

**Saturday, October 29****General Session****8:30 - 10:30 AM****Genetic Therapy for the Potential Treatment of PWS**

Genetic therapy has the potential to address the root cause of PWS and possibly reverse the symptoms of PWS. In this session, you will hear reports from two FPWR funded several researchers who will present on their exciting work to reactivate the genes located on the PWS region of chromosome 15 and identify new targets for therapy. Presentations by Lisa Cole Burnett, Ph.D., Columbia University Medical Center, and Marc Lalande PhD, University of Connecticut.

**Breakout Session****11:00 - 12:30 AM****Introduction to PWS and Nutrition for New Families Ages 0 - 3**

Come meet other new families with young children and learn more about the genetics behind PWS. Melanie Silverman will provide a short presentation on infant/toddler feeding and nutrition which will be followed by an interactive question and answer session.

**Developmental Language Delays and Success in the Classroom**

This presentation will provide parents an understanding of how language delays impact academic and social-emotional development in the classroom. Parents will learn to recognize the problems and receive actionable steps to take home and implement.

**Strategies to Improve Social Functioning in PWS**

Our loved ones with PWS have social motivation and interest in others, but are faced with the challenges of social skills deficits and the need for food security. In this session, Elizabeth Roof will discuss ways we can meet the social needs of our loved ones with PWS.

**General Session****2:00 - 3:30 PM****Preliminary Findings From the PRETEND Telehealth Intervention Program**

What is the feasibility of a parent training and education program delivered via Telehealth? Dr Dimitropoulos will share preliminary findings from the PRETEND study which was designed to increase learning and play between parents and children with PWS while decreasing problem behaviors.

**A Combined miRNA and coding transcript approach to the study of PWS neurons**

Over the past year, Dr. Reiter has been collecting the teeth in order to extract stem cells found in the pulp and transform them into PWS brain cells. In this presentation he will give an update on his work and provide his insight into how PWS fits with other 15q syndromes and autism.

**GEE whiz! Genome and Epigenetic Editng**

What is genome and epigenetic editing? What is its use in PWS Research? What are the implications for PWS? New technology allows making mutations or changing epigenetic information within cells and organisms. Dr. Nicholls' lab is using Genome and Epigenetic Editing to generate new cellular and animal models for PWS, and will provide an update on his work to specifically re-activate the silenced PWS gene domain.

**Clinical Trials Panel****3:30 - 5:00 PM**

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. Time will be reserved for questions at the end of the session.

**Celebration Dinner****6:30 - 9:30 PM**



**Sunday, October 30**

**General Session**

**9:00 - 10:30 AM**

**Real World Data Research Readiness: Engaging the Prader-Willi Syndrome Community**

Real World Data (RWD) such as mobile technology (apps), wearable devices such as a 'fit bit', electronic health records, registries, and other electronic databases provide new opportunities for transforming biomedical research. How can we utilize Real World Data to better understand PWS, and measure outcomes from clinical trials that are important to individuals with PWS and their families?

Presentations by Chris Jones (CJ Jones Strategy & Communications), Brent Clough (Trio), Luciano Castillo (Med-Vi, Professor Texas Tech) and others.

**Breakout Session**

**11:00 - 12:00 PM**

**Getting Started 101: How you can take One SMALL Step**

Learn from other active PWS families how you can get started fundraising for PWS research! A panel of PWS fundraising veterans will share how they got started fundraising and provide tips and tricks to help even the most novice fundraiser be successful.

**Fundraising 202: Beyond the Walk**

Let our team guide you through an informative overview of major events fundraising, corporate giving and planned giving programs. This session is a great opportunity to engage one-on-one, discuss your unique ideas and relations and prepare next steps for PWS research fundraising in your community.

**Advocating for PWS Research**

A successful research strategy requires active engagement from the PWS community. Your actions will make the future brighter for our loved ones! Learn how YOU can communicate our message in order to spread PWS awareness and be an advocate for PWS research.

**Real World Data Breakout Session**

Pre-registration required. 11 AM - 12:30 PM

**General Session**

**1:30 - 3:00 PM**

**Critical Tools for Advancing the PWS Research Agenda**

Research tools and infrastructure are critical to support PWS research and accelerate the work at hand. Once such tool, the Global PWS Registry is helping us better understand the full spectrum of PWS, expedite the completion of clinical trials, and determine areas of needed research and treatments to improve the lives of those affected by PWS. Learn more about this and other collaborative efforts!

**Sleep in PWS: Clinical and Scientific Perspectives**

Many individuals with PWS experience significant disruption of daily life as a result of sleep-related symptoms. Daytime sleepiness, abnormal REM sleep, narcolepsy, and cataplexy are common symptoms in PWS, however their underlying cause is unknown. In this presentation, Dr. Scammell will review the sleep challenges in PWS, how they are addressed, and what we have learned about sleep from studying animal models of PWS.

**The PWS Research Plan: ACTION Changes Tomorrow**

The Foundation for Prader-Willi Research (FPWR), with the input of community stakeholders, has developed a strategic research plan for Prader-Willi syndrome (PWS) for the next five years. Learn more about the plan and the ACTIONS you can take to ensure the plan is successfully completed.