



PWSA | USA 2021 Professional Providers Convention Schedule

PRESENTED BY

Prader-Willi
 SYNDROME ASSOCIATION | USA
 SAVING AND TRANSFORMING LIVES

Tuesday, June 22, 2021

Times are EST

11:00–11:10am	Welcome to the Professional Providers Convention Patrice Carroll, LICSW and Mary K. Ziccardi, B.S., Co-Chairs PPAB, PWSA USA
11:15–12:15pm	Keynote Speaker - PWS Behavior Management Strategies & Interventions Lisa Graziano, MA, LMFT
12:15–12:30pm	BREAK / Sponsor & Virtual Exhibitor Booths
12:30–1:30pm	SESSION I Exercise & Motivation - Keegan Johnson, CEO of Let's Go Fitness
1:30–1:45pm	BREAK / Sponsor & Virtual Exhibitor Booths
1:45–2:45pm	SESSION II Medical Issues in PWS: "What You Didn't Know You Needed to Know..." Tina Didino, LPN, Medical Case Manager, REM Ohio
2:45–3:15pm	LUNCH BREAK
3:15–4:15pm	SESSION III Rights vs. Health & Safety/Best Practice - Mark Lister, B.S., BCaBA, Jeff Covington, MPH, Marguerite Rupnow, MBA, and Mary K. Ziccardi, B.S., and Barbara (BJ) Goff, Ed.D.
4:15–4:30pm	BREAK / Sponsor & Virtual Exhibitor Booths
4:30-6:00pm (20 mins each)	BREAKOUT SESSIONS Workgroup I - Family Interaction, Dynamics & Relationships - Barbara (BJ) Goff, Ed.D, Jeff Covington, MPH Workgroup II - Behavior - Mark Lister, B.S., BCaBA, Mary K. Ziccardi, B.S. Workgroup III - COVID-19 – Lessons Learned - Patrice Carroll, LICSW, Brittini Kliment, M.Ed Workgroup IV - Your Voice - Marguerite Rupnow, MBA & Stacy Ward, MS, Director of Family Support, PWSA USA
6:00–6:15pm	BREAK / Sponsor & Virtual Exhibitor Booths
6:15–6:45pm	SESSION IV Discussion Findings from Breakouts Led by Panel
6:50–7:00pm	Closing Remarks Patrice Carroll, LICSW and Mary K. Ziccardi, B.S., Co-Chairs PPAB, PWSA USA



PWSA | USA 2021 Virtual Medical & Scientific Convention Schedule

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DAY ONE / Wednesday, June 23, 2021

Times are EST

11:00–11:10am	Welcome to the Medical and Scientific Convention James Loker, MD & Ann Manzardo, PhD
11:15–12:15pm	Keynote Speaker - Behavioral Problems in Prader-Willi Syndrome - What to Expect Deepan Singh, MD (NY, USA)
12:15–12:30pm	BREAK / Sponsor & Virtual Exhibitor Booths
12:30–1:30pm	SESSION I A Year in Review: Updates on Care, Treatment and Clinical Trials Jennifer Miller, MD (FL, USA)
1:30–1:45pm	BREAK / Sponsor & Virtual Exhibitor Booths
1:45–2:45pm	SESSION II Pulmonary Issues in Prader-Willi Syndrome Pediatric Pulmonologist - Ameer Revana, MD (TX, USA)
2:45–3:15pm	BREAK / Sponsor & Virtual Exhibitor Booths
3:15–3:35pm	ABSTRACT I Behavioral & Dietary Management for Adults with Prader-Willi Syndrome in a Residential Setting Kasey Bedard, M.S., BCBA
3:45–4:05pm	ABSTRACT II The Impact of COVID19 Quarantines and Stay at Home Orders on PWS Families: Data from The Global PWS Registry Jessica Bohonowych, PhD
4:15–4:35pm	ABSTRACT III Preliminary Results from a Randomized, Placebo-Controlled Phase 2 Trial Using Synthetic Cannabidiol (CBD) Oral Solution in 7 Individuals with Prader-Willi Syndrome Lynne Bird, MD
4:45–5:05pm	ABSTRACT IV Cyclical Catatonia in a 10-Year-Old Boy with Prader-Willi Syndrome Selene M. Etches, MD
5:15–5:35pm	ABSTRACT V PATH for PWS Study 2021 Update: A Non-Interventional, Observational, Natural History Study of Serious Medical Events in Prader-Willi Syndrome Lisa Matesevac, AuD
5:40–5:50pm	Closing Remarks - James Loker, MD and Ann Manzardo, PhD



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DAY TWO / Thursday, June 24, 2021

Times are EST

11:00–11:10am	Welcome to the Medical and Scientific Convention James Loker, MD and Ann Manzardo, PhD
11:15–12:15pm	Keynote Speaker - Recent Developments at IPWSO: The ECHO Programme, COVID-19 Survey and More - Tony Holland, MD (Cambridge, United Kingdom)
12:15–12:30pm	BREAK / Sponsor & Virtual Exhibitor Booths
12:30–1:30pm	SESSION I Adults With PWS In Denmark: Social and Medical Care and Possibilities For Living Suzanne Blichfeldt, MD (Roskilde, Demark)
1:30–1:45pm	BREAK / Sponsor & Virtual Exhibitor Booths
1:45–2:45pm	SESSION II Care of People with PWS in Germany in General and Pandemic Times Norbert Hödebeck-Stuntebeck, PhD (Bad Oeynhausen, Germany)
2:45–3:15pm	LUNCH / Sponsor & Virtual Exhibitor Booths
3:15–3:35pm	ABSTRACT I Intranasal Carbetocin Improves Symptoms of PWS in CARE-PWS Phase 3 Study Davis C. Ryman, MD, PhD
3:45–4:05pm	ABSTRACT II Pharmacogenetic Testing Results in a Case Series of Patients with PWS DEL vs UPD: Implications for Drug Selection and Dosing Janice Forster, MD
4:15–4:35pm	ABSTRACT III Therapeutic Response to DCCR (Diazoxide Choline) Extended-Release Tablets in Patients with Prader-Willi Syndrome Prior to the Onset of the COVID-19 Pandemic Jennifer Miller, MD
4:45–5:05pm	ABSTRACT IV Impacts of ATP-Sensitive Potassium Channel Gene Variants on Baseline Insulin and Hyperphagia in Prader-Willi Syndrome Olivia Veatch, MS, PhD
5:15–5:35pm	ABSTRACT V Ongoing Psychological/Behavioral Evaluations in a Multi-Disciplinary PWS Clinic David Michalec, PhD and Erin Given, B.A.
5:40–5:50pm	Closing Remarks - James Loker, MD and Ann Manzardo, PhD



PWSA | USA 2021 Virtual General Convention Schedule

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DAY ONE / Friday, June 25, 2021

Times are EST

11:00–11:10am	Welcome to the General Convention Paige Rivard, CEO
11:15–12:15pm	Keynote Speaker - Hello World....Ready or Not Here I Come! Clint Hurdle, Former Major League Baseball Manager
12:15–12:30pm	BREAK / Sponsor & Virtual Exhibitor Booths
12:30–1:30pm	WORKSHOP SESSION I (choose one) <ul style="list-style-type: none"> • Tackling Problem Behavior with Applied Behavior Analysis - Kasey Bedard, MS, BCBA • PWSA USA Special Education Advisory Board Education Panel - Barbara J.(BJ) Goff, EdD, Amy McTighe, PhD, Staci Zimmerman, M.Ed, Brittini Kliment, M.Ed, Mary K. Ziccardi, B.S. • Nutrition and PWS - Melanie Silverman, MS, RD, IBCLC • All Dads On Deck - Clint Hurdle, Former Major League Baseball Manager
1:30–1:45pm	BREAK / Sponsor & Virtual Exhibitor Booths
1:45–2:45pm	WORKSHOP SESSION II (choose one) <ul style="list-style-type: none"> • A Grandparent's Love - Chuck and Becky French & Dennis and Julie Kalasek • Recognizing Sleep-Related Symptoms of PWS - Ameer Revana, MD and Maria Picone, CEO of TREND Community, Justice & Kristi Rickenbach, Parent Support Coordinator • An Invitation to Self-Care and the PWS Journey - Emily Felt • International Approaches to Adult Living with PWS - Ms. Karin Birkedal (Solvang, Denmark), Ms. Lee Chamberlain, COO, Latham Centers (USA), Norbert Hodebeck-Stuntebeck, PhD, Project Manager Prader-Willi Syndrome (Bad Oeynhausen, Germany) Project Manager, Matt McCleery, PWSA Board
2:45–3:00pm	BREAK / Sponsor & Virtual Exhibitor Booths
3:00–4:00pm	WORKSHOP SESSION III (choose one) <ul style="list-style-type: none"> • The Orthopedics of Prader-Willi Syndrome - Harold van Bosse, MD • Behavior Problems in Prader-Willi Syndrome-What to Expect - Deepan Singh, MD, FAPA • Financial Management & Special Needs Trusts - Ivailo Grigorov, MBA
4:00–4:15pm	BREAK / Sponsor & Virtual Exhibitor Booths
4:15-5:15pm	Creating A Sensory Diet - Janice Agarwal, PT, CDNT
5:20–5:30pm	Closing Remarks Paige Rivard, CEO



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DAY TWO / Saturday, June 26, 2021

Times are EST

11:00–11:10am	Welcome to the General Convention Paige Rivard, CEO
11:15–12:15pm	Keynote - Medical & Scientific Recap - David Agarwal, MD
12:15–12:30pm	BREAK / Sponsor & Virtual Exhibitor Booths
12:30–1:30pm	WORKSHOP SESSION IV (choose one) <ul style="list-style-type: none"> • Supplemental Therapies - Abbie Ogilbee, DPT • Pharmaceutical Panel Presentation - Harmony Biosciences, Levo Therapeutics, Radius, Saniona, Soleno Therapeutics • Using the Environment to Manage Behavior - Janice Forster, MD
1:30–1:45pm	BREAK / Sponsor & Virtual Exhibitor Booths
1:45–2:45pm	SHARING SESSIONS <ul style="list-style-type: none"> • Sharing Session Age Infant-Five - Christina Argo • Sharing Session Age Six-Twelve - Paige Rivard, CEO, PWSA USA • Sharing Session Age Thirteen-Eighteen - Diane Seely • Sharing Session Age Nineteen and Older - Lisa Graziano, M.A., LMFT
2:45–3:00pm	BREAK / Sponsor & Virtual Exhibitor Booths
3:00–4:00pm	WORKSHOP SESSION V (choose one) <ul style="list-style-type: none"> • Understanding Prader-Willi Syndrome and Autism - Cindy Szapacs, M.Ed. BCBA • GI Issues in Prader-Willi Syndrome-Perspectives for 2020 and Beyond - Ann Scheimann, MD, MBA • A Global, Comprehensive Understanding Food, Behavior and Food and Behavior in PWS - Linda Gourash, MD
4:00–4:15pm	BREAK / Sponsor & Virtual Exhibitor Booths
4:15-5:15pm	A Year in Review - Prader-Willi Syndrome - Jennifer Miller, MD
5:20–5:30pm	Closing Remarks & PWSA USA Updates Paige Rivard, CEO
6:00–8:00pm	Family Fun Night - Superhero BINGO