50
Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

2025 ANNUAL REPORT

Celebrating 50 Years of Lighting the Way Forward

THANK YOU FOR SUPPORTING PWSA | USA IN 2025

aardvark therapeutics

ACADIA™

HARMONY BIOSCIENCES

James Hervey Johnson
Charitable Educational Trust

PANTHER RAREX
The Rare Disease Pharmacy®

SOLENO THERAPEUTICS

Susan A. & Donald P. Babson
Charitable Foundation

TREND Community™
Turning Anecdotes Into Evidence™

— Mission —

To enhance the quality of life and empower those affected by Prader-Willi syndrome.

— Vision —

A world where those affected by Prader-Willi syndrome are empowered and enjoy a productive life in a supportive community.

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES


OLD TOWN TROLLEY TOURS
SILLY GOOSE
ON THE LOOSE
San Diego, California


Nebraska District 02
Junior Congressma
Fun Pack

TABLE OF CONTENTS

A LETTER FROM PWSA | USA'S CEO AND BOARD CHAIR

Stacy Ward, MS, BCBA
PWSA | USA CEO

Marguerite Rupnow, MBA
PWSA | USA Board Chair

As we look back on 2025, we are filled with gratitude, pride, and renewed determination for the work ahead. This past year, our 50th anniversary year, was one of the most meaningful and impactful in PWSA | USA's history. It was a year of reflection and celebration, but even more so, a year of growth, innovation, and deepened commitment to individuals and families living with Prader-Willi syndrome.

Fifty years ago, PWSA | USA was born out of the love, advocacy, and resilience of families who refused to walk this journey alone. Today, that same spirit continues to drive everything we do. And thanks to the generosity of supporters like you, 2025 was a milestone year in which we strengthened every part of our mission.

We expanded our Family Support programs, ensuring parents, caregivers, and individuals with PWS had compassionate guidance at every stage, from diagnosis through adulthood and beyond. Our team provided emotional support, resources, crisis planning, and problem-solving for thousands of families across the country. Our Crisis Hotline and Medical Support Services remained a lifeline during emergencies, offering clinician-to-clinician consultation, behavioral support, safety planning, and critical assistance in moments when families needed us most.

We also made significant strides in advocacy and public policy this year. At the state level, we worked tirelessly fighting for Prader-Willi syndrome to be recognized as an eligible diagnosis for waiver services, giving individuals with PWS access to the supports they need to live safely. We provided testimony before key Pharmacy & Therapeutics and Drug Utilization Review committees to advocate for insurance approval of VYKAT XR, ensuring that individuals with PWS have access to a medication that can meaningfully improve quality of life. These efforts demonstrate our unwavering commitment to breaking down barriers to care.

This was also a landmark year for research and scientific advancement. Through our support of the Global PWS Registry, natural history studies, collaborations with industry partners, and continued investment in research initiatives, we helped accelerate progress toward new treatments and improved clinical understanding. Your generosity fuels work that brings us closer to breakthroughs that once felt out of reach.

We also expanded our Education and Training programs, equipping schools, caregivers, residential providers, and clinicians with the tools needed to support individuals with PWS safely and effectively. Our training efforts continue to strengthen communities and empower those working closest with our families.

Reflecting on this 50th anniversary year, we are struck by how far we have come - and how much possibility lies ahead. None of this work would be possible without our community of donors, partners, volunteers, families, and supporters. You are the heart of this mission, and your belief in our work continues to change lives. As we look to the next 50 years, we do so with unwavering dedication and a shared vision: a world where individuals with PWS are understood, supported, and empowered to live full and meaningful lives.

Stacy Ward

Stacy Ward, MS, BCBA
PWSA | USA CEO

Marguerite Rupnow

Marguerite Rupnow, MBA
PWSA | USA Board Chair

50 YEARS OF HOPE


SENIOR


JAWS


NEVADA
DYNAMITE
FASTPITCH
15

ADVOCACY & AWARENESS

Advancing Policy, Access, and Equity for the PWS Community

In 2025, PWSA | USA entered a new era of advocacy - one defined by measurable policy impact, empowered grassroots leadership, and historic progress in treatment access. Building on decades of groundwork and the momentum of prior years, our Advocacy & Awareness efforts centered on three core pillars: policy change, community-powered advocacy, and ensuring equitable access to care and treatments for individuals with Prader-Willi syndrome.

This year marked a turning point for the PWS community, as advocacy efforts translated directly into regulatory, legislative, and systems-level outcomes that will shape care for years to come.

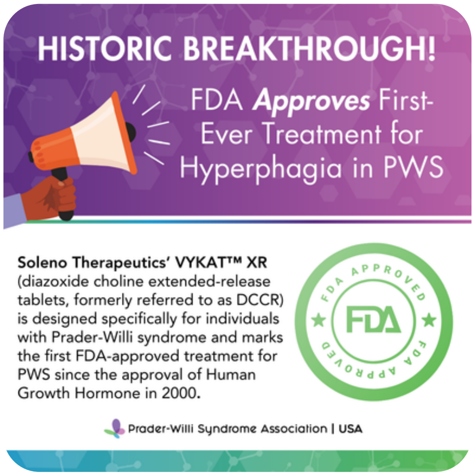
Landmark Federal Advocacy Wins

FDA Approval of the First-Ever Treatment for Hyperphagia in PWS

On March 26, 2025, the FDA approved VYKAT XR (formerly known as DCCR), the first-ever treatment targeting hyperphagia in PWS, a watershed moment for the community. This milestone was the result of sustained, coordinated advocacy over many years, including:

- The 2023 Externally Led Patient-Focused Drug Development (EL-PFDD) Meeting
- Publication and submission of the Voice of the Patient Report
- Direct engagement with The U.S. Food and Drug Administration (FDA) and Center for Drug Evaluation and Research leadership
- Community petitions and congressional sign-on letters
- Strategic collaboration with industry, clinicians, and advocacy partners

PWSA | USA played a central role in ensuring that lived experience informed regulatory decision-making and that urgency around hyperphagia was clearly understood.



HISTORIC BREAKTHROUGH!

FDA *Approves* First-Ever Treatment for Hyperphagia in PWS

Soleno Therapeutics' VYKAT™ XR (diazoxide choline extended-release tablets, formerly referred to as DCCR) is designed specifically for individuals with Prader-Willi syndrome and marks the first FDA-approved treatment for PWS since the approval of Human Growth Hormone in 2000.

National Advocacy & Legislative Engagement

PWSA | USA continued to elevate PWS as a priority within broader rare disease policy conversations. Throughout 2025, our team and advocates engaged lawmakers and federal agencies on issues including:

- **Access and coverage protections** following FDA approval of VYKAT XR
- **Medicaid and waiver recognition** for PWS-related services
- **Rare pediatric disease incentives**, including ongoing efforts to reinstate and strengthen Priority Review Voucher programs
- **Pharmacy Benefit Manager reform**, addressing barriers to medication access
- **Department of Defense Peer Reviewed Medical Research Program**, continuing efforts to add PWS as a designated topic area

Our advocacy emphasized that approval alone is not enough. Policies must ensure timely, affordable, and equitable access for all individuals living with PWS.

Advocacy Ambassador Program: From Training to Action

In 2025, the PWSA | USA Advocacy Ambassador Program transitioned from launch to full-scale activation. Trained ambassadors (caregivers, self-advocates, and family members) represented the PWS community at the state and federal levels, bringing personal stories directly to policymakers.

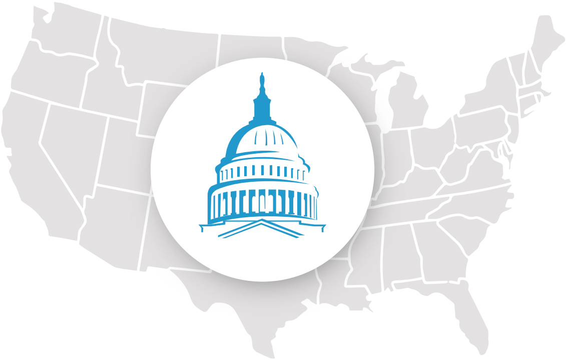
Key highlights include:

- Ambassador participation in Rare Disease Week on Capitol Hill
- State-level meetings addressing Medicaid, education, and disability services
- Media engagement and public awareness efforts across multiple states
- Continued expansion of the Advocacy Master Class to build long-term advocacy capacity

This program strengthened PWSA | USA's grassroots infrastructure and ensured advocacy efforts were informed, coordinated, and sustainable.

ADVOCACY & AWARENESS

State-Level Advocacy & Medicaid Focus



Recognizing that many of the most significant barriers for families occur at the state level, PWSA | USA deepened its focus on:

- Medicaid waiver eligibility and recognition of PWS
- Education of state agencies and legislators on the medical and behavioral complexity of PWS
- Supporting families navigating coverage decisions and appeals

Through testimony, health committee briefings, and collaboration with state-based rare disease coalitions, PWSA | USA worked to ensure PWS is understood as a complex, lifelong genetic condition requiring specialized supports.

Equity, Inclusion, and Community Voice

PWSA | USA continued to prioritize inclusive advocacy in 2025. Through collaboration with the PWS BIPOC Affinity Group "Colors of Hope" and national partners, we worked to:

- Elevate voices historically underrepresented in advocacy spaces
- Expand outreach to diverse communities
- Ensure patient engagement efforts reflect the full spectrum of lived experience
- Advocate for inclusivity to strengthen both the inclusivity and credibility of our work

Awareness, Education, and Public Engagement

Advocacy and awareness go hand in hand. In 2025, PWSA | USA leveraged storytelling, education, and public-facing initiatives to broaden understanding of PWS among policymakers, providers, and the general public. These efforts reinforced that PWS is not rare to those who live it. That awareness drives action.

Looking Ahead to 2026

The advocacy achievements of 2025 represent both an arrival point and a call to action. With the first FDA-approved treatment now a reality, the work ahead is clear: Protect access, expand coverage, invest in research, and continue amplifying the voices of individuals with PWS and their families. PWSA | USA remains committed to leading with integrity, collaboration, and urgency because progress is only meaningful when it reaches every individual who needs it.

FAMILY SUPPORT

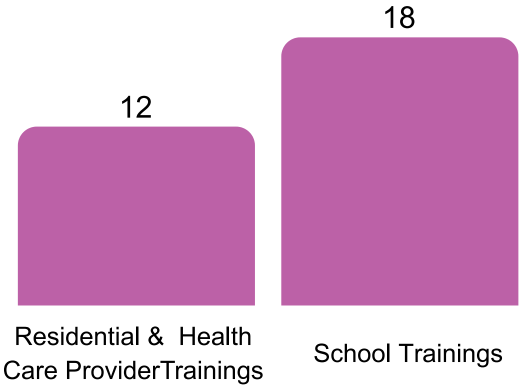
PWSA | USA's Family Support team provides guidance and support to individuals diagnosed with Prader-Willi syndrome, their families, and care providers. The team provides education and training to medical providers, educators, and professional caregivers about the syndrome, and advocates for the comprehensive needs of the entire PWS community.

HOW WE OFFER SUPPORT

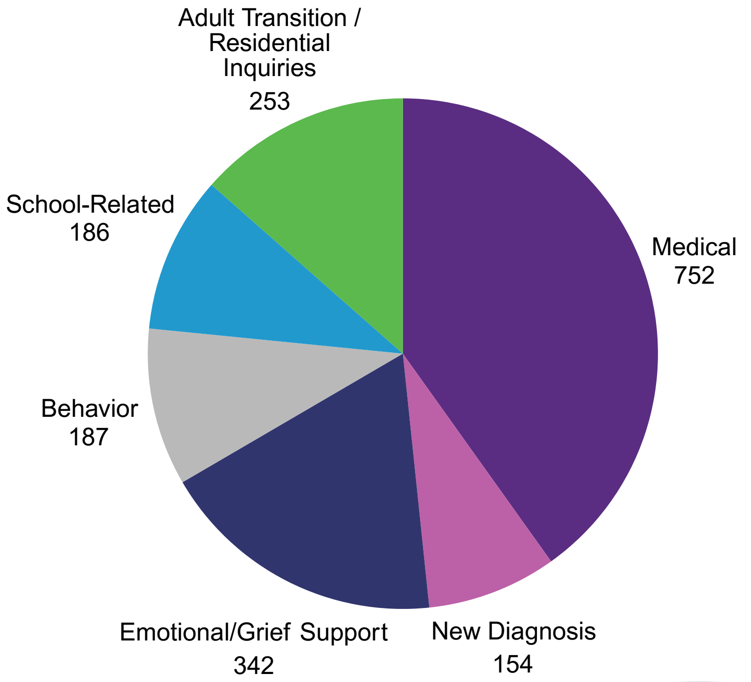
- **Provider Training** - Educating Health Care Professionals
- **Family Support Groups** - Building a Supportive Community
- **School Success** - Diligence and Active Participation
- **Nutrition Guidance** - Weight Management Strategies & Support
- **Financial Support** - Assistance for Care and Resources
- **New Diagnosis Support** - Care Packages and "Packet of Hope" Resource Guide
- **Behavior Support** - Managing Unique Challenges
- **Legal Support** - Navigating Legal and Advocacy Issues
- **Clinical Trials** - Advancing PWS Research and Treatment
- **Community Events** - Empowering Our Community
- **Family Mentor Program** - Parents, Siblings, Grandparents
- **Grief Counseling**
- **Social Stories & Extensive Resource Library**
- **24-hour Crisis Phone Line**

OUR 2025 IMPACT

4,567	**Total Family Support Inquiries**
3,815	**Non-Medical Inquiries**
380	**New Diagnosis Packets Sent Out**



Family Support Inquiry Breakdown



FAMILY SUPPORT

Building Our Social Skills (BOSS) Program

The Building Our Social Skills program, offered by PWSA | USA, is a structured, skills-based program designed to support adolescents and adults with Prader-Willi syndrome in developing practical social communication and interpersonal skills. Grounded in evidence-informed strategies, BOSS focuses on areas such as conversational turn-taking, understanding social cues, emotional regulation, problem-solving, and building healthy peer relationships. In 2025, PWSA | USA delivered three BOSS sessions, serving a total of 16 participants through guided instruction, role-playing, and facilitated group discussion. Each session provided consistent routines, clear expectations, and supportive coaching to promote skill acquisition, confidence, and real-world application, reinforcing PWSA | USA's commitment to expanding meaningful, developmentally appropriate programming for individuals with PWS across the lifespan.

Partnership with EmpowerED Solutions

EMPOWERED SOLUTIONS

PWSA | USA is proud to partner with Destiny Pacha, Ed.D., and EmpowerED Solutions to advance high-quality, PWS-specific educational advocacy and family support nationwide. Through this partnership, families receive expert guidance navigating complex education systems, including the development and review of Individualized Education Programs, Behavior Intervention Plans, and Individualized Healthcare Plans. Dr. Pacha brings deep expertise in both special education law and the unique behavioral, medical, and regulatory features of Prader-Willi syndrome, ensuring that supports are proactive, consistent, and grounded in best practice rather than crisis response.

A key component of this collaboration is the Parent Empowerment Training Program, offered by PWSA | USA and delivered by Dr. Pacha. This structured training equips parents and caregivers with the knowledge, tools, and confidence needed to effectively advocate for their children within school systems. Through education on PWS-specific accommodations, goal development, behavior supports, and communication strategies, parents learn how to engage as informed, collaborative members of their child's educational team. The program emphasizes preparation, clarity, and empowerment, helping families move from feeling overwhelmed to feeling capable and supported.

Partnership with EmpowerED Solutions (Cont.)

Together, PWSA | USA and EmpowerED Solutions ensure that families are not navigating these challenges alone. By pairing individualized consultation with scalable parent training, this partnership strengthens both immediate student supports and long-term family capacity. The result is a more informed parent community, better-prepared school teams, and improved educational experiences for students with Prader-Willi syndrome - rooted in dignity, safety, and opportunity.

PWS Egypt & Middle East Nile Hope Workshop & Camp


In October 2025, PWSA | USA was proud to help support a truly historic milestone for the global Prader-Willi syndrome community: the first-ever PWS Egypt & Middle East Nile Hope Workshop and Camp, held October 1-4 at Beit El Wady in Egypt. This groundbreaking, two-part program, made possible with sponsorship and support from the International Prader-Willi Syndrome Organisation (IPWSO), marked the first event of its kind in the region and represents an important step forward in expanding international connection, education, and support for families affected by PWS.

The program brought together 30 families (nearly 120 individuals) from across the Middle East and Arab world for an experience that combined education, community, and healing. It began with a two-day virtual workshop, followed by a two-day in-person camp, making the event both accessible and deeply personal. Our incredible team member Sarah Kasaby, PWSA | USA's Information & Referral Specialist, played a major role in helping bring this vision to life and attended in person to support families on the ground - an effort that made a lasting impact on everyone involved.

PWS Egypt & Middle East Nile Hope Workshop & Camp (Cont.)

The virtual Nile Hope workshop connected parents with a multidisciplinary group of specialists in behavior, endocrinology, orthopedics, school support, advocacy, and group-home care. With the support of professional interpreters, all sessions were fully accessible, ensuring families could ask questions, receive clear answers, and walk away with practical, PWS-specific guidance they could use right away. A highly attended parents' session focused on the stages of children's psychological development and how to support social and emotional growth at every age, always through the lens of the unique needs of individuals with Prader-Willi syndrome.

When families came together in person for the camp, the focus shifted to connection, confidence-building, and emotional growth. Children participated in thoughtfully designed, age-appropriate activities centered on honesty, cooperation, emotional expression, self-respect, respect for others, and building independence. One of the most powerful moments of the entire program came during a letter-writing activity, when parents wrote letters to their children and children wrote letters to their parents, sharing messages of love, pride, gratitude, apologies, and promises. Each letter was read aloud in front of the group. There were many tears, but also deep healing, understanding, and connection.

The camp concluded with a joyful evening of singing, dancing, and a dress-up party that quickly became the highlight of the experience. The kids danced together, laughed together, and celebrated new friendships before saying goodbye and ended the program on a note of pure joy and togetherness.

This event was more than a successful workshop and camp, it was proof of what's possible when global partners come together with a shared mission. With the leadership of PWS Egypt & Middle East, the support of IPWSO, and the involvement of PWSA | USA, Nile Hope represents a powerful model for future international collaboration and growth. It marks not just a milestone for the region, but a launching point for more global gatherings like this - bringing education, support, and hope to families who have too often had to navigate PWS on their own. Congratulations and deep thanks to Sarah and to everyone who helped make this historic and deeply meaningful event a reality. This is what building a truly global PWS community looks like.


STAY CONNECTED
FRIENDS FOR LIFE
PRADER-WILLI SYNDROME
ADVOCATE


PWS CAMP


Prader-Willi Syndrome Association | USA
50
YEARS OF HOPE
Prader-Willi Syndrome Association | USA

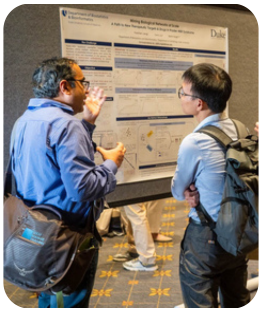
RESEARCH

The year 2025 marked an extraordinary period of progress, collaboration, and momentum for the Medical and Research pillar. One of the most historic milestones for the PWS community occurred in March 2025 with the FDA approval of the first medication specifically indicated for the treatment of hyperphagia in individuals with PWS. This landmark achievement represents decades of advocacy, research, and collaboration between families, clinicians, researchers, and industry partners. In response, members of the Clinical and Scientific Advisory Board (CSAB) worked swiftly to develop and publish a comprehensive Frequently Asked Questions document to help families, providers, and stakeholders better understand the medication, its role in treatment, and considerations for use.

2025 International PWS United in Hope Conference

Clinical & Scientific Program

The 2025 International PWS United in Hope Conference was another major highlight of the year. Hosted in collaboration with the International Prader-Willi Syndrome Organisation (IPWSO) and The Foundation for Prader-Willi Research (FPWR), the clinical and scientific programming drew 413 attendees and featured more than 60 sessions focused on advancing care for individuals with PWS across the lifespan. Experts from around the world gathered to share emerging research, clinical best practices, and innovative models of care. The conference fostered meaningful collaboration among clinicians, researchers, caregivers, and advocates, reinforcing the importance of a multidisciplinary approach to PWS management. Feedback from attendees emphasized the value of both the depth of scientific content and the practical, real-world application of the information presented.



Clinical Scholarship Program

Research efforts also continued to expand. The Research Committee reviewed applications for the Clinical Scholarship Program, ultimately accepting one candidate and inviting a full grant proposal for further consideration. This program represents an important investment in developing the next generation of PWS clinicians and researchers, strengthening the long-term capacity of the field. Continued support for investigator-driven research remains a priority as new questions emerge around lifespan care, mental health, and evolving therapeutic options.

Ask Nurse Lynn Column

The Ask Nurse Lynn column remained a vital resource throughout the year, receiving 118 submissions in 2025 - an average of two to three inquiries per week from individuals and families across the globe. These questions, ranging from medical management to behavioral concerns, highlight the ongoing need for accessible, trustworthy information. In addition, the 24-hour support line continued to provide critical guidance to families navigating urgent medical and behavioral situations.

ask
NURSE LYNN
Prader-Willi Syndrome Association | USA

PWSA | USA's Clinical & Scientific Advisory Board

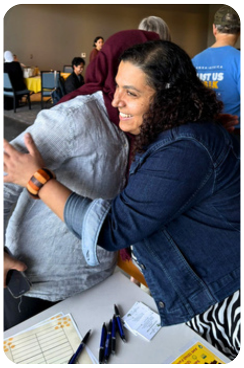
Finally, members of the CSAB continued to offer peer-to-peer consultations upon request. These consultations have proven invaluable, particularly for families and health care providers who lack access to local PWS expertise. By sharing knowledge and clinical experience, the CSAB plays a vital role in improving care, reducing isolation, and strengthening the global PWS community.

PWS Clinical Trials

Below is a list of current clinical trials for Prader-Willi syndrome that are actively recruiting participants for potential treatments.

COMPANY NAME	NAME OF DRUG	CLINICAL TRIAL PHASE	TARGET	AGE OF ELIGIBILITY
Aardvark Therapeutics	ARD-101	Phase 3	Hyperphagia	Ages 7+
Foundation for Prader-Willi Research	VNS4PWS	Phase 3	Behavior	Ages 10-40
Harmony Biosciences	Pitolisant	Phase 3	Excessive Daytime Sleepiness	Ages 6+

FUNDRAISING EVENTS & INITIATIVES



In 2025, the PWSA | USA community once again showed what's possible when people come together with a shared purpose. Across the country, families, friends, volunteers, and partners transformed compassion into action through an extraordinary year of events and fundraising efforts, raising critical funds, building awareness, and strengthening connections for individuals and families affected by Prader-Willi syndrome.

From coast to coast, supporters hosted **11 PWS Hope United** events, helped launch **United We Brunch** during PWS Awareness Month with 9 brunches nationwide, and created nearly **115 Virtual Occasion Fundraisers** through PWSA | USA's fundraising platform Classy and Facebook. From first-time fundraisers to those hosting for the 2nd, 5th, and even 16th year, this incredible community came together to raise more than $700,000 in 2025.

A major highlight of the year was the **Journey of Hope Gala: 50th Anniversary Celebration** which brought together nearly 200 people to honor 12 PWS Pioneer Award recipients and celebrate the legacy and future of the PWS community. We also celebrated the **11th Annual Clint Hurdle Hot Stove Dinner**, a longtime cornerstone event hosted by Clint and Karla Hurdle, and a highly successful **Angel Drive Campaign**, which surpassed its fundraising goal.

2025 also marked the debut of the impactful new event **Prader Silly: A Night of Rare Laughs**. Hosted by PWS parents Lucy Sinsheimer and Aaron Weber, this star-studded comedy night filled Zanies Comedy Club in Nashville, TN.

Every event in 2025 reflected the same truth: This community is united by hope, fueled by generosity, and committed to building a brighter future for everyone affected by Prader-Willi syndrome.

JOURNEY OF HOPE GALA

Celebrating 50 Years of PWSA | USA

On Friday, September 26, 2025, nearly 200 members of the Prader-Willi syndrome community gathered from across the country at The Ritz-Carlton, St. Louis, to celebrate a milestone half a century in the making. Our 50th Anniversary Journey of Hope Gala was nothing short of extraordinary. It was a night filled with connection, laughter, legacy, and of course, plenty of dancing.

The Ritz-Carlton proved to be the perfect setting for this historic evening. Elegant and welcoming, with staff who went above and beyond to make every detail shine, the venue matched the significance of the occasion. One new parent later shared with our staff just how much the evening meant to them:

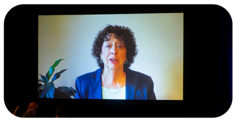
> ***"We are still processing the Gala and just how much it meant to us. We were nervous what our first event would trigger in us emotionally. I've never felt so confident and a sense of peace about the wonderful life our son has ahead. Thank you so much and looking forward to connecting again!"***
>
> \- PWS Parent

The night's emcee, Aaron Weber, a nationally touring standup comedian and dad to Olive (1), who is living with PWS, lit up the room with warmth and humor. His opening remarks had the audience laughing, connecting, and leaning into the joy of the celebration.

The centerpiece of the program was the presentation of **PWSA | USA's Pioneer Awards**, honoring 12 individuals whose groundbreaking work has shaped our organization and the PWS community over the past five decades (click each name below to read more about them):

- Dr. Dan Driscoll
- Dr. Merlin Butler
- Dr. Moris Angulo
- Dr. Suzanne Cassidy
- Janalee Heinemann
- Joan and Jim* Gardner
- Dr. Vanja Holm*
- Lota Mitchell
- Jim Kane
- Fausta and Gene Deterling*

**Posthumously*



To close the formal program, PWSA | USA's Director of Community Engagement, Dorothea Lantz, delivered a speech that perfectly captured the spirit of the evening, honoring the grit and grace of our past while casting a vision for the next 50 years.

> ***"Together, we've built something extraordinary. PWSA | USA created a national home for PWS when there wasn't one. We built networks of care and knowledge where isolation once lived. We showed up in schoolhouses, statehouses, courthouses and on Capitol Hill. We funded research others called 'too small' and proved it was too important to ignore … But anniversaries aren't just about looking back. They're a launch pad. The road ahead is wider, the coalition stronger, and the destination closer. The question isn't if we'll get there, but how fast, and how many people will we bring with us … To fifty years of grit and grace, and the next fifty of discovery, equity, and joy. The next fifty years start now — with us."***
>
> — Dorothea Lantz

PHOTO GALLERY

50th Anniversary Tribute Video

Click the image to watch!

PWSA | USA Difference Makers

Beyond our formal honorees, we proudly recognize PWSA | USA Difference Makers, individuals whose dedication has shaped the lives of families and strengthened our organization. Nominated by our staff, board, and Gala Committee, the names listed below reflect just a fraction of those tirelessly working for the Prader-Willi syndrome community.

David Agarwal, MD
Janice Agarwal, PT, CNDT
Michael Alterman
Paul Alterman*
Kate Beaver, MSW, CSW
Kasey Bedard, PhD
Cindy Beles*
Delfin “Sam” Beltran, MD*
Patrice Carroll, PhD, LICSW
Mary Cataletto, MD
Anna Choraxy, MD
Greg Cherpes, MD
Dale Cooper
Dottie Cooper
Julie Doherty
Barb Dorn, RN, BSN
Jessica Duis, MD, MSc
Pam Eisen*
Evan Farrar, MDiv, MMHC
Jan Forster, MD
BJ Goff, Ed.D
Linda Gourash, MD
Lisa Graziano, M.A., LMFT
Louise Greenswag, PhD*
Jeanne Hanchett, MD
James Hanchett, MD*
Tim Hearn, JD
Carol Hearn, JD
Tony Holland, MD
Waheeda Hossain, MD, MPH
Clint Hurdle
Karla Hurdle
Alexis Labhart, MD*
David Ledbetter, PhD
Steven Leightman
Janet Li, MD
Mark Lister, BS, BCaBA
Carolyn Loker
Jim Loker, MD
Rob Lutz
Bea Maier
Ann Manzardo, PhD, MS
Shawn McCandless, MD
Crissy McGann
Amy McTighe, PhD
Jennifer Miller, MD
Lori Moline*
Destiny Pacha, Ed.D
Jerry Park
Peggy Pipes, MPH, MA, RD*
Andrea Prader, MD*
James Resnick, PhD
Amee Revana, DO, FAASM
Matt Rivard, MD, MBA, FACS
Paige Rivard, MBA
Elizabeth Roof, MA
Daniela Rubin, PhD, FACSM
Marguerite Rupnow, MBA
Parisa Salehi, MD
Ann Scheimann, MD
Diane Seely
Althea Shelton, MD, MPH
Deepan Singh, MD
Ken Smith*
Diane Spencer
Diane Stafford, MD
Lisa Thornton, JD
Michelle Torbert
Olivia Veatch, PhD
Harold Van Bosse, MD
Stefanie Varga, PhD
Kim Weinberg
Denise Westenfield
Marge Wett*
Barb Whitman, PhD
Heinrich Willi, MD*
Steve Willett
Lois Willett
David Wyatt*
Mary K. Ziccardi
Hans Zellweger, MD*

**Posthumously*

FUNDRAISING EVENTS & INITIATIVES

11 Years of Impact: The Clint Hurdle Hot Stove Dinner

In 2025, the 11th Annual Clint Hurdle Hot Stove Dinner continued a remarkable legacy of commitment to the PWS community. Hosted by Clint and Karla Hurdle, whose daughter Madison lives with Prader-Willi syndrome, this beloved event raised an incredible $229,000 in support of PWSA | USA's Family Support programs.

For more than a decade, Clint and Karla have brought together a dedicated and passionate community, raising essential funds and awareness for individuals and families affected by PWS. Their generosity and advocacy continue to make a lasting impact, ensuring families have access to the resources, guidance, and support they need. The Hot Stove Dinner will return in 2026 for its 12th annual event on Saturday, March 21, at the Bradenton Country Club in Bradenton, FL.

Inaugural Prader Silly: A Night of Rare Laughs

Photos taken by Taylor Brown
@word.doc_brown

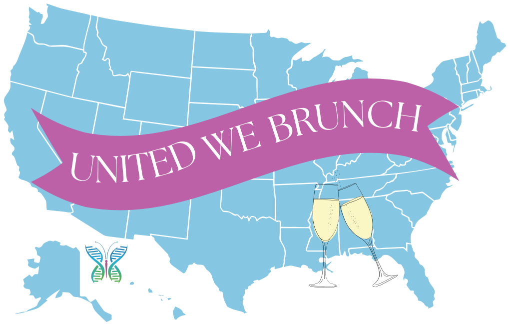
In October 2025, Prader Silly: A Night of Rare Laughs debuted as a Hope United peer-to-peer fundraising event created and hosted by Lucy Sinsheimer and Aaron Weber, parents to Olive, to benefit PWSA | USA. Emceed by Aaron (who is a nationally touring comedian), this star-studded comedy night filled Zanies Comedy Club in Nashville, TN, with nearly 200 supporters and an incredible lineup of comics, including Brian Bates, Fiona Cauley, Dusty Slay, John Crist, Kathleen Madigan, Leanne Morgan, and Nate Bargatze.

The event raised nearly $200,000 in support of individuals and families living with Prader-Willi syndrome.

Reflecting on the night, Lucy shared: ***"We had everyone we love in one room getting behind a cause so near and dear to our hearts. This is not an easy journey, but that night gave us so much hope for the future. It truly was one of the most special nights of our lives."***

With its incredible success, Prader Silly marked the beginning of a powerful new tradition that will return on September 30, 2026!

United We Brunch: A New Tradition Takes Root



During PWS Awareness Month in May 2025, PWSA | USA launched United We Brunch, a new community-driven fundraising and awareness initiative designed to bring people together, one brunch, one family, and one community at a time. Hosted by dedicated community members in nine states, United We Brunch raised $12,000 while generating meaningful awareness for Prader-Willi syndrome.

United We Brunch showed that powerful impact can happen around a table through connection, shared stories, and community-led action. With plans to expand the initiative in 2026, including a large-scale brunch during the D.C. Fly-In, we look forward to growing this meaningful tradition.

Community-hosted United We Brunch events in 2025 included:

- **California:** The Good, The Bad, & The Bubbly *(Host: Anne Fricke)*
- **Colorado:** Magnolias and Mimosas *(Host: Kat Lucero)*
- **Connecticut:** PWS Moms Who Brunch *(Host: Amy Tenbrunsel)*
- **Georgia:** Brunch With Cuties *(Host: Jessica Anderson)*
- **Louisiana:** Muumuus & Mimosas *(Host: Katie Martinez)*
- **Maryland:** A Desi Tea for Prader-Willi *(Host: Dini Rao)*
- **Missouri:** Bagels & Jam for Lola *(Host: Jennifer Hill)*
- **Nebraska:** Hummus & Tahini *(Host: Sarah Kasaby)*
- **New Mexico:** Mimosas y Sol *(Host: Valerie Selinger)*

2025 Angel Drive Campaign

Thanks to the incredible generosity of our community, the 2025 Angel Drive Campaign surpassed its $200,000 fundraising goal, providing vital support for individuals and families affected by Prader-Willi syndrome.

This year's campaign also featured seven new "Hope in Action" videos, sharing powerful stories that highlight the strength of the PWS community and how PWSA | USA is there to offer help and hope at every stage of the journey. Click here to watch them.

To our donors: Thank you. Your generosity made this success possible and continues to bring hope, support, and meaningful impact to families across the country.

GIVE THE Gift OF HOPE
2025 ANGEL DRIVE
Prader-Willi Syndrome Association | USA

FUNDRAISING EVENTS & INITIATIVES

2025 PWS Hope United Events

In 2025, there were **11** in-person PWS Hope United events held around the U.S., and **115** other individual online fundraisers hosted via Classy and Facebook celebrating birthdays, Rare Disease Day, PWS Awareness Month, and more!

Diamonds & Denim
Springfield, IL | February 1, 2025
Hosted by Amy & Chris Avart / Team Esme
Raised $54,000

Zahra’s Night of Light
Bedford, NY | April 5, 2025
Hosted by Pia & David Dorson
Raised $70,000

NC Hope United 5K & Fun Run
Wilson, NC | May 3, 2025
Hosted by the Kreacic, VanHook, & Forster Families
Raised $20,000

4th Annual No Gimmes For Jimmy: Worthington Memorial Golf Event
Ringoes, NJ | September 6, 2025
Hosted by the Gilsenan & Worthington Family
Raised $20,000

16th Annual Hunter Lens Golf Tournament
Lakeville, MA | September 13, 2025
Hosted by the Lens Family
Raised $37,000

2nd Annual Dance Silly for Prader-Willi
Warren, OH | October 11, 2025
Hosted by the Hampton Family
Raised $20,000

Cocktails For A Cause
Troy, NY | October 18, 2025
Hosted by Stacy & Jeff Ward
Raised $20,000

5th Annual Answers for Audrey Trivia Night
Bel-Nor, MO | October 18, 2025
Hosted by the Spring Family
Raised $12,000

Prader Silly: A Rare Night of Laughs
Nashville, TN | October 22, 2025
Hosted by Aaron Weber & Lucy Sinsheimer
Raised $190,000

A Bow For Aine Mirella
Devon, PA | November 7, 2025
Hosted by Irene Moretto
Raised $18,000

Claus For a Cause
Bridgeville, PA |
December 7, 2025
Hosted by the Webster, Day, Leighty, Peretic, & Bertetto Families
Raised $21,000

2025 INTERNATIONAL PWS UNITED IN HOPE CONFERENCE

The 2025 International PWS United in Hope Conference was truly a historic milestone. For the first time ever, the three leading PWS organizations - the International Prader-Willi Syndrome Organisation (IPWSO), Prader-Willi Syndrome Association | USA (PWSA | USA), and the Foundation for Prader-Willi Research (FPWR) - came together to host a single, united global event. Between June 21-24 at the Arizona Grand Resort & Spa in Phoenix, AZ, we welcomed a record-breaking 1,330 attendees, which is the largest turnout in each organization's history!

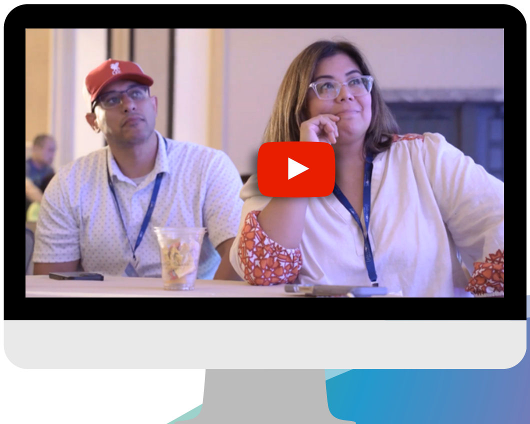
Nearly two years of planning, collaboration, and passion led to this incredible week. You could see and feel all the hard work pay off in every handshake, every hug, every exchange of ideas, and every new connection. This achievement would not have been possible without the unwavering support of our dedicated teams, tireless volunteers, and especially you, our valued sponsors.

Other highlights from the event included the first-ever Adults with PWS Conference, where 58 of our adult loved ones spent Thursday afternoon learning from a range of speakers and from one another, and PWSA | USA's 50th Birthday Party at the Oasis Water Park complete with a spectacular Drone Show.

> ***"Thank you for organizing this. The energy around was so hopeful, from other families, doctors, and sponsors. It can feel so lonely when a diagnosis is delivered and is thought about purely clinically. Thank you for the hope."***
>
> \- Louisa D.

2025 United in Hope Conference Recap Video →

Click the image to watch!



OTHER 2025 HIGHLIGHTS

Celebrating One Year of PWSA | USA's *PWS United* Podcast

In 2025, the *PWS United* Podcast continued to serve as a valuable and trusted resource for the PWS community. The podcast celebrated its one-year anniversary on August 31, 2025, and to date has produced and shared 76 episodes, reflecting a strong commitment to education, connection, and timely conversation.

The podcast reached an important milestone this year, surpassing 10,500 total downloads and expanding its global audience, with listeners tuning in from around the world. A standout moment in 2025 was the podcast's first-ever livestream episode, recorded during the PWS Conference. The three conference-related episodes alone were listened to 873 times, demonstrating the community's strong engagement with this content.

Another significant achievement was securing the podcast's first-ever sponsor, Soleno Therapeutics!

Industry Partnerships: Collaborating for Impact

In 2025, PWSA | USA continued to work closely with industry partners to advance research, education, and awareness for the Prader-Willi syndrome community. Key collaborations included ongoing work with TREND Community to support the PWS Connect Discord Channel and PWS research efforts, and partnerships with Soleno Therapeutics to develop educational resources around VYKAT XR.

PWSA | USA also partnered with Aardvark Therapeutics to raise awareness of the HERO Phase 3 clinical trial for ARD-101, a potential treatment for hyperphagia, with CEO Stacy Ward and Director of Community Engagement Dorothea Lantz invited to attend Aardvark's NASDAQ closing bell ceremony in New York.

Additionally, PWSA | USA continued education efforts with Harmony Biosciences around the TEMPO PWS Trial for pitolisant and provided in-person PWS education and shared lived experience stories with the team at PANTHERx Rare Pharmacy.

These collaborations reflect PWSA | USA's commitment to responsible partnership and progress in improving care and outcomes for individuals and families living with PWS.

2025 FINANCIALS (Unaudited)

Operating Support and Revenue

Contributions and Grants	$2,003,297
Fundraising Events (net of direct donor benefit)	$439,216
Program Event Registrations	$427,188
Other Revenue	$351,149
Total Operating Revenue	**$3,220,850**

Operating Expenses

Program Services

National Convention	$997,304
Family Support	$815,450
Advocacy & Awareness	$363,096
Research	$96,302
Total Program Services	**$2,272,152**

Supporting Services

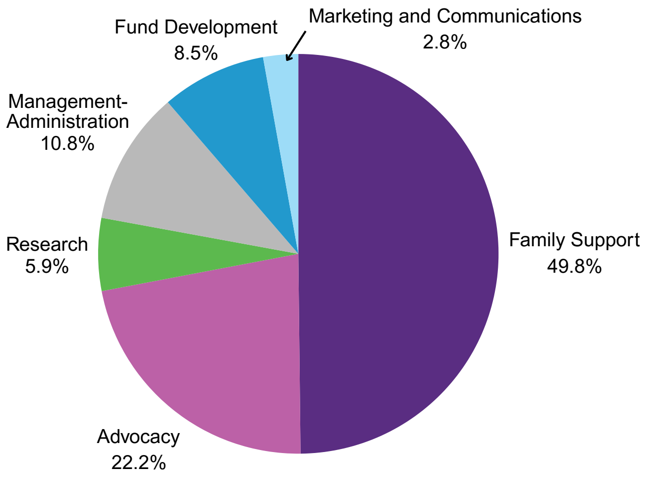
Management & Administration	$176,895
Fund Development	$138,695
Marketing and Communications	$46,244
Total Support Services	**$361,834**
Total Operating Expenses	**$2,633,986**

Net Assets (beginning of the year)	**$2,900,296**
Net Assets (end of year)	**$3,487,163**

Change in 2025 Net Assets | $586,867

FUNCTIONAL EXPENSE BY CATEGORY

- ■ Family Support Program
- ■ Research Program
- ■ Advocacy Program
- ■ Fund Development
- ■ Management & Administration
- ■ Marketing & Communications



OUR PARTNERS IN HOPE

Officers & Directors

Marguerite Rupnow, MBA (Chair), Oconomowoc, WI
Mitch Cohen, BS, JD (Co-Chair), Weston, CT
Denise Servais (Secretary), Lake Elmo, MN
Tina Ihlenfeld, MBA (Treasurer), Oconomowoc, WI
Jeffrey A. Covington, MPH, Albany, NY
Clint Hurdle, Holmes Beach, FL
Lisa Lamb, Gilbert, AZ
John Lens, Lakeville, MA
Kathryn Lucero, Colorado Springs, CO
Matt McCleery, BA, JD, North Chatham, MA
Ann Scheimann, M.D., Owings Mills, MD
Michelle Torbert, Homestead, FL
Tim Hearn, JD, Plymouth, MN

PWSA | USA Staff

Stacy Ward, MS, BCBA, CEO
Charles Conway, Jr., Executive Administrative Assistant
Angela Frazier, Events Coordinator
Anne Fricke, Marketing & Communications Coordinator
Lynn Garrick, MSN, RN, Medical/Research Coordinator
Andrea Hughes, Database Coordinator
Carrie Ilijevich, Director of Marketing & Communications
Sarah Kasaby, Information & Referral Specialist
Dorothea Lantz, Director of Community Engagement
Katie Martinez, Fundraising Coach: Team & Online Events
Amy Maust, CPA, Director of Accounting
Kristi Rickenbach, Parent Support Coordinator
Kristen Starkey, Accounting Clerk
Elaine Towle, Advocacy Specialist
Kim Tula, MS, CSW, Senior Family Support Counselor & Trainer
Melanie Zalman, Director of Development

Clinical & Scientific Advisory Board

Ann Scheimann, MD, MBA (Chair)
Ann Manzardo, PhD, MS (Vice-chair)
David Agarwal, MD
Moris Angulo, MD
Merlin Butler, MD, PhD,FFACMG
Mary Cataletto, MD
Gregory Cherpes, MD
Jessica Duis, MD, MS
Janice Forster, MD
Linda Gourash, MD
Waheeda Hossain, MD, MPH
Janet Li, MD
Jim Loker, MD
Shawn McCandless, MD
Jennifer Miller, MD, MS
James Resnick, PhD
Amee Revana, DO, FAASM
Matt Rivard, MD
Daniela Rubin, PhD
Parisa Salehi, MD
Althea Shelton, MD, MPH
Deepan Singh, MD, FAPA
Harold J.P. van Bosse, MD, FAAOS
Stefanie Varga, PhD
Olivia Veatch, PhD
Barbara Whitman, PhD

Executive Committee

Denise Servais, John Lens, Marguerite Rupnow, Mitch Cohen, Stacy Ward, Tim Hearn, Tina Ihlenfeld

Audit Committee

Jim Kane, Mitch Cohen, Tina Ihlenfeld

Finance Committee

Tina Ihlenfeld (Chair), Amy Maust, Andrew Salak, Jim Kane, John Lens, Kristen Starkey, Marguerite Rupnow, Michelle Torbert, Mitch Cohen, Stacy Ward

Leadership Development Committee

Lisa Graziano (Chair), Jennifer Andrews, Julie Doherty, Michelle Torbert, Mitch Cohen, Stacy Ward, Tammie Penta

Research Committee

Janet Li (Chair), Ann Scheimann, Hanni Menn-Josephy, Joan Gardner, Lauren Willner, Lynn Garrick, Stacy Ward

Advocacy Work Group

Alex Lopez, Amy Harris, Amy Reinmuller, Amy Starkweather, Amy Tummonds, Andrew Gilly, Ann Sinsheimer, Anne Fricke, Arami Zhu, Becki Bigler-Smith, Brandon Lawrence, Caitlin Heckman, Carly Steinauer, Cathy Mallove, Charles Conway, Christina DeFeo, Christina Schaublin, Corey Fuller, Crissy Mcgann, D.G. Harper, Deahl Wilson, Dina Josif Sullivan, Dini Rao, Donna Forster, Dorothea Lantz, Elaine Towle, Erin Carter, Erin Mercandante, Ginger Bihn-Cros, Gwyn Spearman, Heather Hanson, Jamie Prentice, Jen Saunders, Jennifer Andrews, Jennifer Garzia, Jessica Kempa, Jessica Sheldon, Jill Kreacic, Juliana Vera, Juliette Krovi, Kat Lucero, Katie Moureau, Kayla Day, Kebra Hammond, Kelly Guillou, Krissy Gier, Kristi Rickenbach, Kristin Frontiera, Kristin Gilly, Kylie Shelangoski, L Goodwin, Laura Leesburg, Leslie Fuller, Lisa Graziano, Lisa Matesevac, Liz Handy, Maegan Richard, Maggie Andrews, Maggie Senese, Marguerite Rupnow, Maureen Tracey, Megan Dempsey, Melanie Zalman, Melissa Koe, Melissa Matejek, Melissa Mort, Mengyuan Kan, Michele Siegfriedt, Michelle Cox, Michelle Torbert, Mingbo Cai, Miriam Chernick, Nicole Tingley, Oliver Passsemard, Paige Rivard, Patsy White, Phil Sassoc, Pia Dorson, Priyank Aggarwal, Rebecca Krylow, Sarah Kasaby, Sheri Mills, Sierra Erline, Steve Kaufman, Sue Colon, Susan Hedstrom, Tammie Penta, Theresa Strong, Will Greene, Winnie White

50th Anniversary Work Group

Angela Frazier, Ann Scheimann, Carrie Ilijevich, Joan Gardner, Julie Doherty, Melanie Zalman, Michelle Torbert, Stacy Ward

Communications Work Group

Anne Fricke, Carrie Ilijevich, Charles Conway, Chris Benninghoff, Denise Servais, Elaine Towle, Elizabeth Tosson, Emily Felt, Jon Krasnoff, Julie Casey, Kat Lucero, Lisa Graziano

Professional Provider Work Group

Brittni Kliment, Kim Tula, Lynn Garrick, Marguerite Rupnow, Nicole Tingley, Patrice Carroll, Stacy Ward

Family Support Work Group

Kim Tula (Chair), Brittni Kliment, Charles Conway, Cindy Szapacs, Destiny Pacha, Jeff Covington, Jennifer Garzia, Karin Sweeney, Kasey Bedard, Kat Lucero, Kristi Rickenbach, Lisa Lamb, Lynn Garrick, Marguerite Rupnow, Patrice Carroll, Sarah Kasaby, Stacy Ward

Adults with PWS Advisory Board

Abbott Philson, Brooke Fuller, Conor Heybach, James Towle, Kate Kane, Shawn Cooper, Trevor Ryan, Victor Penta

Save the Dates!

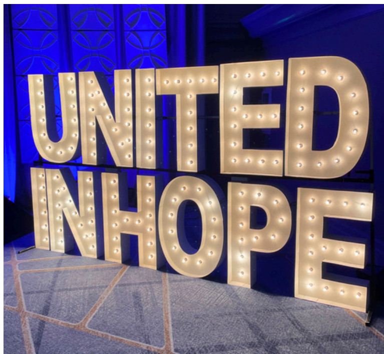
United in Hope
FOR PWS

PWSA | USA 2027
NATIONAL CONVENTION

Prader-Willi Syndrome Association | USA

July 14-17, 2027

Orlando, Florida
Caribe Royale Orlando



THANK YOU FOR YOUR SUPPORT!

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PWSA | USA is serving more individuals and families than ever before. Because we do not charge for the services we provide, we're counting on **YOU** to help us save and transform lives!

Regardless of size, your gift is important and will make a real and meaningful difference in the lives of those affected by Prader-Willi syndrome.

Click here to make an online donation or mail your donation to the address below.

Prader-Willi Syndrome Association | USA
1032 E Brandon Blvd #4744
Brandon, FL 33511

For questions, please email: info@pwsausa.org, or call (941) 312-0400.