

PWCF Annual State Conference Schedule

**October 27, 2018
Doubletree, Sacramento**



8:00 - 8:50 Registration & Booth Exhibits

8:50 - 9:00 Welcome & Announcements

Roger Goatcher, President & Emily Dame, M.Ed., Executive Director

9:00 - 10:15 Keynote Speaker: Behavior and Psychiatric Issues in PWS

Elizabeth Roof, M.A.

When do behavior problems emerge in PWS and what can you do to head them off and manage effectively? Find out the latest from the largest longitudinal study conducted looking specifically at PWS behavior and psychiatric features. Some tips about what works will be provided and will answer questions about your child.

10:15 - 10:45 New Federal Rules Impact Your Future: New Tools to Keep Your Loved One Safe

Lisa Graziano, M.A.

There are new rules and regulations that significantly affect group homes, supported living providers, day programs, vocational work sites, and any provider that receives Federal funding, most often paid via the Regional Center system. These new rules are outlined in the Centers for Medicare and Medicaid Services' Home and Community-Based Services (HCBS) Rules and Regulations. A critical part of these new Rules that directly impacts the health and safety of persons with PWS is they mandate that "Individuals have freedom and support to control their schedules and activities and have access to food any time."

10:45 - 11:00 Break & Booth Exhibits

Proceed to Breakout Sessions

11:00 - 12:00 Educational Breakout Session Options

Breakout 1: New Federal Rules Impact Your Future: New Tools to Keep Your Adult Safe Explained in Detail - Lisa Graziano, M.A.

PWCF's HCBS Task Force has been working closely with various agencies and PWS specialists to develop new tools to help families and providers advocate for a safe environment for your adult in their out-of-home placement, work or day program, recreational settings, and all community settings. This session will provide attendees with an overview of these major issues and introduce all of the new tools developed to keep your adult safe now, and your child safe in the future.

Breakout 2: Food Life & Fads - Leah Blalock, MS, RD, CSP, CDE

Food life is your relationship with food. This breakout will cover the basic principles of nutrition and the various approaches to diet which are out there. Some of the diets discussed are the ketogenic diet (both traditional and Modified Atkins) as well as intermittent fasting and chrono-nutrition.

Breakout 3: Using the Science of Gratitude to Help Manage Daily Family Life - Emily Felt, MPP, CAPP

This session will introduce participants to the science of positive psychology and provide practical tools for putting it to use in the daily management of family life. Positive psychology, also known as the science of human flourishing, is the scientific study of wellbeing. It is a broad field that encompasses aspects of public health, psychology, neuroscience, productivity, spirituality and others. There is significant scientific research that shows that implementing gratitude practices in daily life leads to increased levels of positive emotion, physical and mental health and wellbeing. In this session, participants will learn about the scientific research on gratitude, the effect gratitude has on the body and brain and how gratitude practices can be put to use to support a flourishing family life in the context of PWS. We will discuss simple ways to use the science of gratitude to change our experiences of stress around food and mealtimes and promote positive emotions and joyfulness in the family relationship. A printed toolkit and resource list will be provided.

~OVER~

12:00 - 12:15	Pick Up Lunch / Break and Booth Exhibits <i>Proceed to General Session</i>
12:15 - 12:45	Lunch
12:45 - 1:15	Business Meeting <i>PWCF Board of Directors, Emily Dame, M.Ed., PWCF Executive Director</i>
1:15 - 1:30	PWCF Committees Overview <i>PWCF Board of Directors</i>
1:30 - 1:45	Break & Booth Exhibits <i>Proceed to Breakout Sessions</i>
1:45 - 2:45	<p>Educational Breakout Session Options</p> <p>Break out 1: Financial Planning: Delivering Your Ultimate P.R.O.M.I.S.E. - Patrick McGrath, ChFC, ChSNC <i>At Private Wealth Management Group, we believe in challenging the notion that Special Needs Planning solely centers around governmental support and the possible creation of a Special Needs Trust. We also believe that all families should have access to exceptional financial planning experts with experience in the Special Needs arena. The creation of the P.R.O.M.I.S.E. outline give families the knowledge to begin the life-long process of securing the future for their loved one.</i></p> <p>Break out 2: Managing Challenging Behaviors at Home and Team Approach to Care - Patrice Carroll, MSW - Latham Centers <i>This session will focus on the most common challenging behaviors that we see in individuals with Prader-Willi syndrome (PWS). Session participants will learn the skills and strategies needed to address these behaviors at home and in the community and will have opportunities for questions and answers related to real life experiences with these challenging behaviors. This session will also include proven examples of a team approach to care including clinical, educational, health/wellness and residential components.</i></p> <p>Breakout 3: Building a Fun Physical Activity Routine for children and adults with PWS - Daniela Rubin, Ph.D <i>This session will present the key ingredients to building a physical activity routine in children and adults with PWS. Available mobile application tools will be shown and sample routines will be shared. The session will end with block of questions and answers.</i></p>
2:45 - 3:00	Break & Booth Exhibits <i>Proceed to Breakout Sessions</i>
3:00 - 3:45	Breakout Share Sessions <i>Birth - 5 Years</i> <i>School Age Years (6-18 or 22)</i> <i>Adults</i> <i>Spanish Speaking</i>
3:45 - 4:00	Break & Booth Exhibits <i>Proceed to General Session</i>
4:00 - 5:00	Keynote Speaker: PWS Research Update <i>Elizabeth Roof, M.A.</i> <i>The Vanderbilt PWS longitudinal database holds more than 15 years of data looking at family and PWS child and adult characteristics. What does having a child with PWS mean for siblings and parents? What do we really know about social skills, emotional learning and lifespan needs? Long held beliefs about PWS that may not be true. We will talk about these things in easy to understand chunks for parents and providers.</i>
5:00	Conclude