

# Family Program Agenda

## DAY ONE | Friday, June 27, 2025

7:00 AM	<b>Breakfast - Food Trucks</b> <i>Conference Center Pavilion; Breakfast not included with conference registration</i>
8:00 AM - 5:00 PM	<b>Conference Check-In / Help Desk Hours</b> <i>Conference Center Lobby (first floor)</i>
9:00 AM - 10:00 AM	<p><b>Welcome to the International PWS Conference - Kristi Rickenbach</b>, Parent Support Coordinator, PWSA   USA, <b>Susan Hedstrom</b>, Executive Director, FPWR, <b>Patrice Carroll, LICSW</b>, Director of PWS Services, Latham Centers, <b>Lia Kreacic</b>, Person with PWS</p> <p><b>Panel - (Moderator) Tony Holland, MD</b>, President, IPWSO, <b>Marguerite Hughes</b>, Outgoing CEO, IPWSO, <b>Theresa Strong, PhD</b>, Director of Research Programs, FPWR, <b>Stacy Ward, MS, BCBA</b>, CEO, PWSA   USA <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, Open to All</i></p>
10:00 AM - 10:15 AM	<b>BREAK / Sponsor &amp; Exhibitor Booths</b>
10:15 AM - 11:15 AM	<ul style="list-style-type: none"> <li>• <b>What's Happening in PWS Research - Theresa Strong, PhD</b>, Director of Research Programs, FPWR, <b>Lisa Mateševac, Au.D.</b>, Study Coordinator, FPWR, <b>Marc Ridilla, PhD</b>, Research Program Manager, FPWR and <b>Lauren Schwartz, PhD</b>, Research Psychologist - Behavior &amp; Mental Health Programs, FPWR, <b>Tony Holland, MD</b>, President, IPWSO <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, All Ages</i></li> <li>• <b>Musculoskeletal Issues of Prader-Willi Syndrome: A Few Things to Know - Harold van Bosse, MD</b>, Pediatric Orthopaedic Surgeon <i>Arizona A (Acacia), All Ages</i></li> <li>• <b>The Importance of Exercise and Nutrition Guidance and Recommendations for People Living with PWS - Georgina Loughnan, Physiotherapist</b>, PWS Clinic Coordinator, Metabolism &amp; Obesity Service PWS Clinic Royal Prince Alfred Hospital Sydney, <b>Constanze Lämmer, MD</b>, Senior Physician, KJF Klinikum Josefinum Department of Endocrinology and Diabetology <i>Arizona B (Bougainvillea), Ages 12+</i></li> <li>• <b>Nutrition Recommendations for Children and Families with PWS - Michael Tan, MS, RD, LDN, CDCES</b>, Registered Dietitian, Division of University of Florida <i>Arizona C, D (Copperwood, Desert Willow), Ages 0-11</i></li> </ul>
11:15 AM - 12:45 PM	<b>Lunch</b> <i>Canyon Ballroom; Included in Conference Registration</i>

1:00 PM - 2:00 PM	<ul style="list-style-type: none"> <li>• <b>Aging: Cognitive, Physical, and Social Health in PWS - Laura de Graaff, MD, PhD</b>, Associate Professor Rare Genetic Syndromes, Erasmus MC Rotterdam and Radboudumc Nijmegen <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, Ages 18+</i></li> <li>• <b>Understanding the Sibling Experience in Prader-Willi Syndrome - Meghana Wadnerkar Kamble, PhD</b>, Lecturer in Psychology, University of East Anglia, Norwich, UK, <b>Miriam Chernick</b>, Author and Educator, PWS Sibling, <b>Christian Garzia</b>, PWS Sibling, <b>Tyler Hedstrom</b>, PWS Sibling, <b>Madelyn Roth</b>, PWS Sibling <i>Arizona A (Acacia), All Ages</i></li> <li>• <b>Research Roundup: A Recap of Work Presented at the 2025 Clinical and Scientific Program - Theresa Strong, PhD</b>, Director of Research Programs, FPWR <i>Arizona B (Bougainvillea), All Ages</i></li> <li>• <b>Dynamic Movement Intervention (DMI) - Jo-Anne Weltman, B.ScPT, MRSc</b>, Co-Founder, DMI Therapy, <b>Abigail Ogilbee, PT, DPT</b>, Physical Therapist, Owner, Mat-Su Pediatric Physical Therapy <i>Arizona C, D (Copperwood, Desert Willow), Ages 0-5</i></li> </ul>
2:00 PM - 2:15 PM	<b>BREAK / Sponsor &amp; Exhibitor Booths</b>
2:15 PM - 3:15 PM	<ul style="list-style-type: none"> <li>• <b>Management of Behavioral Problems in Prader-Willi Syndrome - Deepan Singh, MD</b>, Vice Chair of Ambulatory Services, Chief of Research &amp; Grants, Department of Psychiatry, Maimonides Medical Center <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, Ages 6+</i></li> <li>• <b>Empowered Fathers of Exceptional Children - Charles Conway (Moderator)</b>, Dad to Angelica (4), <b>Anju Rao</b>, Dad to Ayoni (8), <b>Daniel Hedstrom</b>, Dad to Jayden (16), <b>Matt Rivard</b>, Dad to Jake (15) <i>Arizona A (Acacia), Dads Only</i></li> <li>• <b>Building Our International PWS Community - Lantz Yap</b>, Trustee, International Prader-Willi Syndrome Organisation, <b>Lin Xiaojing</b>, Chairperson, Zhejiang Prader-Willi Rare Disease Care Center, China, <b>Jennifer Saunders</b>, Founder, ASOPRAWI (PWSA - Costa Rica), <b>Josefina Pérez Rodriguez</b>, Founder and Director, Fundación María José, <b>Dr. Elisabeth Oyenusi</b>, Paediatric Endocrinologist and Senior Lecturer, College of Medicine, University of Lagos, Nigeria, <b>Menbere Kahssay, MD</b>, Consultant Paediatric Endocrinologist, Aga Khan University Hospital, Nairobi, Kenya <i>Arizona B (Bougainvillea), Open to All</i></li> <li>• <b>Starting Out Right: Behavioral Strategies for the Early Years and Beyond - Cindy Szapacs, M.Ed., BCBA</b>, Behavior Analyst, Bucks County Intermediate Unit #22 <i>Arizona C, D (Copperwood, Desert Willow), Ages 0-5</i></li> </ul>
3:15 PM - 3:30 PM	<b>BREAK / Sponsor &amp; Exhibitor Booths</b>
3:30 PM – 4:30 PM	<ul style="list-style-type: none"> <li>• <b>Advancing Treatments for PWS: PWS Clinical Trials</b> - Representatives from Currently Recruiting Clinical Trials <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, All Ages</i></li> <li>• <b>Healing, Hope, and Acceptance - Kim Tula, MS, CSW</b>, Senior Family Support Counselor and Trainer, PWSA   USA, <b>Kristi Rickenbach</b>, Parent Support Coordinator, PWSA   USA <i>Arizona A (Acacia), Ages 0-3</i></li> <li>• <b>FAMCARE – Education and Support for PWS Families and Carers Worldwide - Georgina Loughnan, Physiotherapist</b>, PWS Clinic Coordinator, Metabolism &amp; Obesity Service PWS Clinic Royal Prince Alfred Hospital Sydney, <b>Verena Wanker- Gutmann, PhD</b>, Educational Management - Retired, PWS Austria, IPWSO-FAMCARE <i>Arizona B (Bougainvillea), Open to All</i></li> </ul>
6:00 PM - 8:30 PM	<b>Night Under the Stars Gala</b> (For individuals with PWS and their siblings; Ticketed event) <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance; Dinner included</i>
<b>Family Event</b> 6:30 PM – 9:00 PM	<b>50th Birthday Celebration Party</b> (Free to attend, Drone Show at 8:45 PM) <i>Oasis Waterpark; Dinner on your own</i>

# Family Program Agenda

## DAY TWO | Saturday, June 28, 2025

7:00 AM	<b>Breakfast - Food Trucks</b> <i>Conference Center Pavilion; Breakfast not included with conference registration</i>
8:00 AM - 12:00 PM 8:00 AM - 5:00 PM	<b>Conference Check-In</b> <i>Conference Center Lobby (first floor)</i> <b>Help Desk Hours</b> <i>Conference Center Lobby (first floor)</i>
9:00 AM - 10:00 AM	<ul style="list-style-type: none"> <li>• <b>PWS Around the World - Tony Holland, MD</b>, President, IPWSO <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, All Ages</i></li> <li>• <b>Finding Joy in the Journey - Kristi Rickenbach</b>, Parent Support Coordinator, PWSA   USA, <b>Kristen White</b>, Managing Director and Chief Operating Officer, Beacon Global Strategies <i>Arizona A (Acacia), Ages 0-2</i></li> <li>• <b>From First Steps to School Success: Navigating the IFSP-to-IEP Transition - Destiny Pacha, EdD</b>, President, EmpowerED Solutions <i>Arizona B (Bougainvillea), Ages 3-5</i></li> <li>• <b>Advocacy in Action: Elevating Voices and Driving Change - Dorothea Lantz</b>, Director of Community Engagement, PWSA   USA, <b>Elaine Towle</b>, Advocacy Specialist, PWSA   USA, <b>Justice Rickenbach</b>, Advocate living with PWS, <b>Jessica Kempa</b>, Mom and Advocate, <b>Jen Garzia</b>, Mom and Advocate, <b>Paige Rivard, MBA</b>, Mom and Advocate <i>Arizona C, D (Copperwood, Desert Willow), All Ages</i></li> </ul>
10:00 AM - 10:15 AM	<b>BREAK / Sponsor &amp; Exhibitor Booths</b>
10:15 AM - 11:15 AM	<ul style="list-style-type: none"> <li>• <b>Keeping Your Relationship Intact: Strategies to Create a Strong and Healthy Marriage or Partnership - Lisa Graziano, M.A., LMFT</b>, PWS Education &amp; Training Consultant, Prader-Willi California Foundation <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, All Ages</i></li> <li>• <b>Sleep Disorders in PWS - Althea Shelton, MD</b>, Associate Professor of Neurology, Vanderbilt University Medical Center, <b>Olivia Veatch, PhD</b>, Assistant Professor, University of Kansas Medical Center <i>Arizona A (Acacia), All Ages</i></li> <li>• <b>PWS IEP Roadmap: Essential Components for School Safety &amp; Success - Destiny Pacha, EdD</b>, President, EmpowerED Solutions, <b>Stacy Ward, MS, BCBA</b>, CEO, PWSA   USA <i>Arizona B (Bougainvillea), Ages 3+</i></li> <li>• <b>Endocrine Issues in Teens and Adults - Diane Stafford, MD</b>, Clinical Professor of Pediatrics, Stanford University School of Medicine <i>Arizona C, D (Copperwood, Desert Willow), Ages 10+</i></li> </ul>
11:15 AM - 12:45 PM	<b>Lunch</b> <i>Canyon Ballroom; Included in Conference Registration</i>

1:00 PM - 2:00 PM	<ul style="list-style-type: none"> <li>• <b>Endocrinology Issues for Children with PWS - Jennifer Miller, MD, MS</b>, Pediatric Endocrinologist, Professor of Pediatric Endocrinology, University of Florida <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, Ages 0-9</i></li> <li>• <b>Caring for the Caregiver - Emily Felt</b>, PWSA Parent Mentor and Life Coach <i>Arizona A (Acacia), All Ages</i></li> <li>• <b>Supporting People with PWS to Move Out of the Family Home - Lynn Garrick, MSN, RN</b>, Medical/Research Coordinator, PWSA   USA, <b>Berit Otterlei, MS</b>, Health Care Manager, Prader-Willi Syndrome Organisation - Norway, <b>Gary Brennan</b>, National Development Manager, The Prader-Willi Syndrome Association - Ireland, <b>Rory Tierney</b>, Chairperson, The Prader-Willi Syndrome Association - Ireland <i>Arizona B (Bougainvillea), Open to All</i></li> <li>• <b>Making and Keeping Friends - Patrice Carroll, LICSW</b>, Director of PWS Services, Latham Centers, <b>Elizabeth Roof, M.A.</b>, Senior Research Specialist, Vanderbilt University <i>Arizona C, D (Copperwood, Desert Willow), Ages 16+</i></li> </ul>
2:00 PM - 2:15 PM	<b>BREAK / Sponsor &amp; Exhibitor Booths</b>
2:15 PM - 3:15 PM	<ul style="list-style-type: none"> <li>• <b>Guardianship and Special Needs Trusts for Those with PWS - Lisa Thornton, JD</b>, Attorney, Lisa Thornton Law <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, All Ages</i></li> <li>• <b>Update on GI Issues and Management in Prader-Willi Syndrome - Ann Scheimann, MD, MBA</b>, Professor of Pediatrics, Johns Hopkins School of Medicine <i>Arizona A (Acacia), All Ages</i></li> <li>• <b>Mental Health Challenges in People with PWS - Lauren Schwartz, PhD</b>, Research Psychologist - Behavior &amp; Mental Health Programs, FPWR <i>Arizona B (Bougainvillea), Ages 10+</i></li> <li>• <b>Teaching Emotional Regulation in Individuals with Prader-Willi Syndrome: ABA Strategies for Lasting Success - Kasey Bedard, PhD, BCBA-D</b>, Assistant Professor, The Chicago School <i>Arizona C, D (Copperwood, Desert Willow), Ages 5+</i></li> </ul>
3:15 PM - 3:30 PM	<b>BREAK / Sponsor &amp; Exhibitor Booths</b>
3:30 PM - 4:30 PM	<p><b>Trailblazers: Stories of Inspiration from Leaders in Our Community - Janice Agarwal, PT</b>, President and Executive Director, Watch Us Farm, Inc., <b>Liane Motta</b>, Co-Founder, Associação Brasileira de Prader Willi, <b>Vonnie Sheadel</b>, President, PWSA of Oregon and Washington, <b>Dini Rao</b>, Community Organizer, Undoing Racism <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, All Ages</i></p>
4:30 PM - 4:45 PM	<p><b>Closing Remarks - Marguerite Hughes</b>, Outgoing CEO, IPWSO <i>Main Ballroom - Eucalyptus or Honeysuckle Entrance, All Ages</i></p>