2024 ANNUAL REPORT

Prader-Willi Syndrome Association | USA

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Charitable Foundation**

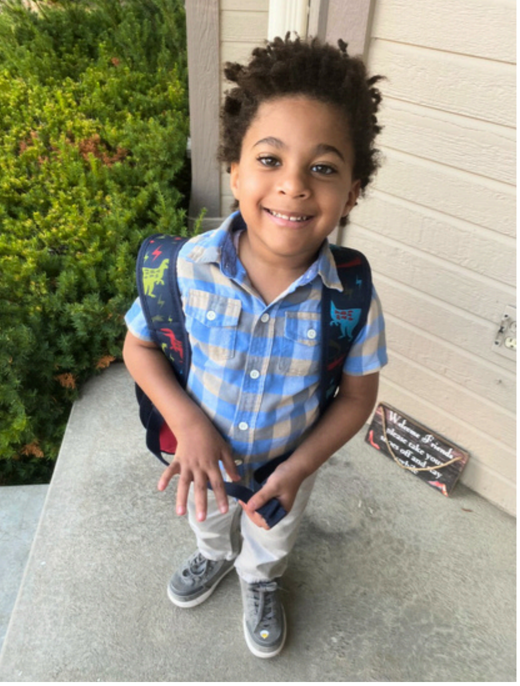
Mission

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

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Charles
Conway, Jr.

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

Stacy Ward, MS, BCBA
PWSA | USA CEO

Marguerite Rupnow, MBA
PWSA | USA Board Chair

Celebrating 50 Years of Impact and Looking Ahead

As we reflect on the past years of service and celebrate the **50th anniversary of PWSA | USA**, we are filled with immense gratitude for this incredible community. From the families we support and those who advocate fiercely for the community, to the researchers, professional providers, medical professionals, and dedicated supporters who play a vital role in advancing our mission, we are truly grateful for each and every one of you!

Over the past five decades, PWSA | USA has been a pillar of support, advocacy, and research for individuals with Prader-Willi syndrome (PWS) and their families. In 2024, we continued this legacy by expanding critical programs to alleviate unmet needs and further support individuals with PWS and their families. We strengthened our advocacy efforts at national and local levels and fostered innovative research that has brought us closer to improved treatments, and ultimately, a brighter future for all impacted by PWS. Here are a few highlights:

- We hosted the first-ever **Residential Providers Conference**, gathering 100 professionals to improve care and support for individuals with PWS.
- ***PWS United*, the first PWS-specific podcast**, launched on August 30, providing weekly expert insights, advocacy updates, and personal stories.
- The **Adults with PWS Advisory Board** held its first in-person meeting in years, planning the 2025 Adults with PWS Conference and sharing their experiences. **Click here** to learn more about their time in Phoenix!
- We partnered with **16 states** to advocate for PWS to be recognized for waiver services and played a key role in the creation of the **FDA Rare Disease Innovation Hub**.
- We worked with Soleno Therapeutics and the PWS Advocacy Coalition to submit the **New Drug Application (NDA) for a potential hyperphagia treatment**, which was APPROVED by the FDA on March 26, 2025 - a historic moment for the PWS community.
- We co-published the **Voice of the Patient Report**, capturing insights from the 2023 EL-PFDD Meeting.
- Senior Family Support Counselor & Trainer Kim Tula provided **24** in-person trainings at group homes, schools, hospitals, and law enforcement agencies nationwide.
- Our Family Support team assisted **more than 4,000** families, educators, and medical professionals, hosted a free monthly webinar series, and launched the **Ask Nurse Lynn** initiative, which received **92** community-submitted medical questions in 2024.
- We began shipping **care packages** to newly diagnosed families and those grieving the loss of a loved one with PWS.
- **PWS Hope United** grew significantly, with community-led events raising critical funds, and we welcomed two new fundraising coaches to support our dedicated volunteers.
- The **2024 Angel Drive** campaign raised **$246,000**, featuring a $25,000 Giving Tuesday match, a new prize raffle, and the Hope in Action video series highlighting PWSA | USA's impact.
- The **Rare Aware Art Share** showcased more than 100 creative submissions from individuals with PWS, which were featured in advocacy efforts, communications, and will be a centerpiece at the 2025 International PWS Conference.

This milestone anniversary is not just a celebration of our past achievements but a commitment to the future and the successes still to come. As we move forward into this next chapter of our organization, we remain committed to supporting and empowering families and advocating for necessary policies and scientific research that promote a better life for individuals with PWS. We envision a world where individuals with PWS not only navigate their challenges with ease and security but also lead fulfilling, thriving lives. Here are some new initiatives we're looking forward to implementing in 2025:

- **50th Anniversary Gala (Sept. 26, 2025, St. Louis, MO):** A milestone celebration featuring inspiring stories, special tributes, live entertainment, and a silent auction to support PWSA | USA's mission.
- **PWS Hope United & Classy Fundraising Platform:** We're launching Classy, a user-friendly fundraising tool empowering our community to host events like United We Brunch, Diamonds & Denim, Zahra's Night of Light, and multiple golf tournaments, runs, and trivia nights.
- **Advocacy Initiatives:** 2025 marks the launch of the Advocacy Ambassador Program, mobilizing a trained network to connect the PWS community with policymakers, and the PWS Advocacy Master Class, a six-week program equipping individuals with advocacy skills. We also welcome Elaine Towle as our new Advocacy Specialist to support these efforts.
- **Parent & School Support:** We're introducing the Parent Empowerment IEP Training led by Dr. Destiny Pacha, ED.D., offering strategies to help families navigate IEP meetings confidently.
- **PWS Research Consortium:** Led by Dr. Kasey Bedard, this initiative focuses on behavior research, emotional regulation training, and BCBA education to enhance PWS understanding and support.
- **Residential & Direct Support Provider Training:** Monthly Zoom meetups will provide education, peer connections, and mentorship for care providers, fostering collaboration and problem-solving.
- **2025 International PWS Conference (June 24-28, Phoenix, AZ):** Our biggest conference yet, in partnership with IPWSO and FPWR, will feature scientific, professional, family and adults with PWS programs, plus a 50th Birthday Celebration for PWSA | USA.

Thank you for being part of this journey. Your dedication and commitment fuels our mission, and we are honored to stand alongside you as we continue to transform hope into action for the PWS community.

Stacy Ward

Stacy Ward, MS, BCBA
PWSA | USA CEO

Marguerite Rupnow

Marguerite Rupnow, MBA
PWSA | USA Board Chair

ADVOCACY & AWARENESS

In 2024, PWSA | USA strengthened its advocacy efforts through meaningful engagement, strategic initiatives, and impactful events. This year marked a significant expansion in our commitment to amplifying the voices of individuals with Prader-Willi syndrome and their families. Our advocacy initiatives focused on legislative engagement, community empowerment, and fostering critical discussions on medical advancements and policy needs. We also welcomed new PWSA | USA team member **Elaine Towle** as our Advocacy Specialist. She is mom to James (39) who is living with PWS.

Legislative and Rare Disease Policy Advocacy

PWSA | USA took a proactive stance in legislative advocacy, ensuring that the needs of individuals with PWS were heard at both state and federal levels. A key highlight was our participation in the PWSA | USA **D.C. Fly-In**, where 147 PWSA | USA advocates (50 of them living with PWS) met with policymakers to discuss critical issues such as access to treatments, research funding, and policy reforms for PWS and other rare diseases.

PWSA | USA also played a critical role in shaping rare disease policy in 2024. We worked alongside policymakers and advocacy organizations to push for legislative reforms that would directly benefit the PWS community. Our efforts were instrumental in advocating for the reinstatement of **Priority Review Vouchers (PRVs)** for rare pediatric diseases, ensuring that pharmaceutical companies have continued incentives to develop treatments for underserved conditions like PWS.

Additionally, we actively worked on **pharmacy benefit manager (PBM) reform**, addressing barriers that prevent individuals with rare diseases from accessing life-saving medications. Through strategic coalition-building and targeted legislative outreach, we pushed for increased transparency and accountability in PBM practices, advocating for policies that put patient needs at the forefront.

Another key policy initiative was our involvement in the **Kids' Access to Care Act**, a crucial piece of legislation aimed at improving access to specialized care for children with rare diseases. By engaging with congressional leaders, mobilizing grassroots advocates, and providing expert testimony, we helped drive momentum for policies that ensure children with PWS receive the comprehensive care they need.

2024 D.C. Fly-In

Between May 13-15, 2024, PWSA | USA held its second biennial **D.C. Fly-In** to speak directly with changemakers on Capitol Hill and to celebrate PWS Awareness Day (May 15). This event was a resounding success, drawing 147 dedicated advocates from 31 states. Together, these advocates attended a remarkable total of 131 Congressional meetings, highlighting the widespread support and commitment to advancing our cause. Our advocates engaged in meaningful discussions, ensuring the voices of those affected by Prader-Willi syndrome were heard loud and clear on Capitol Hill. We gathered congressional support for adding Prader-Willi syndrome to the Department of Defense Peer Reviewed Medical Research Program, gathered co-sponsors for the Promising Pathway Act, and obtained congressional support for PWS research and development with the FDA. The fly-in was an inspirational and educational experience for all involved. Our advocates left with a renewed sense of purpose and a deeper understanding of the legislative process.

131
Congressional Meetings

147
Attendees (50 individuals living with PWS)

31
States & Districts Represented

67
Senate Meetings

64
House Meetings

74
Democratic Offices

55
Republican Offices

2
Independent Offices

WATCH: 2024 D.C. Fly-In Mini Documentary

Thanks to Soleno Therapeutics for sponsoring the production of this documentary. Produced by Believe Limited: The Patient People.

VIEW: 2024 D.C. Fly-In Photo Gallery

CLICK HERE

ADVOCACY & AWARENESS

PWSA | USA Advocacy Ambassadors

In 2024, PWSA | USA launched our **Advocacy Ambassador program**, equipping 15 dedicated advocates through our Advocacy Master Class and preparing them for their first trip to Washington, D.C. for the 2025 Rare Disease Week. These ambassadors have been actively representing PWS and rare diseases at the state level, gaining media attention and driving awareness nationwide. In 2025, our state advocacy efforts continue to grow, and we are beginning conversations on Capitol Hill to have PWS added as a designated topic area in the Department of Defense's Peer Reviewed Medical Research Program.

EL-PFDD: Strengthening the Patient Perspective

Building on the momentum from the 2023 **Externally Led Patient-Focused Drug Development (EL-PFDD)** meeting for the PWS community, which PWSA | USA co-hosted with FPWR and IPWSO, we took a critical step forward in 2024 by filing the official **Voice of the Patient Report** with the FDA. This comprehensive document captured the lived experiences of individuals with PWS and their families, providing essential insights into the unmet medical needs, treatment priorities, and daily challenges faced by the community.

Prader-Willi Syndrome
Externally-Led Patient Focused Drug Development Meeting (EL-PFDD)
Voice of the Patient Report

"I am not a scientist, researcher, or doctor. I am not a statistician or in government and public policy. What I am…Who I am…is a parent. A PWS parent.

It is true when they say that 'Being a parent is to have your heart forever walk outside your body.'

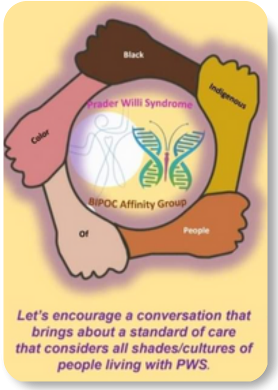
Our hearts are burdened with PWS but our minds, our minds are clear- we are focused on treatments.

Thank you for listening, thank you for asking. Thank you for working with our community."

The Voice of the Patient Report played a pivotal role in influencing regulatory discussions and industry decision making. It served as a key reference for pharmaceutical companies and the FDA, shaping the future direction of clinical trials and therapeutic development for PWS. Additionally, PWSA | USA led efforts to mobilize legislative support through a congressional letter to the FDA, reinforcing the urgent need for new treatment options. Furthermore, we spearheaded a community petition filed with the FDA, amplifying the collective voice of caregivers and advocates in the regulatory process.

CLICK HERE TO DOWNLOAD THE REPORT

BIPOC Advocacy Leadership and Collaboration



Let's encourage a conversation that brings about a standard of care that considers all shades/cultures of people living with PWS.

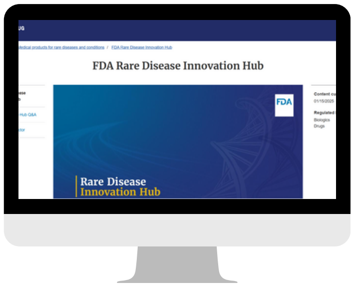
In 2024, PWSA | USA strengthened its collaboration with FPWR through the **PWS Black, Indigenous, and People of Color (BIPOC) Affinity Group**. With advocacy leaders Dini Rao, Charles Conway, Gen Conway, and Karine Nsula, this partnership focused on expanding outreach to underrepresented communities, ensuring diverse voices were included in advocacy efforts, and increasing access to critical research initiatives. By fostering cross-organizational collaboration, we have made significant strides in engaging the broader PWS community and amplifying the impact of our advocacy work.

CTEEP Program and Industry Collaboration

In 2024, PWSA | USA launched the **Clinical Trial Education and Engagement Program (CTEEP)**, a groundbreaking initiative designed to increase awareness, accessibility, and participation in PWS clinical trials. This program aimed to bridge the gap between families, researchers, and pharmaceutical partners by providing educational resources, hosting informational sessions, and facilitating direct engagement between industry stakeholders and the PWS community.

A key component of CTEEP was our deep collaboration with industry partners in the PWS space. Through frequent strategy meetings, shared data insights, and patient-centered discussions, we worked closely with pharmaceutical companies to ensure that clinical trial designs reflected the real needs of individuals with PWS. By fostering these partnerships, we strengthened the pipeline for potential treatments, improved trial accessibility, and advocated for more inclusive research opportunities that directly benefit the PWS community.

Rare Disease Innovation and Collaboration



PWSA | USA remained at the forefront of rare disease advocacy through its active involvement in the development of the **FDA Rare Disease Innovation Hub**, a dedicated initiative designed to accelerate research, shape policy, and foster collaboration among patient organizations, researchers, and industry leaders. This initiative represents a critical step toward addressing the unique challenges faced by individuals with PWS and the broader rare disease community.

In 2024, PWSA | USA worked closely with key advocacy organizations, including the EveryLife Foundation and National Organization for Rare Disorders (NORD), to ensure that the PWS community's needs were prioritized within the Hub's objectives. Through these efforts, we successfully advocated for stronger regulatory frameworks, improved access to innovative therapies, and a more inclusive approach to rare disease research. By playing a pivotal role in the Hub's development, PWSA | USA reinforced its commitment to driving meaningful policy changes, ensuring that the voices of those affected by PWS are heard in critical decision-making processes.

The FDA Rare Disease Innovation Hub is expected to create lasting impact by fostering collaboration between patient groups, researchers, and regulatory bodies, ultimately driving progress in treatment access and medical innovation. Through partnerships like these, PWSA | USA continues to lead efforts that bring hope and tangible advancements to the PWS community.

Looking ahead: The advocacy milestones of 2024 lay the foundation for an even greater impact in 2025. With expanded ambassador programs, deeper policy engagement, and innovative awareness efforts, PWSA | USA remains committed to amplifying the voices of those affected by PWS. Our progress is driven by the dedication of advocates, caregivers, and the entire PWS community. Together, we will keep pushing forward, creating lasting change.

FAMILY SUPPORT

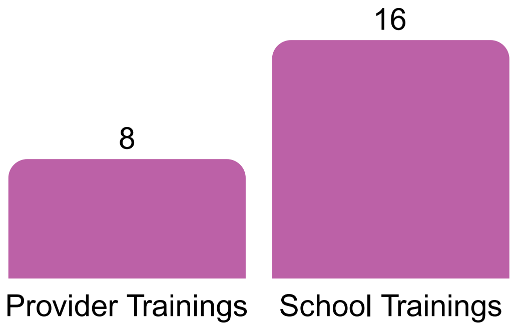
PWSA | USA's Family Support team provides guidance and support to individuals diagnosed with Prader-Willi syndrome, their families, and care providers. The team provides education and training to medical providers, educators, and professional caregivers about the syndrome, and advocates for the comprehensive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

HOW WE OFFER SUPPORT

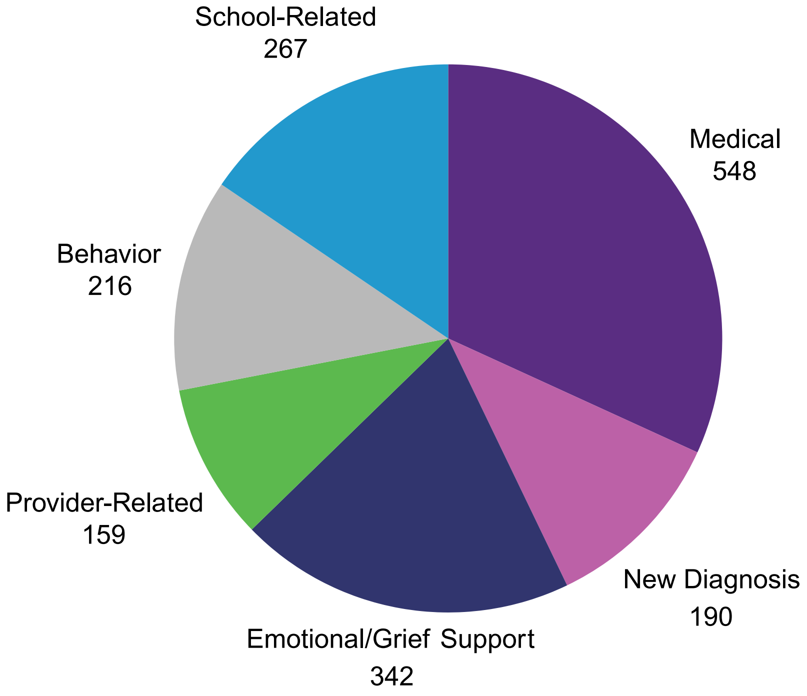
- **Provider Training** - Educating Healthcare Professionals
- **Family Support Groups** - Building a Supportive Community
- **School Success** - Diligence and Active Participation
- **Nutrition Guidance** - Weight Management Strategies & Support
- **Financial Support** - Assistance for Care and Resources
- **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 2024 IMPACT

4,043	**Total Family Support Inquiries**
3,495	**Non-Medical Inquiries**
389	**New Diagnosis Packets Sent Out**



Family Support Inquiry Breakdown



Residential Providers Conference

In 2024, PWSA | USA hosted our first-ever **Residential Providers Conference** in Savannah, GA. This conference was held August 18-20, both virtually via zoom and in-person and offered a variety of lectures and workshops where more than 100 professionals from around the country met to share their knowledge and experiences. The goal of this event was to enhance the care provided to individuals and develop new methods of support on a range of topics like research, relationships, technology, the role of therapies, diagnostic instruments in behavior management, autonomy, aging, and more.

“There is nothing more inspiring than spending time with people who are so committed to improving the lives of people with PWS! The learning, sharing, brainstorming, and connecting was a priceless experience, and I can’t wait to do it again! Thank you PWSA | USA for highlighting the importance and dedication of professional providers.” - Patrice Carroll, Latham Centers

PWSA | USA Trainings

PWSA | USA Senior Family Support Counselor and Trainer Kim Tula, MS, CSW, does an incredible job traveling around the country to provide trainings to several residential group homes, schools, and hospitals (as well as law enforcement staff). In 2024, she provided 24 trainings.

“After the trainings, I can just tell my staff’s confidence has gone a step up. Kim reviews our dietary items and really helps us with our menus. You can tell the staff know they're doing it right. They're coming in every day, they're sticking to the tasks, and they're sticking to the menus. They’re also sticking to the programming and the scheduling. I would say our biggest take away from the training is confidence. Knowledge builds our confidence. I know I feel a lot more comfortable now talking about Prader-Willi syndrome and helping our PWS population.”
– Nicole Tingley, DD Homes

Building Our Social Skills (BOSS) Program

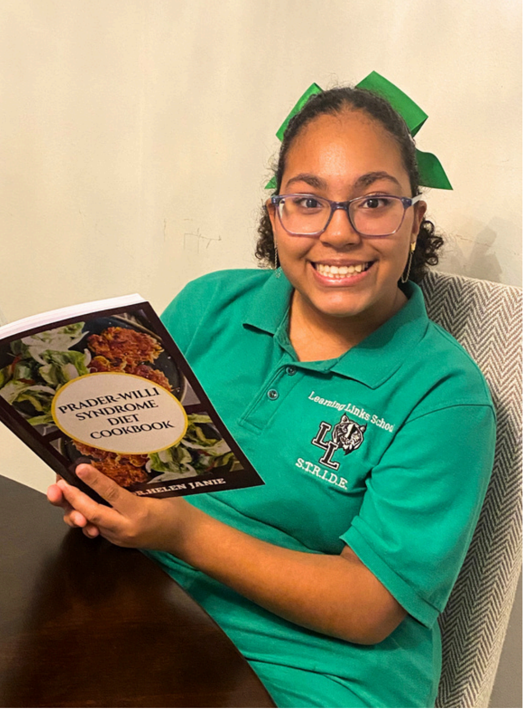
Introduced in 2023, the **BOSS Program** significantly helps adults living with PWS regulate emotions, reducing frustration, anxiety, and impulsivity. These meetings lead to more positive relationships and fewer behavioral challenges, making social interactions smoother. Participants successfully integrate into schools, workplaces, and community activities, demonstrating greater confidence and adaptability.

Families and caregivers also benefit, as individuals with PWS learned to advocate for their needs and set healthy boundaries, reducing household stress and improving communication. The program also raises awareness within the broader community, fostering empathy and inclusivity. In the long term, participants gain independence, confidently navigating daily tasks and social situations, reducing isolation and enhancing well-being. In 2024, six groups of 5–6 individuals completed a 10-week session, meeting three times per week.

Monthly Family Support Webinars

In 2024, PWSA | USA launched a free Family Support Webinar Series, providing monthly webinars on a variety of important topics for families and providers. Featuring expert speakers from across the PWS community, these sessions offered valuable insights, guidance, and resources to help navigate life with PWS. We were thrilled to see more than 2,000 registrations and recording views for these webinars. Below, you'll find a breakdown of each webinar, including topics and speakers. You can also explore past webinars anytime by visiting our **Family Support Webinar Playlist**.

DATE	TOPIC	SPEAKER(S)
2/27/24	Lessening Challenges by Focusing on Strength	Patrice Carroll, LICSW
3/26/24	Psychosis is PWS: Early Signs, Diagnosis, and Treatment	Elizabeth Roof, M.A.
4/23/24	Everything You Need to Know About Extended School Year	Destiny Pacha, EdD
5/28/24	Romancing the PWS Parent: Strategies to Create a Strong and Healthy Marriage	Lisa Graziano, M.A., LMFT
6/25/24	What's the Big Deal About Exercise	Kat Lucero
7/30/24	PWS Aging and Research Part 1	Barb Dorn, RN, BSN
8/6/24	PWS Aging and Research Part 2	Barb Dorn, RN, BSN
8/27/24	Individualized Health Plan	Destiny Pacha, EdD
9/24/24	Friendship and Beyond	Patrice Carroll, LICSW
10/22/24	Why, What, and How of TREND Community and PWS Connect	Maria Picone & Chris Defelice
11/19/24	Babysitter and Care Provider Training	Lisa Graziano, M.A., LMFT


PRADER-WILLI SYNDROME DIET COOKBOOK
Learning Links School
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S.T.R.I.D.E.


NIKE

Supporting Research to Make Each Day a Better Tomorrow

Many of the world's most renowned PWS researchers and clinicians are members of PWSA | USA's Clinical and Scientific Advisory Board (CSAB) and Research Committee. Together, they dedicate thousands of hours yearly to enhance research, write educational materials, and provide consultation; nearly all the major breakthroughs in understanding and treating PWS have come from these pioneers and heroes. PWSA | USA has been supporting research since 1983 and remains committed to supporting future advancements and breakthroughs. At PWSA | USA, we work to integrate what we have learned about the needs of our families through our support programs with research we think will make an important and practical difference in the lives of those affected by PWS

Cultivating the Future of PWS Research

In 2024, the Research Committee proudly launched a new fellowship program aimed at supporting emerging providers in enhancing their understanding of Prader-Willi syndrome. This initiative is a significant step forward in advancing knowledge in the field, with the program currently offering a fellowship in collaboration with the prestigious Chicago School of Psychiatry. The committee is diligently working to refine the Letter of Intent (LOI) process, with the goal of engaging more researchers and expanding the scope of research on PWS. These efforts are critical in fostering the next generation of professionals dedicated to improving the lives of individuals affected by this rare and complex disorder.

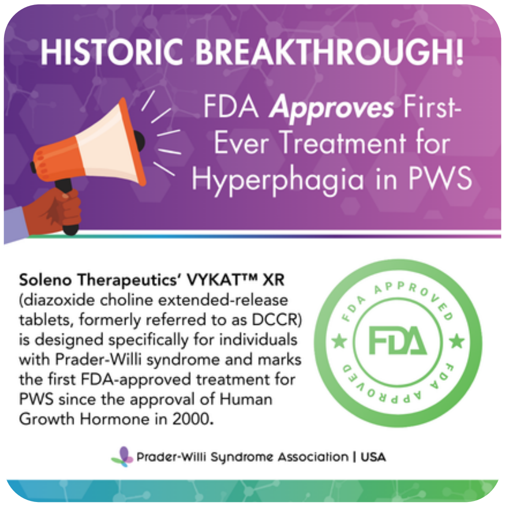
Under the leadership of Janet Li, MD, chair of the committee and CSAB member, the grant review process has been carefully refined to ensure a thorough and impactful evaluation of research proposals. Dr. Li continues to build upon the foundation of success established by PWSA | USA over the past 40+ years, guiding the organization toward even greater progress in PWS research. Her unwavering commitment and strategic vision are instrumental in advancing the mission of the Research Committee, as they work to promote groundbreaking discoveries and improve treatment outcomes for individuals with PWS.

PWS Clinical Trials

2024 was a pivotal year in advancing PWS treatments. The first-ever NDA for a hyperphagia treatment was submitted to the FDA, and multiple Phase 3 clinical trials began, bringing new hope to our community. With seven clinical trials either concluded or currently underway, we are closer than ever to more approved treatments. A heartfelt thank you to the families and individuals who have participated in these trials - your dedication is driving progress and shaping the future of PWS care!

COMPANY NAME	NAME OF DRUG	CLINICAL TRIAL PHASE	TARGET
Aardvark Therapeutics	ARD-101	Phase 2 *(complete)*	Hyperphagia
Acadia Pharmaceuticals	ACP-101 (Carbetocin)	Phase 3	Hyperphagia
Gedeon Richter	RGH-706	Phase 2 *(enrollment complete)*	Hyperphagia
Harmony Biosciences	Pitolisant	Phase 3	Excessive Daytime Sleepiness
Montefiore Medical Center	Cannabidivarin (CBDV)	Phase 2	Behavior
Soleno Therapeutics	DCCR	Phase 3 *(complete)*	Hyperphagia
Foundation for Prader-Willi Research	VNS4PWS	Phase 3	Behavior

FDA Approves First-Ever Hyperphagia Treatment for 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.

On March 26, 2025, the FDA approved Soleno Therapeutics' DCCR, now known as **VYCAT XR**, marking a historic milestone for the PWS community. For the first time, families have access to a treatment for hyperphagia - the hallmark symptom of PWS.

This achievement was made possible through relentless advocacy efforts over the past several years, along with the dedication of researchers, clinicians, and the entire PWS community. Here are just a few ways we made an impact in 2024:

- The D.C. Fly-In and direct engagement with FDA/CDER representatives.
- Powerful testimonials at the Externally-Led Patient-Focused Drug Development meeting, which were compiled into the Voice of the Patient Report.
- A petition urging the FDA to prioritize DCCR's review, submitted by the PWS Advocacy Coalition.

The approval of VYCAT XR is the result of years of dedication, and PWSA | USA remains committed to supporting families in this new era of treatment.

FUNDRAISING EVENTS & INITIATIVES

In 2024, the PWSA | USA community came together like never before, breaking records and expanding impact through fundraising events and initiatives. From peer-to-peer campaigns to signature fundraising events, our supporters showed up in full force to fuel PWSA | USA's mission. A record number of community-hosted fundraisers supported our **PWS Hope United** campaign, thanks in part to our transition to a more user-friendly peer-to-peer platform. We also welcomed two new fundraising coaches, Pia Dorson and Katie Martinez, to provide hands-on support to our incredible fundraisers.

To further empower our community, we launched a **Make an Impact** section on the PWSA | USA website, offering new resources for fundraising, including a planned giving page featuring a heartfelt video with John Lens, a PWS dad and PWSA Board of Directors member, sharing why legacy gifts are so meaningful.

PWSA | USA's Family Support Campaign and Angel Drive Campaign together raised more than $300,000, fueling vital programs and services. The 10th Annual Clint Hurdle Hot Stove Dinner continued its legacy of generosity, raising an incredible $240,000 for family support services. Our biennial Walk a Mile in Their Genes campaign generated critical funds for PWSA | USA's advocacy work.

As we look ahead to 2025, we are excited to build on this momentum with major fundraising events, including our PWS Awareness Month United We Brunch campaign, Journey of Hope 50th Gala, and even more peer-to-peer and community-led events across the country.

10 Years of Impact: The Clint Hurdle Hot Stove Dinner

In 2024, the **10th Annual Clint Hurdle Hot Stove Dinner** marked a decade of unwavering commitment to the PWS community. Hosted by Clint and Karla Hurdle, whose daughter Madison lives with Prader-Willi syndrome, this milestone event raised an incredible **$240,000** in support of PWSA | USA's Family Support programs. Over the past ten years, Clint and Karla Hurdle have brought together a dedicated community, raising essential funds and awareness for PWS. Their generosity and advocacy have made a lasting impact, providing families with the resources and support they need.

Family Support Campaign: Strength in Community

Each year, the **Family Support Campaign** unites our community to fund the life-changing programs and services that PWSA | USA provides to families throughout their PWS journey. In 2024, supporters from across the country rallied together, sharing personal stories and raising awareness about the vital resources PWSA | USA offers. Thanks to this collective effort, the campaign raised **$75,700** to ensure that families continue receiving expert guidance and support when they need it most.

> *"The PWSA Family Support team has helped us every step of the way! At the beginning, we were reached out to and given so many answers to too many questions to count. Whenever I panic about what is going on with my daughter, they are there to help and make me feel like I am not alone. I am truly blessed for us to have the support that's there, especially when the rest of the world doesn't know about PWS."*
>
> \- Kebra, mom to Saphira (2) (OH)

THANK YOU FOR MAKING AN IMPACT!

Your gifts help provide:

- Family Mentor Program
- 24-Hour Crisis Line
- Grief Support Counseling
- New Diagnosis Support
- School Success Toolkits
- Intensive Supports and Services
- And so much more!

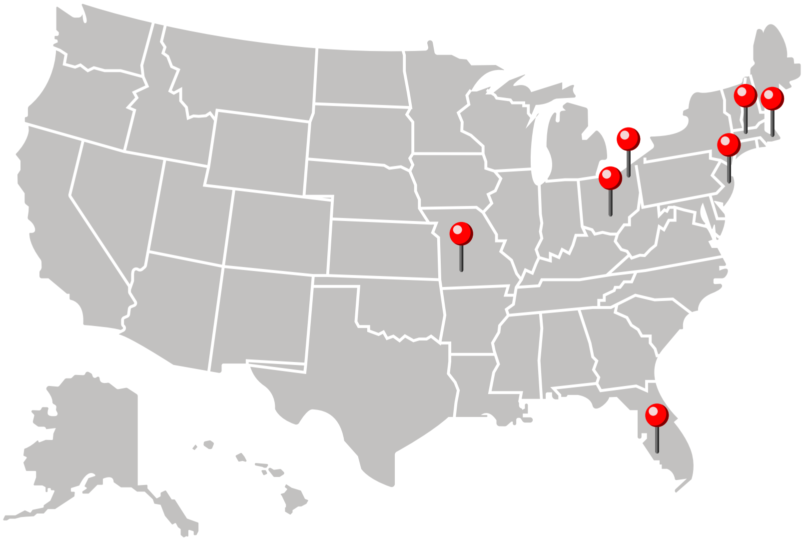
FUNDRAISING EVENTS & INITIATIVES

Welcome New Fundraising Coaches!

In 2024, we were thrilled to welcome **Pia Dorson** (pictured left) and **Katie Martinez** (pictured right) to PWSA | USA's development team as peer-to-peer fundraising coaches! Pia, our Fundraising Coach for DIY & Special Events, is mom to Zahra (7), who is living with PWS. Katie, our Fundraising Coach for Team & Online Events, is mom to Samuel (7), who is also living with PWS. Both bring incredible passion and firsthand experience to our community, working one-on-one with families to create meaningful fundraisers - whether online or in person. From planning to execution, they're here to support you every step of the way! Interested in starting your own fundraiser? Contact our team at hopeunited@pwsausa.org to get involved!

2024 PWS Hope United Events

In 2024, there were **seven** in-person PWS Hope United events held around the U.S., and **172** other individual online fundraisers hosted via Facebook celebrating birthdays, Rare Disease Day, PWS Awareness Month, and more!



Hope United 5k & Family Fun Run
Columbus, OH | April 20, 2024
Hosted by the Zak, Hammonds, Seely, Leighty, and Carter Families

Gavin Gill Golf Classic
Duxbury, MA | September 7, 2024
Hosted by the Gill Family

RMC Foundation Golf Outing
Sarasota, FL | September 30, 2024
Hosted by the Garzia Family

15th Annual Hunter Lens Golf Tournament
Lakeville, MA | October 4, 2024
Hosted by the Lens Family

No Gimmes for Jimmy Memorial Golf Tournament
West Orange, NJ | October 10, 2024
Hosted by the Gilsenan & Worthington Family

Dance Silly for Prader-Willi
Warren, OH | October 12, 2024
Hosted by the Hampton Family

Answers for Audrey Trivia Night
Bel-Nor, MO | October 12, 2024
Hosted by the Spring Family

Angel Drive Campaign

From November 1 to December 31, 2024, PWSA | USA hosted our annual Angel Drive campaign, our largest and most impactful fundraiser of the year - and what a success it was! Thanks to the support of our community, we raised **$245,112** in just two months. The 2024 campaign featured several exciting initiatives:

- Giving Tuesday Match: On December 3, 2024, a $25,000 matching gift from PWSA's generous board members helped double donations and amplify impact.
- Prize Raffle Giveaway: New in 2024, we introduced a special prize raffle with four incredible prizes donated by supporters, including an Apple Watch, a $300 Amazon gift card, customizable PWS Nike shoes, and a PWSA swag bag.
- Hope in Action Video Series: Each week for eight weeks, we shared an inspiring video, highlighting personal stories from our community and showcasing how PWSA | USA turns hope into action for families and individuals affected by PWS. **Click here** to be directed to the "Hope in Action" playlist.

Watch: John Lens, a devoted father and PWSA | USA board member, shares his personal journey and the peace of mind that planned giving has brought to his family.

Planned Giving with PWSA | USA

Leaving a legacy is more than a choice; it's an opportunity to be remembered in a meaningful way. As you consider the impact you wish to make, think about how you can reflect your core values and aspirations for the future. If supporting those affected by Prader-Willi syndrome holds a special place in your heart, we encourage you to include a gift to the Prader-Willi Syndrome Association | USA in your estate or financial planning. Your generosity will help us continue our vital work and make a lasting difference in the lives of individuals and families impacted by this condition. **Click here** to learn more.

Looking Ahead to 2025

We're thrilled to expand our fundraising efforts in 2025 with more exciting events! Moving forward, we have even more reason to come together - celebrating the FDA approval of VYKAT XR, the first-ever treatment for hyperphagia in PWS. Together, we've reached an incredible milestone, but there's still work to do. Let's keep the momentum going and ensure that every individual living with PWS can access life-changing treatments.

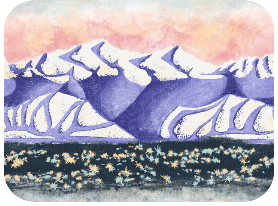
- **United We Brunch**
- **PWSA | USA's 50th Anniversary Journey of Hope Gala**
- **New PWS Hope United events**, including: Diamonds & Denim (IL) – Hosted by the Avart Family; Zahra's Night of Light (NY) – Hosted by the Dorson Family; Hope United 5K (NC) – Hosted by the VanHook & Kreacic Families; Tri-Harder for Belle (CO) – Hosted by the Kramer Family; Cocktails for a Cause (NY) – Hosted by Stacy Ward; Pittsburgh for PWSA Winter Wonderland (PA) – Hosted by 8 Pittsburgh Area Families

OTHER 2024 HIGHLIGHTS

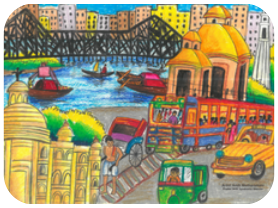
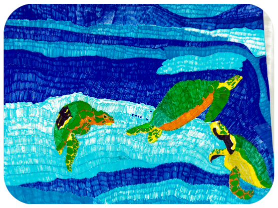
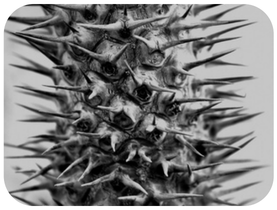
Launch of PWSA | USA's "PWS United" Podcast

PWS United launched on August 30, 2024, and is PWSA | USA's official podcast – the first PWS-specific podcast to hit podcast streaming platforms! The purpose of *PWS United* is to connect, inform, and inspire the PWS community. The podcast features conversations with experts, caregivers, individuals with PWS, and advocates, addressing key topics like research advancements, family support, advocacy efforts, and personal stories. Released weekly on Tuesdays, *PWS United* highlights the diverse experiences within the PWS community, offering practical insights and resources for families and professionals. The podcast aims to amplify the voices of those affected by PWS, foster a sense of community, and drive awareness and understanding of the syndrome. **Click here** to be directed to our official podcast website.

PWS Rare Aware Art Share






In 2024, PWSA | USA launched an inspiring new initiative, the **PWS Rare Aware Art Share**, celebrating the creativity and unique perspectives of individuals living with Prader-Willi syndrome. With three engaging themes, *What's Your Superpower?*, *What's Something Unique About Where You Live?*, and *What Is Your Favorite Birthday Memory?*, we were thrilled to have 60 individuals participate, contributing more than 100 incredible pieces of art. Submissions ranged from colorful drawings and beautiful photographs to heartfelt song lyrics and creative videos. These artistic expressions became a cornerstone of our communications, proudly showcased on PWSA's website, emails, and social media, helping to amplify the voices of those living with PWS. A collage of these pieces was even printed and shared with elected officials and their staff during the D.C. Fly-In, leaving a lasting impression about the strength and creativity of our community. Looking ahead, we are excited to feature these remarkable art pieces as one of the centerpiece displays at the 2025 International PWS Conference, bringing this vibrant collection to a larger audience and celebrating the incredible talents of individuals with PWS. **Click here** to visit the virtual art gallery.

2024 FINANCIALS (Unaudited)

Operating Support and Revenue

Contributions and Grants	$1,181,152
Fundraising and Special Events	$311,039
Other Revenue	$129,011
Total Operating Revenue	**$1,621,202**

Operating Expenses

Program Services

Family Support	$673,246
Advocacy & Awareness	$438,455
Research	$44,879
Total Program Services	**$1,156,580**

Supporting Services

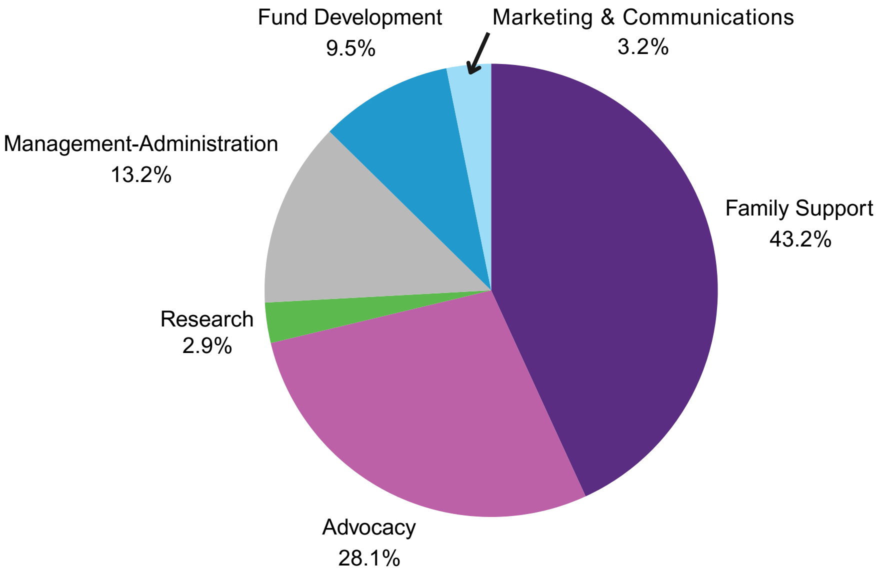
Management & Administration	$206,264
Fund Development	$147,695
Marketing and Communications	$49,469
Total Support Services	**$403,428**
Total Operating Expenses	**$1,560,008**

Change in Net Assets from Operations | $61,194
Net increase/(decrease) in fair value of investments | $95,132
Net increase/(decrease) in beneficial interest in trust | $73,359
Net Gain/(Loss) on Sale | $3,413
Change in Net Assets | $233,098

Net Assets (beginning of the year)	**$2,698,623**
Net Assets (end of year)	**$2,931,721**

FUNCTIONAL EXPENSE BY CATEGORY

- 🟪 Family Support Program
- 🟩 Research Program
- 🟪 Advocacy Program
- 🟦 Fund Development
- ⬜ Management & Administration
- 🟦 Marketing & Communications



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Denise Servais (Secretary), Lake Elmo, MN
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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
Pia Dorson, Fundraising Coach: DIY & Special Events
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

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Olivia Veatch, PhD
Barbara Whitman, PhD

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

Audit Committee

Mitch Cohen, Jim Kane, Tina Ihlenfeld, Amy Maust

Finance Committee

Marguerite Rupnow, Mitch Cohen, John Lens, Tina Ihlenfeld, Amy Maust, Michelle Torbert, Andrew Salak, Stacy Ward

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Janet Li (Chair), Michelle Torbert, Ann Scheimann, Lynn Garrick, Stacy Ward, Joan Gardner, Ann Manzardo

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50th Anniversary Work Group

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

Communications Work Group

Julie Casey, Lisa Graziano, Denise Servais, Elaine Towle, Emily Felt, Charles Conway, Jen Andrews, Chris Benninghoff, Anne Fricke, Carrie Ilijevich

Professional Provider Work Group

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

Family Support Work Group

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Adults with PWS Advisory Board

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


United in HOPE
2025 PWS CONFERENCE

2025 INTERNATIONAL PWS CONFERENCE | PHOENIX, AZ

June 24-28, 2025

Arizona Grand Resort & Spa

Something for everyone!

- Clinical & Scientific Program
- Professional Providers Program
- Family Program
- Adults with PWS Program

Scan to Register!

OR CLICK HERE

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SAVING AND TRANSFORMING LIVES

IPWSO
International Prader-Willi Syndrome Organisation

FOUNDATION FOR PRADER-WILLI RESEARCH

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.