Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

2022 Annual Report

Mission: To enhance the quality of life of 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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PWSA | USA's
Annual Report 2022

A digital version of this publication can be viewed on our website.

www.pwsausa.org/annualreport

YEAR IN REVIEW

A message from PWSA | USA's CEO and Board Chair

Dear Friends,

As we take a moment to reflect on the past year, we are inspired by the progress our association and community has made. In 2022, we set out to implement new initiatives and organizational changes to strengthen our three pillars – **Advocacy and Awareness, Family Support, and Research**. We are confident that with these changes and additions now in place and in practice, the future holds endless possibilities for our loved ones and families affected by Prader-Willi syndrome.

In 2022, PWSA | USA once again served a record number of families in all 50 U.S. states and in 20 countries around the world (read more on page 7). We experienced major progress with our advocacy and awareness initiatives as well. More than 50 advocates took their efforts to new heights during PWSA | USA's first-ever D.C. Fly-In (read more on page 3). Our research goals are also taking shape with a reinvigorated outlook on how we can best support pharmaceutical companies working on PWS drug development and health care professionals conducting PWS-specific research initiatives. We have already set this plan in motion. In 2022, PWSA | USA secured an FDA Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD) for our 2023 National Convention - a historic FIRST for our PWS community (read more on page 11).

We know living with PWS can sometimes be a tough journey and can present daily challenges for our families. That is why PWSA | USA is here to offer help, hope, and support 24 hours a day, 365 days a year. We are by your side through the most challenging times and to share in your important celebrations, successes, and hard-earned milestones.

As we begin 2023, we see a year full of new programs and engagement for our community! A few of these opportunities include:

- Our **37th National Convention** in Orlando, FL, which is back in-person for the first time since 2019, featuring the **FDA EL-PFDD meeting**
- **Continued educational opportunities** for both families and providers through webinars, community conversations, and special "summit" programs
- A refreshed **Family Mentor Program,** where parents, siblings, and grandparents will offer support to other PWS families
- PWSA | USA's first-ever **Moms' Retreat**, which will offer opportunities for connection and self-care
- And many other great initiatives planned for 2023!

Again, as we reflect on the great accomplishments of 2022 and the amazing roadmap set out for 2023, we move forward with passion, hope, and gratitude for our PWS community. We have a wonderful staff, Board of Directors, industry professionals and the best volunteers! Together, we will be united in **HOPE** for the future of our loved ones.

Paige Rivard

Paige Rivard, MBA
CEO, Mom to Jake (12) living with PWS

Marguerite Rupnow

Marguerite Rupnow, MBA
Chair, Board of Directors

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

ADVOCACY

Raising awareness and effective advocacy are essential to ensuring health, safety, and enhanced quality of life for those affected by Prader-Willi syndrome. 2022 was spent implementing our **ONE Voice Advocacy** plans, including the Advocacy in Action Webinar Series and D.C. Fly-In for PWSA | USA advocates.

DC Fly-In

On Monday, September 19, 2022, 51 PWSA | USA advocates from 21 States touched down in Washington, D.C. for the first-ever D.C. Fly-In! We hosted a welcome party for our attendees Monday evening, which gave them an opportunity to get to know each other and brainstorm for Tuesday's meetings on Capitol Hill.

We woke up bright and early Tuesday morning to catch our bus to the Senate and House of Representatives buildings. Our teams divided and conquered more than 76 meetings with elected officials from around the country. During each meeting, our advocates touched on three key items:

- Ask for a resolution declaring May 15th as PWS Awareness Day
- Find co-sponsors for the Orphan Drug COVID-19 Mitigation Act (HR 8641)
- Add Prader-Willi Syndrome as a recognized topic area for DOD research under Congressionally Designated Medical Research Program's Peer Reviewed Medical Research Program (PRMRP)

Special thanks to all the members of PWSA's Advocacy Work Group who led our team!

D.C. FLY-IN BY THE NUMBERS

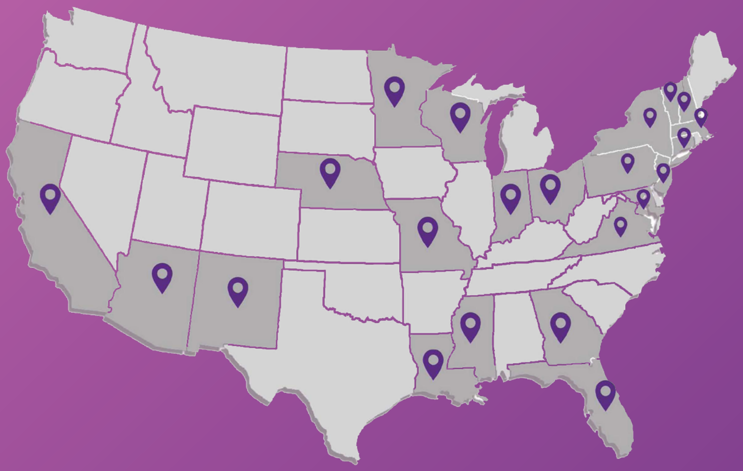
ADVOCACY IN ACTION
Prader-Willi Syndrome Association | USA
D.C. FLY-IN 2022

76 Confirmed Meetings
5 Member-Level Meetings
51 Attendees
21 States Represented
42 Senate Meetings
31 House Meetings
43 Democrat Offices
30 Republican Offices

76
Congressional Meetings

51
Attendees

21
States Represented



ARIZONA
Christina Burgstaler
Chelsee Loucks
Tammy Penta
Rob Lutz

CALIFORNIA
Michelle Cox
Samantha Keefe

CONNECTICUT
Tommy Tran

FLORIDA
Jennifer Garzia
Maggie Senese
Michelle Torbert
Dorothea Lantz
Maria Gonzalez
Randall Johnson
Hunter Johnson

GEORGIA
Amy Harris
Jamie Prentice

INDIANA
Anna Landseadel

LOUISIANA
Katie Martinez
Donna K. Stephens

MARYLAND
Christina Argo
Oaklyn Argo
Dr. Ann Scheimann

MASSACHUSETTS
Andrea Glass

MINNESOTA
Jennifer Andrews
Kristi Rickenbach
Justice Rickenbach

MISSOURI
Brian Hill

MISSISSIPPI
Andrew Gilly
Kristen Gilly
Joseph Gilly

NEBRASKA
Paige Rivard
Matt Rivard
Jake Rivard
Brian Kalasek

NEW HAMPSHIRE
Melanie McDonald

NEW JERSEY
Amanda DiPascale

NEW MEXICO
Valerie Selinger

NEW YORK
Beth Krause
Amy McDougall
Dr. Deepan Singh
Stacy Ward

OHIO
Erin Carter
Carrie Larsen
Diane Seely
Rob Seely
Reagan Seely

PENNSYLVANIA
Erin Mercadante
Cindy Szapacs

VIRGINIA
Charles Conway
Charles Conway III
Gennelle Conway
Angelica Conway

WISCONSIN
Katie Moureau

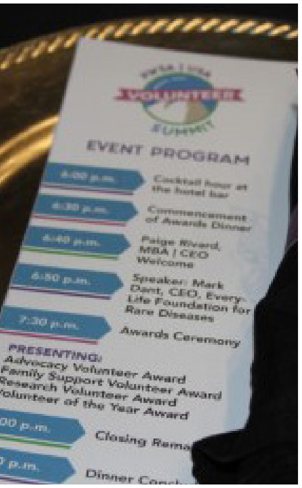
ADVOCACY IN ACTION WEBINARS

PWSA | USA hosted five Advocacy in Action webinars throughout 2022 to best inform our PWS community how to be effective advocates and share details about upcoming advocacy opportunities and events.

Advocacy in Action featured:

- Guest presenter Guy Stephens, Founder and Executive Director for the Alliance Against Seclusion and Restraint (ASSR)
- An FDA Webinar with speakers Susan Chittooran, MSW (FDA Patient Listening Session Program Manager) and Sadhna Khatri, Pharm.D., MPH, MS, MED (Public Health Service Supervisory Associate Director - Engagement Team). This informative webinar discussed topics such as:
  - Understanding patient engagement at the FDA
  - Patient voice
  - FDA patient listening
  - Submitting questions and meeting requests
  - Patient-focus drug development
  - CDER listening sessions
  - 15-minute Q & A opportunity
- A legislative update by Rachel Derby, Executive Director of Patients Rising Now (Patient Advocate Education | Access to Healthcare | Patients Rising)
- A virtual roundtable and panel discussion on effective communication with elected officials and stakeholders. Our panelists included:
  1. State Sen. Ana Maria Rodriguez, FL
  2. U.S. Sen. Amy Klobuchar, MN – Legislative Assistant Ruth McDonald
  3. State House Delegate Emily Shetty, MD
  4. State Rep. Maureen Mooney, NH
- A “Share Your Story” instructional webinar, featuring Jim Sliney, Director of Patient Outreach at Patients Rising Now and writing consultant at Columbia University

You can listen to all our recorded webinars by visiting PWSA | USA’s YouTube page ▶



EVENT PROGRAM

6:00 p.m.	Cocktail hour at the hotel bar
6:30 p.m.	Commencement of Awards Dinner
6:40 p.m.	Paige Rivard, MBA / CEO Welcome
6:50 p.m.	Speaker: Mark Dant, CEO, Every-Life Foundation for Rare Diseases
7:30 p.m.	Awards Ceremony

PRESENTING:
Advocacy Volunteer Award
Family Support Volunteer Award
Research Volunteer Award
Volunteer of the Year Award

00 p.m.	Closing Rema
p.m.	Dinner Conc

PWSA | USA VOLUNTEER SUMMIT

If there is one word to describe the events of PWSA | USA's first-ever **Volunteer Summit** in Dallas, April 29, 2022 - May 1, 2022, it would be magical. We had more than 30 of our dedicated volunteers in attendance for a day filled with hope and brainstorming on how to continue making life better for our families battling PWS.

The agenda included three incredible speakers:

- Rachel Radomski, Senior Director of Patient Advocacy for Harmony Bioscience
- Jennifer Pastiloff, a bestselling author, public speaker, and aunt to a child with PWS
- Mark Dant, the Board Chair of the EveryLife Foundation and father to Ryan Dant. Mark was instrumental in developing a therapy, which saved the life of his son Ryan and many others battling Mucopolysaccha ride (MPS-1) disease.

We explored new and innovative ways to connect with PWS families and are in the process of launching several of those ideas, including:

- Adding a new PWSA | USA text message campaign
- Offering video tutorials to help families navigate all the information on our website
- Listing PWSA | USA volunteer opportunities and time commitments
- Continuing to streamline the Pulse (our bi-monthly newsletter) and other communication methods

We also presented four awards to individuals who have gone above and beyond in furthering with our advocacy and awareness, family support, and research efforts!

RESEARCH VOLUNTEER AWARD

Presented to Joe Gill

FAMILY SUPPORT VOLUNTEER AWARD

Presented to Elaine Towle

VOLUNTEER OF THE YEAR AWARD

Presented to Melissa Rivas

ADVOCACY VOLUNTEER AWARD

Presented to Jennifer Garzia

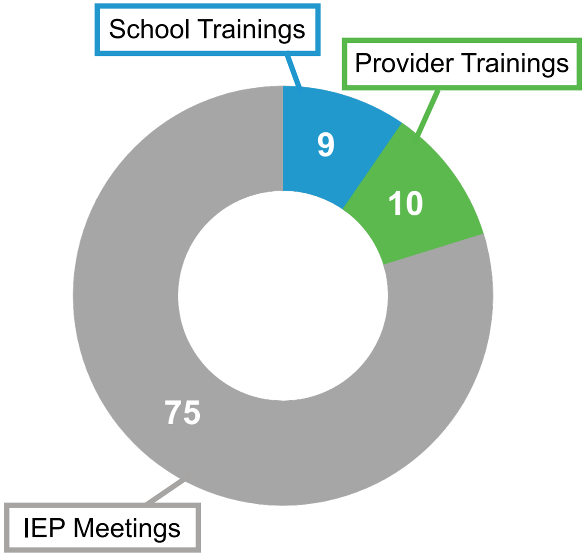
FAMILY SUPPORT

PWSA | USA's Family Support team members are your partners in Help & Hope. With more than double the amount of inquiries asked by families compared to 2021, this past year was a record year for our Family Support team. They also provided support to families in all 50 U.S. states and 20 different countries.

Our amazing Family Support team is here to provide guidance and support to individuals diagnosed with Prader-Willi syndrome, their families, and care providers 24/7/365. 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.

2022 Family Support Impact

Top Family Support Inquiries



2022 FAMILY SUPPORT CAMPAIGN

Thanks to the generosity of our community, PWSA | USA's 2022 Family Support Campaign, which was held June 1 - July 31, was a huge success. The funds raised during this time period helped to support our Family Support programs! More than 250 donors, 27% of whom were first time contributors to PWSA | USA, helped to make an impact! Through personal stories and photos shared by PWS families from across the U.S., we were able to showcase the amazing work our Family Support Team does daily.

Sue Colon | Mom to Shealynn (3) living with PWS

"My motivation to donate to PWSA | USA was due to the tremendous amount of help and support they gave my family and I in such a difficult and dark time in our lives. Also, all the support they gave the NICU staff. I can truly say that without their guidance, I don't know where things would have gone or where we would be today."

Rob Lutz | Dad to Isabel (22) living with PWS

"Our daughter, Isabel, gradually fell behind her classmates academically and exhibited more and more food seeking behaviors and behavioral problems. After speaking with PWSA | USA and the contacts we made through PWSA | USA, we understood that this was generally typical. Those contacts were invaluable as a source of knowledge and comfort. PWS is challenging and everyone should have access to the expertise, comfort, and connections provided by PWSA | USA."

THANK YOU FOR MAKING AN IMPACT!

Your gifts help provide:

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

RESEARCH

At PWSA I 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. It is our intention to put a stronger focus on research initiatives in 2023 and beyond by assisting with the development of new PWS drugs and supporting potential treatments currently in trial phases. We will also continue to offer funding for PWS-specific research studies to better understand the syndrome and our loved ones needs. In 2022, we received the findings from three of our grant funded projects, which you can learn more about on page 11. More details can be found by clicking **here**.

Research 2023 and Beyond

While all Prader-Willi syndrome research is important, PWSA I USA is particularly interested in facilitating research that can more immediately enhance quality of life of individuals affected by PWS.

The desire to find more and better treatment options to manage and diminish challenges inherent to Prader-Willi syndrome will guide PWSA I USA's research initiatives now and into the future. PWSA I USA's Clinical and Scientific Advisory Board aims to:

- Devote more resources to support development of new therapeutic interventions
- Increase efforts to collaborate with external research partners
- Evaluate the current grant-making process to ensure a treatment-based research focus
- Encourage innovative research models
- Create new opportunities for researchers and scientists to promote collaboration and information sharing

> “Supporting Research to Help Make Each Day a Better Tomorrow”

PWS Clinical Trials

(Currently in Progress)

Find more information about PWS clinical trials at clinicaltrials.gov.

Company Name	Name of Drug	Clinical Trial Phase	Target
Aardvarck Therapeutics	ARD-101	Phase 2	Hyperphagia
FPWR	Guanfacine	Phase 4	Aggression, behavior
FPWR	VNS	Phase 1	Behavior
Gedeon Richter	RGH-706	Phase 2	Hyperphagia
Harmony Biosciences	Pitolisant	Phase 2	Excessive Daytime Sleepiness
Montefiore Medical Center	Cannabidivarin (CBDV)	Phase 2	Behavior
Montefiore Medical Center	Oxytocin	Phase 2	Behavior
Neuron	NNZ-2591	Recruiting soon	Behavior
Soleno Therapeutics	DCCR	Phase 3	Hyperphagia

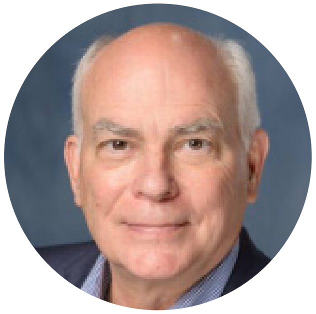
PWSA | USA RESEARCH FUNDED GRANTS

At PWSA | USA, we work to integrate what we have learned about the needs of our families through our support programs with research that we think will make an important and practical difference in the lives of those affected by PWS. PWSA | USA offers grant assistance for scientific researchers with an interest in improving the lives of those with PWS. In 2021, we received several Letters of Intent (LOIs) and in 2022, PWSA | USA accepted the following research grants to fund:

Kasey Bedard, Ph.D., BCBA-D

PWS Home Base: A Multi-Tiered System of Support for Residential Programs Caring for Individuals with PWS

Grant funding: $90,000



Daniel Driscoll, MD, Ph.D., FAAP, FFACMGG

PWS Rare Disease Clinical Research Network (RDCRN) Database and Statistical Support at the Data Management Coordinating Center (DMCC) Located at the University of South Florida

Grant funding: $25,000

Jessica Duis, MD

Do Pharmacogenomic Findings Correlate with PWS Genetic Subtypes, Behavioral Phenotype and Medication Response?

Grant funding: $90,000

Externally-Led Patient-Focused Drug Development Meeting

Bringing Together the PWS Patient Voice

In an effort to bring together the PWS patient voice, PWSA | USA is excited to host the first **FDA Externally-Led Patient Focused Drug Development (EL-PFDD) meeting** for the Prader-Willi syndrome community. You won't want to miss this historic and truly impactful event at PWSA | USA's **37th National Convention**, June 21-24, 2023, in Orlando, FL. The EL-PFDD meeting itself will take place Thursday, June 22, 2023, from 12:00 - 4:30 p.m. All are welcome and highly encouraged to attend, free of charge with lunch provided. You will be prompted to select to attend the EL-PFDD meeting while registering for the 2023 National Convention.

PWSA | USA Taking Action

In September 2022, an in-person meeting (the first in-person meeting of ANY organization since the onset of COVID-19) was held with high-ranking members of the FDA (CDER Division) who oversee the department that evaluates potential therapies to treat PWS.

The outcome of that meeting was the suggestion by the FDA to hold an Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD). The FDA explained this program was developed 12 years ago to assist patients and patient advocacy groups to help document the real, unmet needs of their communities.

Now that we have been approved to host this meeting, we look forward to the opportunity for our community's voice to be heard! The EL-PFDD meeting on June 22, 2023, will include patient testimonials, as well as remote audience participation. The meeting agenda will focus on two patient panels and audience discussion sessions on living with PWS, treatments for the disease, and potential clinical trials for PWS.

PWS hope united

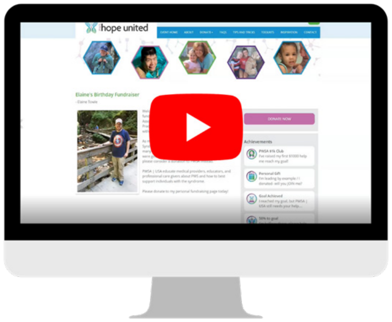
BUILDING **BRIGHT** FUTURES FOR PWS FAMILIES

Prader-Willi Syndrome Association | USA

In May 2022, PWSA | USA launched our much-anticipated and first-ever peer-to-peer fundraising platform, PWS Hope United, utilizing Blackbaud's Teamraiser software. Our PWS community members who created Hope United fundraisers in 2022 raised much-needed funds for PWSA | USA's Research initiatives.

Elaine Towle | Mom to James (36) living with PWS

"I would really recommend hosting a Hope United fundraiser to anyone out there – parents, grandparents, siblings of people with Prader-Willi syndrome. Be a voice and help support PWSA | USA. You will gain more than you will give!"



Giving hope has never been easier, and you can make it happen! Help us become stronger and more united than ever as a community. Hope is here to stay.

*If you're interested in hosting a PWS Hope United fundraiser in 2023, **click here** to learn more. Questions? Contact Development Director Melanie McDonald at **mmcdonald@pwsausa.org**.*

GAVIN’S SWEET 16 BOSTON MARATHON RUN

Joe Gill | Brother to Gavin (16) living with PWS

“Watching my brother Gavin, 16, grow up and seeing the struggles and ongoing obstacles that PWS presents have been a constant reminder of his resilience in the face of this rare disease, as well as a reminder of the importance of a loving supportive family - which we are so fortunate to have. I can’t begin to thank everyone who helped us surpass my goal of $32,000. You all completely blew our whole family away!”

2ND ANNUAL ANSWERS FOR AUDREY TRIVIA

Michelle Spring | Mom to Audrey (2) living with PWS

“We held our 2nd annual (Trivia) Answers for Audrey, and it was a great success! We were able to get some additional tables and new faces join us and that was wonderful! The support we feel from our friends and family is unmatched when it comes to this event. We are so happy to be able to tell Audrey’s story and spread awareness about Prader Willi Syndrome.”

13TH ANNUAL HUNTER LENS GOLF TOURNAMENT

John Lens | Dad to Hunter living with PWS

“On October 1st, we hosted our 13th annual Hunter Lens PWSA Golf Event in Lakeville, MA for family, friends, and colleagues to support families in need. Even with Hurricane Ian’s rain showers throughout the day, the weather couldn’t stop 100 plus golfers and many families join us for dinner, a raffle, and many laughs. One of the highlights of the day was that Hunter was able to meet a younger boy, Lincoln, who also has PWS, and Joe Gill whose brother Gavin has PWS as well. It is not often that Hunter has the chance to be with other families who are like him and his own family. This is one day Hunter will never forget.“

FUNDRAISING CAMPAIGNS

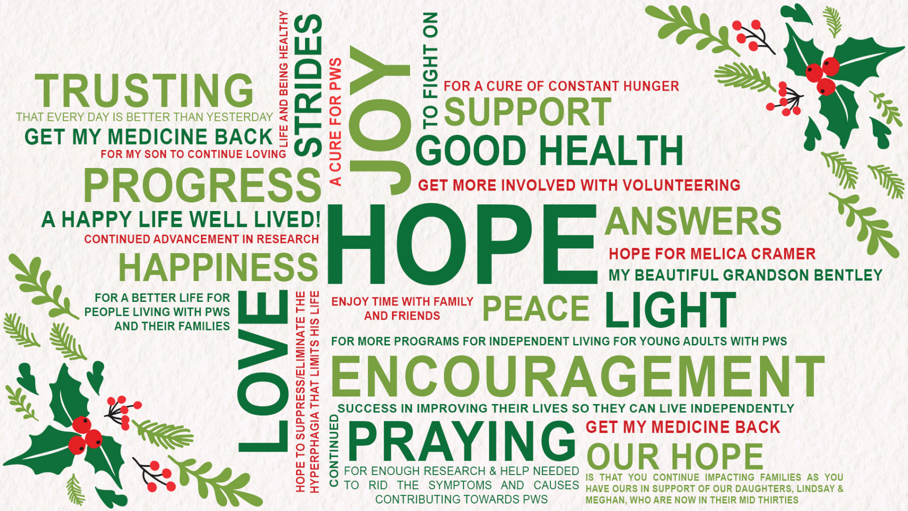
OUR LARGEST FUNDRAISING EVENT

8th Annual Clint Hurdle Hot Stove Dinner

On March 26, 2022, surrounded by palm trees, the sandy beaches of Anna Maria Island, and our PWSA family, the **8th Annual Hot Stove Dinner** was truly something to celebrate. Due to the support of our attendees and amazing community, a record amount was raised to support PWSA | USA's Family Support programs.

Thank you to Clint and Karla Hurdle for hosting this amazing event and for being incredible supporters of PWSA | USA. We also want to thank our event partner Leaving Legacies Foundation and all other sponsors for making this year's Hot Stove Dinner a huge success.

2022 ANGEL DRIVE CAMPAIGN



The 2022 Angel Drive was a great success, with funds raised to help fulfill PWSA | USA's mission year-round! More than 670 Donors, 26% of whom were first-time contributors to PWSA | USA, made donations by mail and online. The 2022 Angel Drive theme "Have HOPE, Take ACTION" emphasized the importance of staying hopeful and taking action to raise awareness, despite the challenges our community faces. New in 2022, we launched the Hope United Selfless Elf Fundraiser to benefit the Angel Drive. This enabled community members to become a "Selfless Elf," and to give HOPE rather than GET GIFTS during the holidays by creating a special personal fundraising page. This added to our success and helped us reach many more supporters as a result!

GRANTS

2022 saw the development and execution of several new grant-funded initiatives, thanks to an ever-growing and diversified list of Foundation Funders, Corporate Philanthropy Partners, and grants made via Donor Advised Funds (DAFs)

Advocacy | 2022 DC Fly-in: PWSA | USA's Day on Capitol Hill provided an opportunity for our advocates to engage with their individual members of Congress. Over 50 advocates attended, representing 21 states and over 70 meetings held.

Our platform consisted of the following topics:

- Encourage a resolution declaring May 15th as PWS Awareness Day
- Orphan Drug Mitigation Act (HR) 8641
- Request PWS be added as topic area for DOD research under the CDMRP's PMRPP

Thanks to generous grants from **Harmony Biosciences, Saniona, Everylife Foundation, and Horizon Therapeutics' RAREis Grant**, we were able to successfully execute PWSA | USA's first-ever large-scale fly-in. We are still experiencing the results of this hard-work as our advocacy efforts continue into 2023.

The **NICU Education and Support Project** is a NEW initiative to meet several critical needs for our rare disease community. As a result of a generous grant from the **Susan A. & Donald P. Babson Charitable Foundation**, PWSA | USA's Family Support Team was able to fulfill a long-time vision of creating tools, resources, and programs for families and medical providers to improve their experience and resources during their NICU stay.

LEARN MORE HERE

"RARE(ly) Missed Opportunities" A Financial Literacy toolkit for PWS families: Thanks to a grant from **Global Genes**, PWSA | USA was able to create a free, web-based downloadable kit with resources addressing the direct and indirect financial issues PWS caregivers may face throughout their journey caring for their loved one.

LEARN MORE HERE

General Operations/Donor Advised Funds: We are grateful to the many individuals who designated grants to support PWSA | USA in the form of Donor Advised Funds. These resources are directed to wherever they are needed most in the PWS community and help to sustain the critical operations we carry out in our three pillars year-round.

*To learn more about how your Foundation or Donor Advised Fund can support PWSA | USA's programs, contact Melanie McDonald, Director of Development, at (941) 487-6742 or by email at **mmcdonald@pwsausa.org**.*

FINANCIALS *(Audited)*

OPERATING SUPPORT AND REVENUE

Contributions and Grants	$1,759,045
Fundraising and Special Events	$463,156
Other Revenue	$26,536
Total Operating Revenue	**$2,248,736**

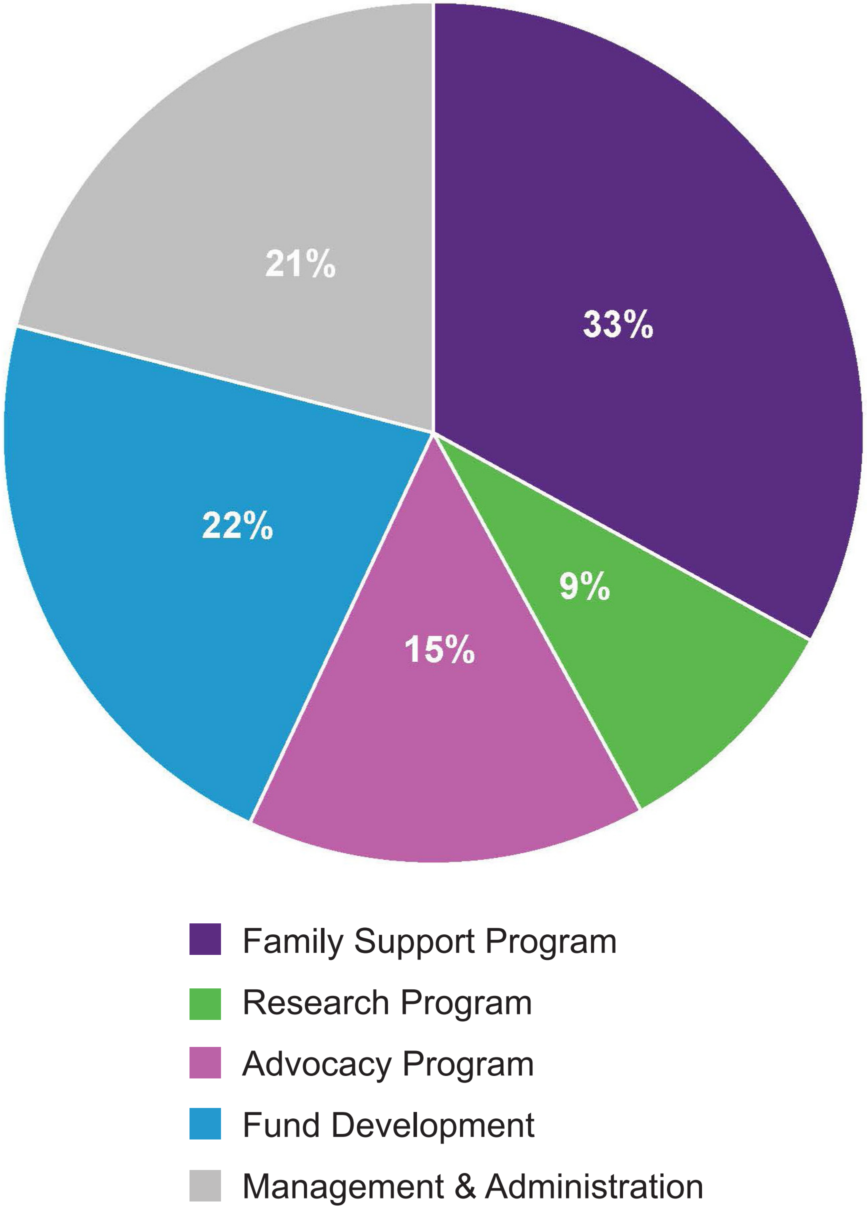
OPERATING EXPENSES

Program Services	
Family Support	$539,923
Advocacy & Awareness	$253,615
Research	$154,447
Total Program Services	**$947,985**
Supporting Services	
Management & Administration	$341,126
Fund Development	$367,354
Total Support Services	**$708,480**
Total Operating Expenses	**$1,656,465**

Change in Net Assets from Operations | **$592,272**
Net increase/(decrease) in fair value of investments | **($141,115)**
Net increase/(decrease) in beneficial interest in trust | **($71,388)**
Net Gain/(Loss) on Sale | **$1,667**
Change in Net Assets | **$381,436**

Net Assets (beginning of the year)	**$2,386,555**
Net Assets (end of year)	**$2,767,991**

FUNCTIONAL EXPENSE BY CATEGORY



PARTNERS IN HOPE

Officers and Directors

- **Marguerite Rupnow, MBA (Chair),** *Oconomowoc, WI*
- **Julie Doherty (Secretary),** *Tallahassee, FL*
- **Pam Zambrotta, CPA (Treasurer),** *Sarasota, FL*
- **Jeffrey Covington, MPH,** *Albany, NY*
- **Mitch Cohen, BS, JD,** *Weston, CT*
- **Tim Hearn, JD,** *Plymouth, MN*
- **Clint Hurdle,** *Holmes Beach, FL*
- **Jim Kane,** *Naples, FL*
- **Lisa Lamb,** *Gilbert, AZ*
- **John Lens,** *Lakeville, MA*
- **Kathryn Lucero,** *Colorado Springs, CO*
- **Rob Lutz,** *Phoenix, AZ*
- **Matt McCleery, BA, JD,** *North Chatham, MA*
- **Tammie Penta,** *Oro Valley, AZ*
- **Ann Scheimann, MD,** *Owings Mills, MD*
- **Denise Servais, M. Ed, CCC-SLP,** *Lake Elmo, MN*
- **Michelle Torbert,** *Homestead, FL*

PWSA | USA Staff

- **Paige Rivard, MBA,** CEO
- **Angela Frazier,** Events Coordinator
- **Lynn Garrick, RN,** Medical/Research Coordinator
- **Jennifer Hill, CPA,** Director of Accounting
- **Andrea Hughes,** Development Database Coordinator
- **Paige Jackson,** Graphic Designer
- **Sarah Kasaby,** Information & Referral Specialist
- **Anna Landseadel,** Executive Assistant to the CEO
- **Dorothea Lantz,** Director of Community Engagement
- **Carrie Larsen,** Director of Marketing & Communications
- **Melanie McDonald,** Director of Development
- **Kristi Rickenbach,** Parent Support Coordinator
- **Kristen Starkey,** Accounting Clerk
- **Kim Tula, MS, CSW,** Alterman Family Support Counselor
- **Stacy Ward, MS,** Director of Family Support

Clinical and Scientific Advisory Board

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- **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 Forester, 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 VanBosse, MD, FAAOS**
- **Stefanie Varga, PhD**
- **Olivia Veatch, PhD**
- **Colonel Karen Vogt, MD**
- **Rachel Wevrick, PhD**
- **Barbara Whitman, PhD**

Audit Committee

Jim Kane *(Chair),* **Mitch Cohen**

Executive Committee

Marguerite Rupnow *(Chair)*, **Mitch Cohen, Tim Hearn, John Lens, Paige Rivard, Pam Zambrotta**

Finance Committee

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