

Eliminating the Challenges of Prader-Willi Syndrome through the Advancement of Research



"The Time Is Now"

2014 FPWR Research Conference



***November 15-16, 2014
Garden City, New York***

"The Time Is **Now**"

Friday, November 14, 2014

7:30 p.m.	<p>Meet n' Greet Location: Cotillion Room, 2nd Floor</p> <p><i>Don't go it alone the evening before the conference officially starts! Join us at our Meet n' Greet – a casual cash-bar gathering. Kick off your conference experience by making new friends and reconnecting with old.</i></p>
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Saturday, November 15, 2014

8:30 - 9:00 a.m.	<p>Conference Sign-In Location: Society Room, 2nd Floor</p>
8:30 - 9:00 a.m.	<p>Children's Program Sign-In Location: Hubbell Room, 2nd Floor</p>
9:00 - 9:15 a.m.	<p>Opening Remarks Susan Hedstrom, Executive Director, FPWR Jessica Howard, Chairman of the Board, FPWR</p>
9:15 - 10:00 a.m.	<p>Identifying characteristics of social functioning in PWS: what are they and why should we care? Anastasia Dimitropoulos Ph.d., Case Western Reserve University</p> <p><i>A review of research on social-cognitive functioning in PWS in relation to and in direct comparison to autism spectrum disorders (ASD). Clinical and research implications for continued examination of ASD symptomatology in PWS will be highlighted.</i></p>
10:00 - 10:45 a.m.	<p>Ghrelin acylation as a target to treat hyperphagia in Prader-Willi syndrome James L. Hougland, Ph.D., Assistant Professor of Chemistry, Syracuse University</p> <p><i>The appetite hormone ghrelin has been linked to hyperphagia in PWS. Ghrelin must be modified by enzymes to allow hunger signaling. By understanding how ghrelin is recognized and modified, we aim to lay the foundation for a new option for treating hyperphagia in PWS.</i></p>
10:45 - 11:00 a.m.	<p>Break</p>
11:00 - 12:00 p.m.	<p>Using stem cells to understand the pathogenesis of PWS Rudy Liebel, MD</p> <p><i>What are the physiological bases for the great difficulty in the long term treatment of obesity and what efforts are being made to gain insights into the control of body weight using PWS-derived stem cells?</i></p> <p>Can the silent genes in PWS be re-activated? Marc Lalande Ph.D., Director Stem Cell Institute, University of Connecticut</p> <p><i>Using human stem cells models of PWS, we discovered that the protein ZNF274 is involved in silencing the maternal copies of PWS genes. By targeting ZNF274 for degradation, PWS genes are partially re-activated thus offering the possibility of therapeutic intervention.</i></p>

The time is NOW to learn about cutting edge PWS research!

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Saturday, November 15, 2014 continued ...

12:00 - 1:00 p.m.	<p>Lunch Choose from a selection of entrees and enjoy the company of new friends.</p>
1:00 - 1:15 p.m.	<p>One SMALL Step Prize Draw</p>
1:15 - 2:00 p.m.	<p>The MAGEL2 gene in the context of Prader-Willi syndrome: Translating from bedside to bench Christian Schaaf, MD, Ph.D., Assistant Professor, Molecular and Human Genetics, Baylor College of Medicine <i>Individuals with point mutations in MAGEL2, a gene in the PWS critical region, display a subset of PWS features. Familial cases with mutations in this gene highlight the unusual inheritance pattern, and the need for genetic counseling. Behavioral investigations of a Magel2 mouse model bridge the gap between bench and bedside, and contribute to a multi-faceted appreciation of the gene's role in PWS.</i></p>
2:00 - 2:30 p.m.	<p>Pre-clinical models of Prader-Willi syndrome: advances and opportunities Rachel Wevrick, Ph.D., University of Alberta <i>PWS is caused by loss of function of multiple genes. The growth and behavior of animals lacking PWS genes can be compared to PWS symptoms. Preclinical testing of novel therapies and drugs is being carried out in PWS model mice.</i></p>
2:30 - 3:00 p.m.	<p>Break</p>
3:00 - 3:45 p.m.	<p>Hippotherapy (Equine Movement) - a treatment approach in physical therapy, occupational therapy and speech and language therapy Lori Garone, MS,PT,HPCS - Physical Therapy In Motion <i>Lori will present the history, theory application, clinical application and current neurological application for the patient with Prader-Willi syndrome as a treatment approach in PT, OT, and Speech and Language Therapy. A short round table discussion for questions and inquires will be given at the end of the presentation.</i></p>
3:45 - 5:15 p.m.	<p>FPWR Research Program Updates, Outcomes and Opportunities Theresa Strong, Ph.D. Director of Research Programs, FPWR Jessica Bohonowych, Ph.D., Associate Director of Research Programs, FPWR <i>FPWR is advancing the PWS research landscape by supporting a diverse portfolio of projects and initiatives to better understand and treat PWS. Join us for an update of FPWR programs and learn how we are working to accelerate solutions for our loved ones with PWS.</i></p>
5:15 - 5:30 p.m.	<p>The Time is Now! Keegan Johnson, Member Board of Directors, FPWR <i>PWS research has never looked so bright! Why is now the time to get involved?</i></p>
6:30 - 9:00 p.m.	<p>FPWR Family Dinner <i>Join us for an evening of inspiration as we celebrate this year's accomplishments and key contributions from our community.</i></p>

The time is NOW to come together as a community!

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Sunday, November 16, 2014

8:00 - 9:00 a.m.	Clinical Trial Booths Location: Grand Ballroom
8:30 - 9:00 a.m.	Children's Program Sign-In Location: Hubbell Room, 2nd Floor
9:00 - 10:15 a.m.	Patient Views Forum Theresa Strong, Ph.D. Director of Research Programs, FPWR Lauren Roth, Ph.D., Clinical Psychologist <i>The Patient Views Forum session is your chance to help pharmaceutical companies and regulatory agencies (FDA) understand how PWS impacts the individual with PWS and their family. We'll discuss the biggest challenges our loved ones with PWS face and how we would define an "effective" therapy.</i>
9:00 - 10:15 a.m.	Lovebug / Caterpillar / Butterfly Breakout Sessions Location: Lovebugs (ages 0-2) - Concorde Salon, Caterpillars(ages 2-4) - Society Suite, Butterflies (ages 4-6) - Society Suite <i>Meet with your age level groups to review the patient centered outcomes survey, exchange tips and strategies for overcoming challenges and learn about exciting tools available to our community!</i>
9:00 - 10:15 a.m.	Grandparent Session Location: Petite Salon <i>Being a grandparent of a child with PWS presents its own unique challenges. Meet other grandparents at this interactive session and learn how you can further impact Prader-Willi research.</i>
10:15 - 10:45 a.m.	Break
10:45 - 12:15 p.m.	Clinical Trial Presentations <i>Learn more about current and upcoming PWS clinical trial opportunities and the impact they may have on your family. Clinical trial representatives will present on new investigational drugs for children and adults with PWS.</i>
12:15 - 1:15 p.m.	Lunch <i>Choose from a selection of entrees and enjoy the company of new friends.</i>
1:15 - 2:00 p.m.	Clinical Trial Panel <i>Join us for this interactive and information question and answer panel with clinical trial representatives.</i>
2:00 p.m.	Conference Close

The time is NOW to learn about clinical trial opportunities!