr. Theresa Strong, Director of Research Programs and Dr. Tom Hughes, Zafgen.

Friday's Meet n' Greet allowed families to network, share stories and get to know one another before Saturday's research presentations.

Saturday evening we celebrated our year's successes which include funding 17 projects as well as raising over \$3,000,000 for Prader-Willi research; and we acknowledged 4 key contributors:

- Volunteer of the Year:** Becky McWilliams
- Hosts of the year:** Melissa Demand
Angela Frazier
- Rookie of the Year:** Laura Miesle
- Host of the Decade:** Tanya Johnson

Parents were given the opportunity to meet with their age level groups Sunday morning and representatives from 4 PWS clinical trials were present to answer questions from parents and share trial information.



"I am blown away by [the FPWR Research Conference]. It has been an honor and a privilege to come and present. FPWR is an amazing foundation. The families I met are just the most wonderful people. The spirit amongst you, the motivation, and the energy is totally infectious. I just feel like I want to do research on PWS for the rest of my life, because of this great foundation, and all these amazing families."

— Dr. Christian Schaaf





In 2014 alone, One SMALL Step fundraisers raised a record-setting \$1.5 Million for Prader-Willi research. This passionate community knows no bounds in its dedication to eliminating the challenges of Prader-Willi Syndrome. Below are the top event fundraisers of 2014.

Thank you to all of our 2014 One SMALL Step fundraisers!

\$20,000+

Dana and Frank Capobianco
Samantha Chipetz and Dan Chorney
Angela and JD Frazier
Katie and Josh Gilliam
Amber and Chad Harkin
Colette and Eric Joncas
Katie and Adam Larson
Alice and Sergio Viroslov

\$10,000 - \$19,999

Veronica Baker
Carmen Barone
Ryan Cohen
Adriana De Luca
Melissa Demand
Kelly Garner
Brooke Gibson
Linsey Grover

Tracey Henry
Joy Ludwig
Andrew Mcvey
Laura Miesle
Norah Miller
Andrea Piercey
Tammy Renwick

continued next page

2014 One SMALL Step Event Hosts

Our sincerest gratitude to our dedicated One SMALL Step hosts who make this fundraising campaign possible!

Erica Acosta
Miranda Aspeland
Lori Avery
Vee Baker
Jennifer Bender
Rebecca Borgen
Anissa Bradley
Jeenie Breen
Dianne Bryden
Dana Capobianco
Heather Christiansen
Ryan Cohen
Renee Compere
April Cregg
Adriana De Luca
Dominique Deleague
Melissa Demand
Tanya Ducharme
Liz Fletcher
Angela Frazier
Anne Fricke
Sydney and Ben Gebo
Brooke Gibson
Linsey Grover
Megan Hammer

Susan Hedstrom
Stacey Howard
Ronda Jensen
Elaine Johnson
Tanya Johnson
Colette Joncas
Belinda Jones
Katie Larson
Joy Ludwig
Irene McDougal
Andrew McVey
Rebecca McWilliams
Laura Miesle
Glenn Olason
Joe and Cyndi Olivacz
Heather Osterman
Stacy Painter
Sarah Peden
Amber and Jason Rector
Tammy Renwick
Maegan Richard
Gracie Simmons
Kristin Simms
Gwyn Spearman
April Steffan

Susanne Szabo-MacDonald
Amy Tenbrunsel
Lauren Unger
Sergio Viroslov
Morgan Waters
Stephanie Young



Dana Capobianco, host extraordinaire cheers on event participants in Long Island, NY.

\$5,000 - \$9,999

Lori Avery
Diana Baird
Karlie Bergen
Bon Ton Fundraiser
Craig and Becky Borgen
Lindsey and Tiffany Breeden
Maureen Brosso
Laura Capone
Nancy Chorney
Sally and Harris Chorney
Jim Clooney
Renay Compere
Adrian Connerty
Genevieve CURrie
Gary and Pat Demand
Melissa Demand
Christine Geraci
Gretchen Golub

Ariana Held
ICG Inc.
Ronda Jensen
Elaine Johnson
Marilyn and Pierre Joncas
Belinda Jones
Avram Joseph
Mark Joseph
Elliot and Lori Kloper
Wendy Kosmak
Annabel Lyerly
Rebeca McWilliams
Perla Mondriguez
Megan O'Neil
Heather and Steve Osterman
Sarah Peden
Ruth Perry

Kristy Pulkrabek
Brandy Randall
Amber and Jason Rector
Maegan Richard
Steph Root
Rosemarie Rouse
Alice Shapley
Renee Snyder
April Steffan
Susanne Szabo-Macdonald
Monica Tackitt
Stephanie Thomas
Lauren and Justin Unger
Matthew Weeks
Amanda Young

APPROXIMATELY
8,000
ONE SMALL STEP
WALKERS
TOOK AN ESTIMATED
16,000,000 STEPS TO
ELIMINATE THE
CHALLENGES OF PWS

\$2,000 - \$5,000

Brittney Ackerman
Miranda Apesland
Karen Armstrong
Rose Bakx
Jeffrey Baldwin
Erin Bale
Holly Barnard
Jose Berenguel
Michelle Boyer
Anissa Bradley
Mary Ann Burrows
Jillian Byrd
Mary Capobianco
Heather Christiansen
Amandine Cordelier
Paul Costa
Pat Crne
Alexis Dardet
Melissa Demand
Amanda Everett
Jeannine Faasen

Jeffrey Feinerman
Darren and Amanda Fichter
Deborah Flannigan
Liz and Bruce Fletcher
Ali Foley Shenk
Anne Fricke
Bernadean Gaucher
Ben Gebo
Susie Grant
Megan Hammer
Kristen Hammill
Rachel, Reuben and Elias Hansen
Susan Hedstrom
Sara Hicks
Jessica Howard
Tanya and Keegan Johnson
Jack Jones
Darryl Jones
Irene Juriens
Karen Kubes

Stacey Letovsky
Felicia Loney
Tara Loseth
Quyem Ma
Kimberley Manders
Celine Martinez
Raffle McWilliams
Melissa Meiate
Jane and Mike O'Connor
Gelen Olauson
Stacy Painter
Ted and Karen Palen
Sukanya Pillay
Samantha Pomeroy
Barbara and Warren Powell
Breanna Rice
PapaMamaRomane
Richard
Kristi Rickenbach
Allison Shelton
The Shingleton Family

Gracie Simmons
Kristin Simmons
Susan Sims
Andrew Smyth
Linda and Peter Starcevic
Ken Sweeney
Sweet Ellie Belle Cookies
Cindy Szapacs
Suzanne Tate
Maria and Terry Tenbrusel
Amy Tenbrunsel
Kelly Theriot
Rhea Utley
Verita Van Diemen
Hannah Viroslav
Judy and Gary Walker
Veronique Warlomont
Amber White
Jeannette Young



Annual Golf and Tennis Tournament Raises Funds and Brings Awareness to our Nation's Capital

Long-time FPWR supporter Amy Porter, Congressman Ed Royce and the California Delegation hosted the 9th Annual DC Golf and Tennis Tournament to benefit the Foundation for Prader-Willi Research in September 2014. The 9th annual event was held at the Belle Haven Country Club in Alexandria, Virginia and raised more than \$200,000 for PWS research. In addition to enjoying a beautiful day on the greens, sponsors and guests enjoyed taking photos with Representative Royce and the star of the day, Abby Porter.

Abby is Amy Porter's 12 year old niece who is the source of inspiration for this incredibly successful, long-running event. The Porter family's willingness to share Abby's journey with PWS combined with Abby's incredible spirit and her aunt's hard work have made this annual event one of the most notable gatherings for PWS research. The tournament brings together representatives from dozens of national corporations, including Cisco, Allergan and Diageo, and political offices for a day of non-partisan fun and friendly competition all in the name of PWS research.

Over the last ten years, this event has raised more than \$1 Million for FPWR research

programs. FPWR is immensely grateful for the continued support of Amy Porter, Representative Royce, all of the generous event sponsors and the entire Porter family. Our incredible hosts are already planning for the 10th annual event to be held September 14, 2015 at Belle Haven Country Club.

This event is open to all FPWR supporters, please visit www.FPWR.org/events to learn more and register.



The annual golf and tennis tournament is hosted by Amy Porter, in honor of beautiful Abby Porter, age 12.

FPWR loves New York: 2nd Annual New York City Live Life Full Gala is a smash hit!

On November 17, 2014, More than 400 guests gathered at Stage 48 in midtown Manhattan for an unforgettable evening of dancing, dining, cocktails, and philanthropy all to benefit FPWR's research programs. Thanks to the NYC Live Life Full Gala committee's hard work and dedication, the event featured three talented live performers, including New York's own Eternity Band Orchestra, an unparalleled silent auction featuring the city's finest retailers and a live auction that featured prizes so unique it received a "Page Six" write up in the New York Post!

In addition to a great showing of passionate families from the PWS community, the gala event drew well-known New Yorkers like television personality Donny Deutsch and American Ballet Theater principal dancer Misty Copeland along with an eclectic group of New York city's business and philanthropic leaders.

The event was as glamorous as the evening's honorees, Irina and Leon Shaulov. 2014 was a record-setting year for FPWR and thanks to the incredible support of Irina and Leon, their network and friends, 2015 will be another year of unparalleled investment in PWS research.

The 2014 NYC Live Life Full Gala returned more than \$1.3 million for FPWR research programs!



"I am so proud and honored to have co-chaired the 2nd Annual NYC Live Life Full Gala and to have had the opportunity to speak to so many amazing and generous donors and supporters. What a surreal and unbelievable night! A million thank you's to our Co-Chair Irina Shaulov and to everyone who supported our event and is making a cure for PWS within our reach."

*-- Rebecca McWilliams
Founder of the Live Life Full Galas and
2014 NYC Co-Chair*



2014
LEADERSHIP
CIRCLE

Thanks to over 11,900 individuals and corporate donors, the Foundation for Prader-Willi Research funded over \$1.2 million in research in 2014. The top donors and fundraisers, contributing \$5,000 or more in 2014 are listed here. We thank you for your passionate support of our mission and families!

Anonymous
Akin, Gump, Strauss, Hauer & Field, LLP
American Express
American Financial Services Association
Lori and Chris Avery
Diana Baird
Veronica and Kyle Baker
Bank of America Merrill Lynch
Baptist Health Systems
Barclay's
Carmen Barone
Karlie Bergen
Sanford C. Bernstein & Co. LLC
Craig and Becky Borgen
Natasha and Robert Boucai
Jared Brecher
Paula and Joseph Brecher
Lindsey and Tiffany Breeden
Gary Brody
Maureen Brosso
BTIG, LLC
Intercontinental Capital Group Inc.
Dana and Frank Capobianco
Laura Capone
Chevron
Samantha Chipetz and Dan Chorney
Sally and Harris Chorney
Nancy Chorney
Citi
Jim Clooney
Steven and Alexandria Cohen Foundation
Renay and Tom Compere
Adrian Connerty
Robert Crespi
Genevieve Currie
CWPS Inc
Adriana De Luca
Russell and Jane Defauw
Melissa and Andrew Demand
Gary and Pat Demand
David Denbow
Donald Deutsch
Discover Financial Services
Disney Worldwide Services, Inc.
Edison International
Sergey Egorov and Victoria Logvinsky
Farmers Insurance Group
First American Title Insurance Company
GE Foundation
Angela and JD Frazier
Gregg and Jean Frankel Foundation
John Gagliardi
Joseph Gamerale
Stephen Gans
Gantcher Family Foundation

Kelly Garner and Dr. Brian Dula
General Atomics Aeronautical Systems
Georgia Pacific
Christine Geraci
Brooke Gibson
Katie and Josh Gilliam
Goldman Sachs & Co.
Jay Goldman
Gretchen Golub
Nadia Gonzalez
Linda Grimmer
Linsey Grover
Carol Hanna and Ed Korn
Amber and Chad Harkin
Jessica Harooni
Baptist Health System
Ariana Held
Sandy Heller
Tracey Henry
Highvista Strategies
Imago Dei Foundation
Investment Company Institute
Investment Technology Group
Imageo Dei Foundation
Investment Technology Group
JAT Capital Management
Ronda Jensen
Elaine Johnson
Colette and Eric Joncas
Marilyn and Pierre Joncas
Belinda Jones
Mark Joseph
Avram Joseph
JP Morgan Chase & Co.
The Robert J. Kahn Foundation
The Khoury Foundation
Kids Need Cures
Elliot and Lori Kloper
Wendy Kosmak
Shirley Kuess
KXR Inspection, Inc.
Angel Lance
Katie and Adam Larson
Beth and Brian Levine
Annabel Lyerly
Sonterra Medical Management Group
Andrew McVey
Rebecca and Blair McWilliams
Ranee Bartalocci-Meir and Nir Meir
Jamie and Amy Mergler
Laura and Jim Miesle
Norah Miller
Perla Mondriguez and David Acosta

Monness, Crespi, Hardt & Co, Inc.
Taylor Morrison, Inc.
National Credit Union Foundation
National Association of Realtors
Net Return Asset Management, LLC
Nomura
Megan O'Neil
Kongsberg Oil
Heather and Steve Osterman
Sarah and Phillip Peden
Ruth Perry
Michael Pettinger
Andrea Piercey
Performance Office Papers
PWSA Colorado
Prudential Financial
Kristy Pulkrabek
Mitchell P. Rales Family Foundation
Brandy Randall
Michael Rapino
Janet Rauch
Amber and Jason Rector
Tammy Renwick
Steph Root
Susan and Gary Rosenbach
Rosemarie Rouse
SA Recycling
Joy Sanders-Ludwig
Sandler Capital Management
Schools First Federal Credit Union
Hooman Sedighi
Alice Shapley
Paul E. Singer Foundation
Renee Snyder
April Steffan
Scott Steinman
Sterne Agee
Storr Family Foundation
Sun Capital Partners Foundation, Inc.
Daniel Sundheim
Susanne Szabo-Macdonald
Monica Tackitt
Stephanie Thomas
Technip Stone & Webster Process
Technology
Lauren and Justin Unger
USAA
Dr. Alice Viroslav
Dr. Sergio Viroslav
VISA
Matthew Weeks
Wells Fargo
WIAF Investors Co.
Ragan Williams
Amanda Young

2014

Financial Highlights

The Foundation for Prader-Willi Research is extremely conscientious with the donations entrusted to our care. In 2014, 87% of every dollar spent went directly to research programs. As our most dedicated friends and supporters, you make our work possible. Thank you for all that you do!

As of December 31	2014	2013	2012	2011
Assets				
Cash	\$3,669,858	\$ 2,223,507	\$1,838,387	\$ 1,229,080
Receivables	\$363,108	\$ 50,000	\$5,000	\$ 315,400
Other Assets	\$34,756	\$ 3,102	\$1,204	\$ 1,173
Total Current Assets	\$4,067,722	\$2,276,609	\$1,844,592	\$1,545,653
Liabilities				
Grants Payable	\$751,108	\$ 642,625	\$189,332	\$ 351,694
Accounts Payable	\$42,798	\$ 2,088	\$3,901	\$ 28,661
Accrued Liabilities	\$24,397	\$ 4,286	\$1,663	--
Total Liabilities	\$818,303	\$648,998	\$194,896	\$380,355
Total Net Assets	\$3,249,419	\$1,627,611	\$1,699,396	\$1,165,289
Total Liabilities and Net Assets	\$4,067,722	\$2,276,609	\$1,894,292	\$1,545,653
Revenue	\$3,249,443	\$1,499,989	\$1,311,850	\$1,422,776
Total Expenses	\$1,686,403	\$1,294,949	\$693,575	\$693,671
Programatic Expenses	\$1,465,038	\$1,062,386	\$538,355	\$523,572
Programatic Expense Percentage	87%	82%	78%	75%
Increase in Net Assets	\$1,563,040	\$205,040	\$618,275.16	\$729,105
Total Projects Funded	\$1,177,360	\$1,041,718	\$457,264.00	\$489,381
Number of Projects Funded	20	18	7	11

Our mission is to eliminate the challenges of Prader-Willi syndrome through the advancement of research.

FPWR is dedicated to fostering and supporting research that will advance the understanding and treatment of PWS. To date, FPWR has invested \$5,000,000 in funding to leading scientists and research laboratories around the world. More than 100 research projects have been funded covering:

- genetics and pathophysiology of PWS
- development of mouse models of PWS
- hunger, obesity, and reward circuits of the brain
- development of new therapies for PWS
- understanding sleep disturbances in PWS
- improving academic and learning skills for children with PWS

For a complete listing of FPWR projects and details on the research, please visit <http://fpwr.org/funded-projects>

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