

PWSA | USA 2023 Family Conference Schedule



DAY ONE / Friday, June 23, 2023

7:45 a.m 8:30 a.m.	Breakfast Main Sabal Ballroom
8:30 a.m. – 9:15 a.m.	Welcome to PWSA USA's 37th National Convention - Paige Rivard, MBA, PWSA USA CEO and Marguerite Rupnow, MBA, PWSA USA Board Chair Stories of Hope from those Living with PWS - Dante Johnson, Justice Rickenbach, and Sophia Tweel Main Sabal Ballroom
Keynote Presentation 9:15 a.m. – 10:15 a.m.	Caring for the Caregivers: From Brokenhearted to Belonging Using the Raregivers™ Emotional Journey Map Speaker - Cristol O'Loughlin, Founder and CEO of ANGEL AID (A Nonprofit Group Enriching Lives, Inc.) Main Sabal Ballroom
10:15 a.m. – 10:30 a.m.	BREAK / Sponsor & Exhibitor Booths
10:30 a.m. – 11:30 a.m.	Genetics in PWS 101 / Standards of Care for PWS - Jessica Duis, MD, Pediatric Geneticist, Special Care Pediatrician Main Sabal Ballroom
11:30 a.m. – 11:45 a.m.	BREAK / Sponsor & Exhibitor Booths
Lunch 11:45 a.m. – 12:45 p.m.	Medical and Scientific Conference Recap - David Agarwal, MD, FSIR, Associate Professor of Clinical Radiology, IU Health Radiology Main Sabal Ballroom
12:45 p.m 1:00 p.m.	BREAK / Sponsor & Exhibitor Booths
1:00 p.m. – 2:00 p.m.	 WORKSHOP SESSION I (choose one) DadVocacy - Clint Hurdle, Colorado Rockies Special Assistant to General Manager, Charles Conway, Lieutenant Colonel, Jonathan Andrews, Director of Marketing and Product Development, Advantage Technologies, Inc., and Brian Kalasak, Vice President, Special Risk Mutual of Omaha Sabal A Best Practices on GI Issues in PWS - Ann Scheimann, MD, MBA, Pediatric Gastroenterologist Sabal B Finding Your Community - Jessica Patay, Founder and Executive Director, We Are Brave Together Sabal C
2:00 p.m 2:15 p.m.	BREAK / Sponsor & Exhibitor Booths
2:15 p.m. – 3:15 p.m.	 WORKSHOP SESSION II (choose one) Journal Therapy: DIY Therapy for Parents, Siblings, and Caregivers - Anne Fricke, Poet, Author, Walking with Freya Podcast Sabal A What's That Orthopaedist Talking About - Harold van Bosse, MD, Pediatric Orthopaedic Surgeon, SSM Health/Cardinal Glennon Children's Hospital/St. Louis University Sabal B Parenting for Interdependence - Amy McDougall, MS, School Psychologist and Noelle McDougall, living with PWS Sabal C
3:15 p.m 3:30 p.m.	BREAK / Sponsor & Exhibitor Booths
3:30 p.m. – 4:30 p.m.	 WORKSHOP SESSION III (choose one) Sibling Panel "Glass Children" - Jessica Duis, MD, Pediatric Geneticist and Special Care Pediatrician, Joe Gill, PWS Sibling, Jordan Rivard, PWS Silbling Sabal A ABA Therapy, Potty Training, and Sleep - Kasey Bedard, PhD, BCBA-D, Behavior Analyst, Delta Behavior Services, Annette Griffith, PhD, The Chicago School of Professional Psychology Sabal B Supportive Living Options - Lynn Garrick, RN, PWSA USA Medical/Research Coordinator, Patrice Carroll, MSW, Manager of Prader-Willi Syndrome Services, Lee Chamberlain, LCSW, VP and Chief Strategy Officer, Latham Centers, Rob Lutz, MBA, CFO and CBO, iBio Inc., Brian Hughes, PhD, Professor of Psychology, University of Galway, Scott Arant, Founder and Former CEO, American Health Imaging, and Emily Lawrence, adult with PWS living independently Sabal C
4:00 p.m. – 6:00 p.m.	Dad's Den (Room - Blue) Get ready for Hope United Gala
Family Event 6:00 p.m. – 9:30 p.m.	Hope United Gala - Dueling Pianos, Silent and Live Auction (Pavillion) Night under the Stars Gala (ages 7+) (Main Sabal Ballroom) (Childcare available from 5:45 - 9:30 for ages 0 – 6. Does not include dinner. Please bring a healthy snack for your child.)



PWSA | USA 2023 Family Conference Schedule



DAY TWO / Saturday, June 24, 2023

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7:45 a.m. – 8:30 a.m.	Breakfast Main Sabal Ballroom
8:30 a.m. – 8:45 a.m.	Welcome - Paige Rivard, MBA, PWSA USA CEO Main Sabal Ballroom
8:45 a.m. – 9:45 a.m.	WORKSHOP SESSION IV • Clinical Trials Update - Representatives from Soleno Therapeutics, Harmony Biosciences, Aardvark Therapeutics, Acadia Pharmaceuticals, and Gedeon Richter Main Sabal Ballroom
9:45 a.m. – 10:00 a.m.	BREAK / Sponsor & Exhibitor Booths
10:00 a.m. – 11:00 a.m.	 WORKSHOP SESSION V (choose one) OH NO FIVE-0 and the Dark Web - Tammie Penta, Retired Police Sergeant Sabal A Prader-Willi Syndrome: Nutrition Guidance and Recommendations - Jennifer Miller, MD, Pediatric Endocrinologist, Michael Tan, MS, RD, LDN, CDCES, Pediatric Dietitian Sabal B The Role of Medications for the Management of Behavior Issues in Prader-Willi syndrome - Deepan Singh, MD, Vice-Chair of Ambulatory Psychiatry Services, Maimonides Medical Center Sabal C
11:00 a.m. – 11:15 a.m.	BREAK / Sponsor & Exhibitor Booths
11:15 a.m. – 12:15 p.m.	 WORKSHOP SESSION VI (choose one) Guardianship and Creating Financial Security for a Loved One with Special Needs - Ivailo Grigorov, MBA, ChSNC®, Financial Advisor, Northwest Mutual and Lisa Thornton, J.D., Lisa Thornton Law Sabal A Improving Mental Health and Well-being for People with PWS - Tony Holland, MD, Clinical and Academic Psychiatrist, President of IPWSO Sabal B Special Topics in Behavior at Home and School - Kasey Bedard, PhD, BCBA-D, Behavior Analyst, Delta Behavior Services, Annette Griffith, PhD, The Chicago School of Professional Psychology, Destiny Pacha, Ed.D., Alanna Morrissey M.A., BCBA Main Sabal Ballroom
12:15 p.m. – 1:10 p.m.	PWSA USA Luncheon and Volunteer Awards Main Sabal Ballroom Pick up boxed lunch in the Sabal Foyer
1:10 p.m. – 1:15 p.m.	BREAK / Sponsor & Exhibitor Booths
1:15 p.m. – 2:15 p.m.	 WORKSHOP SESSION VII (choose one) Maximizing Success: The Role of Therapy in Supporting Children with PWS - Angela Gustafson, MS, CCC-SLP, Speech-Language Pathologist, Janice Agarwal, PT, CNDT, President, Executive Director, Watch Us Farm, Inc. Sabal A Transitioning from an IFSP to an IEP - Stacy Ward, MS, PWSA USA Director of Family Support, Amy McDougall, MS, School Psychologist Sabal C Sleep Disordered Breathing in Prader Willi Syndrome - Amee Revana, DO, FAASM, Associate Professor of Pediatrics, Baylor College of Medicine/Texas Children's Hospital, Maria Picone, Co-Founder and CEO, TREND Community Sabal B
2:15 p.m. – 2:30 p.m.	BREAK / Sponsor & Exhibitor Booths
2:30 p.m. – 3:45 p.m.	WORKSHOP SESSION VIII (Fireside Chat) Conversation with the Clinicians: A Synergistic, Multidisciplinary Approach - Jennifer Miller, MD, Pediatric Endocrinologist, Amee Revana, DO FAASM, Associate Professor of Pediatrics, Deepan Singh, MD, Vice-Chair of Ambulatory Psychiatry Services, Maimonides Medical Center, Maria Picone, Moderator, Founder/CEO TREND Community Main Sabal Ballroom
3:45 p.m. – 5:00 p.m.	Closing Ceremony - Paige Rivard, MBA, PWSA USA CEO Main Sabal Ballroom PWS Campers & Sibling Camp Production (Pick up campers back in program areas following Closing Ceremony)
5:00 p.m. – 7:00 p.m.	Family Den Blue