

## PWSA | USA Bi-Weekly Pulse: June 2, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS

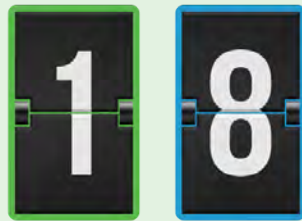


**Vol. 76**

June 2, 2023

[www.pwsausa.org](http://www.pwsausa.org) | 941.312.0400

*Countdown to Convention*



DAYS TO GO!

**Only ONE WEEK LEFT to Register for the 2023 National Convention!**



Friday, **June 9, 2023** is the **LAST DAY** to register for PWSA | USA's 37th National Convention! This much-anticipated event will provide exciting opportunities to learn, connect (and reconnect), and hear about the latest PWS research. Taking place June 21-24, 2023, at the Hilton Orlando Buena Vista Palace in Orlando, FL, this world-class event will include Medical & Scientific, Professional Providers, and Family Conferences. We are also honored to host and include all PWS stakeholders during our [Externally-Led Patient-Focused Drug Development \(EL-PFDD\) meeting](#), which is an FDA program. Learn more about the EL-PFDD meeting below.

Whether you have a loved one with PWS, are a professional provider, a physician, or scientist, the 2023 Convention has something for everyone.


**IMPORTANT NOTE: Registration for the PWS Camps (formerly known as YIP and YAP) is now CLOSED.**



# Spread Hope



PWSA | USA 2023  
**NATIONAL CONVENTION**

 Prader-Willi Syndrome Association | USA



Send PWSA | USA a video of yourself, your family, or your loved one living with PWS saying the word "Hope" and then the phrase "United in Hope!" We will share these Hope videos as part of our 37th National Convention. Upload your video at the button below and contact [communications@pwsausa.org](mailto:communications@pwsausa.org) with any questions. Thank you!

[SHARE YOUR HOPE VIDEO](#)



## Join us In-Person or Virtually for the FDA Externally-Led Patient-Focused Drug Development Meeting

Thursday, June 22, 2023 | 12:00 - 4:30 p.m. EST

Bringing **Together** the **PWS Patient Voice**

Don't miss the chance to be part of a historic conversation for our PWS community and have your voice heard! You can attend the FDA [Externally-Led Patient-Focused Drug Development \(EL-PFDD\)](#) meeting in-person on June 22, 2023, at the Hilton Orlando Buena Vista Palace by registering for the [National Convention](#) OR **virtually** via Zoom by clicking the button below. Participation, both virtually and in-person, is FREE for all!

[LEARN MORE HERE](#)

[REGISTER HERE TO ATTEND VIRTUALLY](#)



### Childcare Available During the EL-PFDD Meeting

If you are in need of childcare services during the EL-PFDD meeting, let us know! We will have caregivers from our PWS Camps available for those interested. There is no age limit for who can utilize this childcare option. Your loved ones are also welcome to attend the EL-PFDD meeting, but we do want to make sure our parents are aware there may be information discussed that could be sensitive and/or uncomfortable for them to hear.

If you are interested in the childcare opportunity, please email us at [info@pwsausa.org](mailto:info@pwsausa.org) with the child's name and age.

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### How to Register to Attend the Meeting In-Person

You can register for the EL-PFDD meeting when you register for PWSA | USA's 37th National Convention. As shown in the image below, you will see on the 2nd page of our registration process the option to select how many people in your group will be attending the in-person EL-PFDD meeting. The meeting is FREE to attend and a boxed lunch will be available to those who register.

If you are interested in attending and have **already** registered for the 37th National Convention, simply click on "*Modify my registration*" at the bottom of



the confirmation email you received, and select that you will be attending the EL-PFDD meeting (as pictured below).

**NOTE: If you do not register yourself and your guests to attend the in-person EL-PFDD meeting through our Convention registration website, you will not be able to receive a free lunch.**

If you have questions or experience any issues during the registration process, contact us at [info@pwsausa.org](mailto:info@pwsausa.org) or (941) 312-0400.

## Additional Item

### Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting

Free

On Thursday, June 22, 2023, in conjunction with our PWSA | USA National Convention in Orlando, Florida, PWSA | USA will host an Externally-Led Patient-Focused Drug Development meeting (EL-PFDD) where the U.S. Food and Drug Administration (FDA) and other stakeholders will be in attendance. The meeting will take place between 12:00 - 4:30 p.m. EST at the Hilton Orlando Buena Vista Palace.

Select

This historic event is intended to help educate the Agency, the public, and other stakeholders about the challenges of living with Prader-Willi syndrome (PWS) and to underscore the unmet needs of the PWS community. Boxed lunches will be served to all attendees. **FREE TO ATTEND.**



PWSA | USA *Hope United Gala*  
AUCTION SNEAK PEEK



**Drew Brees**  
Autographed Football



**Arizona White Stallion**  
Ranch Getaway Stay



**Gucci Ophidia GC**  
Supreme Mini Bag



**Barbie 60th Celebration**  
DreamHouse Playset

***The Hope United Gala Auction site will be live soon for bidding. Please note, you don't need to attend the Hope United Gala to bid on the silent auction items.***



## Don't Miss the Party!

PWSA | USA is putting an exciting twist on our 2023 National Convention Gala event! On Friday, June 23, 2023, from 6:00 - 9:30 p.m. EST, we will host the highly anticipated **Hope United Gala**. Bring your best singing voice because our special entertainment will be performed by "Fun Pianos," with their amazing **Dueling Pianos for Prader-Willi syndrome**.

You can purchase tickets for the Hope United Gala and Night Under the Stars Gala when you register for the National Convention [here](#). We hope to see you there!

## Thank You Sponsors!

*If you are interested in sponsoring PWSA | USA's 2023 National Convention, contact Paige Rivard at [privard@pwsausa.org](mailto:privard@pwsausa.org).*

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Nexus Children's Hospital - The Woodlands  
Novo Nordisk  
OT4B  
Prader-Willi Homes

EL-PFDD SPONSORS

The Steele Family  
Jamie and Tiffany



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Prader-Willi Syndrome Association of Colorado  
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PWSA of Ohio  
Texas Prader-Willi Association  
Utah Prader-Willi Syndrome Association

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**Hope Partner**

Gedeon Richter  
Mainstay Life Services  
OT4B  
Sir Speedy



**ADVOCACY**

**Learn More About the EL-PFDD Meeting During Open  
Office Hours with Dorothea Lantz!**

TODAY kicks off **Open Office Hours** with PWSA | USA's Community Engagement Director Dorothea Lantz to discuss the EL-PFDD Meeting. The open office hours will take place **June 2nd, June 9th, and June 16th from 4:00 - 6:00 p.m. EST** and are for anyone who has questions about the EL-PFDD or would like assistance in crafting their story.

**Use the link at the button below to join during the allotted open office hour dates and times.**





OPEN OFFICE HOURS ZOOM LINK



## FAMILY SUPPORT

### Adoption Spotlight



A family in Washington state is seeking to make an open adoption plan for their approximately 3-week-old baby who was just diagnosed with Prader-Willi Syndrome. The family is hoping to find an adoptive family who feels prepared to meet the child's needs throughout their life, and open adoption is very important to them, including having in-person visits from time to time. The baby is being discharged from the hospital with a feeding tube in place.

If you feel prepared to be considered for this situation, please email Leah

at Open Adoption & Family Services, [leah@openadopt.org](mailto:leah@openadopt.org), ideally by Wednesday, June 7, 2023.



## RESEARCH

**DEADLINE EXTENDED: Submit a Letter of Intent by July 1, 2023 to Receive Research Funding from PWSA | USA**



PWSA | USA is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with PWS. PWSA | USA is seeking to fund two projects that will each receive **\$25,000** for a one-year grant support.

Letters of Intent (LOI) submissions can be submitted to Paige Rivard at [privard@pwsausa.org](mailto:privard@pwsausa.org) through **Saturday, July 1, 2023 at 12:00 p.m. EST**. Learn more by clicking the button below.

**LEARN MORE HERE**

**Kasey Bedard, PhD, BCBA-D, Publishes Article to Share Findings from PWSA | USA Funded Research Project**



Behavior Analyst Kasey Bedard, PhD, BCBA-D, recently published an article to share the data collected through survey studies during the development phase of her PWSA | USA research funded project "Smart Start." Click the button below to read the full article, *Behavioral services for individuals with Prader-Willi Syndrome: An initial examination of experiences, needs, and wants of caregivers*.

[READ MORE HERE](#)

## Request for Caregivers of Children with PWS (ages 7-17) to Participate in Focus Group



Primary caretakers of children with PWS (between 7-17 years of age) who will be attending the 2023 PWSA | USA 2023 National Convention are needed to provide feedback on wearable devices during 90-minute focus groups, tentatively planned for Friday, June 23, 2023.

Families interested should contact either Dr. Ann Scheimann ([ascheim1@jhmi.edu](mailto:ascheim1@jhmi.edu)) or Dr. Jessica Duis ([Jessica.Duis@childrenscolorado.org](mailto:Jessica.Duis@childrenscolorado.org)) **no later than June 14, 2023**, for further

information. Thank you!

## YOU Can Help Determine the Future of Research for PWS

We are collecting testimonials from our PWS community ahead of the Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting. You can share your personal story, the struggles your family and loved one living with the syndrome have faced, or anything else you want others to consider.



**“**

**Have Your Voice HEARD!**

Submit a testimonial for the FDA EL-PFDD meeting

These testimonials will be included in our ***Voice of the Patient Report***. The report will be publicly accessible, meaning pharmaceutical companies can utilize it to develop protocols that best fit our community's needs. With this report, **WE** can assist with the development of drugs to help our entire community. Submit your testimonial by clicking the button below.



[SUBMIT A TESTIMONIAL HERE](#)

## PWSA | USA ANNOUNCEMENTS

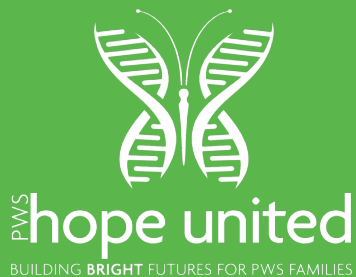
### PWSA | USA'S **SPOTLIGHT ON HOPE**





We want to give a special thank you to Maggie and Jonathan Andrews for hosting the AXES FOR HOPE fundraiser in Albuquerque, New Mexico last weekend to support PWSA | USA! If you were not able to attend but would still like to show your support, click the button below.

[SUPPORT AXES FOR HOPE](#)



If you're interested in hosting a PWS Hope United fundraiser, click the button below or email us at [hopeunited@pwsausa.org](mailto:hopeunited@pwsausa.org).

[VISIT THE PWS HOPE UNITED WEBSITE HERE](#)

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope they so desperately need. Thank you!

[Donate](#)



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



# PWSA | USA Bi-Weekly Pulse: June 16, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



**Vol. 77**

June 16, 2023

[www.pwsausa.org](http://www.pwsausa.org) | 941.312.0400

*Countdown to Convention*



DAYS TO GO!

**Registration is now CLOSED for PWSA | USA's 2023 National Convention Conferences and PWS Camps**

*You Can Still Register to Attend the In-Person FREE FDA Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting and Hope United Gala (find registration details below)!*



## Join us In-Person or Virtually for the FDA Externally-Led Patient-Focused Drug Development Meeting

Thursday, June 22, 2023 | 12:00 - 4:30 p.m. EST

Bringing **Together** the **PWS Patient Voice**

Don't miss the chance to be part of a historic conversation for our PWS community and have your voice heard! You can attend the FDA [Externally-Led Patient-Focused Drug Development \(EL-PFDD\)](#) meeting in-person on June 22, 2023, at the Hilton Orlando Buena Vista Palace by registering for the [National Convention](#) OR **virtually** via Zoom by clicking the button below. Participation, both virtually and in-person, is FREE for all!

[LEARN MORE HERE](#)

[REGISTER HERE TO ATTEND VIRTUALLY](#)

### How to Register to Attend the Meeting In-Person

Everyone is welcome to join us Thursday, June 22nd from 12:00 - 4:30 p.m. at the Hilton Orlando Buena Vista Palace for the in-person EL-PFDD meeting! The meeting is FREE to attend and a boxed lunch will be available to those who register.

If you are interested in attending and are **not** registered for the 2023 National Convention, click the button below to sign up for the in-person EL-PFDD meeting. If you have **already** registered for the 37th National Convention,

simply click "*Modify my registration*" at the bottom of the confirmation email you received, and select that you will be attending the EL-PFDD meeting.

**REGISTER TO ATTEND THE MEETING IN-PERSON**

***Please Note: If you do not register yourself and your guests to attend the in-person EL-PFDD meeting through our Convention registration website, you will not be able to receive a free lunch.***

If you have questions or experience any issues during the registration process, contact us at [info@pwsausa.org](mailto:info@pwsausa.org) or (941) 312-0400.



**PWSA | USA'S** *Hope United Gala*  
**AUCTION IS NOW LIVE FOR BIDDING!**

***Anyone can bid on our amazing Hope United Gala Auction items!  
Click the images below to check out just a few of the 40+  
experiences, sports memorabilia, jewelry, baskets, and more.  
There's truly something for everyone to enjoy.***

**[CLICK HERE TO VISIT THE AUCTION SITE](#)**



Greece & Greek Islands Odyssey



iPad 10th Generation



Kendra Scott Amethyst Necklace



Drew Brees Autographed Football





Lots of LEGO Prize Pack!

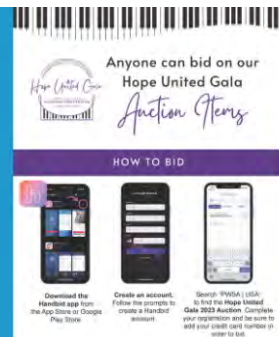


Yellowstone Superfan Basket:  
Whiskey & Cowhide Crossbody

## ANYONE can bid from ANYWHERE!

Download the Handbid App on your mobile phone and start bidding today. Click the button below to find instructions on how to download the Handbid app.

[CLICK HERE TO LEARN MORE](#)



## There's Still Time to Purchase Hope United Gala Tickets!

PWSA | USA is putting an exciting twist on our 2023 National Convention Gala event! On Friday, June 23, 2023, from 6:00 - 9:30 p.m. EST, we will host the highly anticipated **Hope United Gala**. Bring your best singing voice because our special entertainment will be performed by "Fun Pianos," with their amazing **Dueling Pianos for Prader-Willi syndrome**.

You can purchase tickets for the Hope United Gala [here](#). We hope to see you there!



**[PURCHASE HOPE UNITED GALA TICKETS HERE](#)**

## **Thank You Sponsors!**

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handbid

##### Hope Partner

Gedeon Richter  
Mainstay Life Services  
OT4B  
Sir Speedy



## ADVOCACY

PWSA | USA Advocates Made Their Voices Heard on

## Capitol Hill!



This week, nine of our dedicated PWS advocates journeyed to Washington, D.C. to work on behalf of our PWS community. They joined a group of more than 100 rare and chronic disease patients and caregivers, coordinated by PatientsRising, to engage with members of Congress and make their voices heard.

They shared stories about their experiences with co-pay accumulators, pharmacy benefit managers and QUALY. In addition, they continued to gather support for the issues specific to our asks from our D.C. Fly-In last September. They met with eight offices, interacted personally with four members of Congress from all over the country, and participated in vital discussions regarding the FDA and CMS (Center for Medicaid & Medicare Services) on the importance of patient experience in the accelerated drug approval process.

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### Congressman Paul Tonko Receives PWSA | USA's 2023 Legislative Champion Award

Finally, our advocates were able to meet in person with Congressman Paul Tonko (D-NY) and award him our **PWSA | USA Legislative Champion Award for 2023!** This past year, Congressman Tonko was responsible for fulfilling the first of three asks from our D.C. Fly-In last September, filing legislation dedicating May 15th, and every May 15th thereafter, as Prader-Willi Syndrome Awareness Day in the United States of America.

Not only did he sponsor this resolution for PWSA | USA, he is also supportive of our additional asks from the fly-in, including having PWS listed as a recognized topic area for the Department of Defense's Congressionally Designated Medical Research Program. During a recent trip to Capitol Hill only days ago, Congressman Tonko expressed his interest in supporting our third and final ask





from our fly-in last year, which has been re-introduced by Representative's Josh Gottheimer (D-NJ) and Don Bacon (R-NE) for the 2023 Congress. This ask is particularly special to us because our organization, alongside other stakeholders, was helpful in brainstorming its creation several years ago. Although those of you who were with us in D.C. last year knew it as the Orphan Drug Mitigation Act, it is currently being proposed in the 2023 Congress as "Leo's Law." It proposes that pharmaceutical companies who

worked to create therapies in the rare disease space during COVID receive a claw back of an additional 6 months of exclusivity when their drug comes to market. As if all of this wasn't enough, Congressman Tonko has committed his assistance in ensuring PWS is added to Social Security's list of compassionate allowances.

*"His unwavering commitment to help our PWS community thrive is unparalleled and it was with great pleasure that I and several of our fierce PWSA | USA advocates presented him with PWSA | USA's first ever Legislative Champion award in person this week on Capitol Hill,"* said Community Engagement Director Dorothea Lantz.

PWSA | USA would like to encourage all our families who reside in Congressional District 20 (upstate New York) to email his office and thank him for his support.



## FAMILY SUPPORT

### It's Not Too Early to Schedule School Trainings for the 2023-2024 School Year!

PWSA | USA's Family Support team is passionate about ensuring educational teams are knowledgeable about Prader-Willi syndrome. Each year, they provide trainings around the country, both virtually and in-person, to assist those who support individuals affected by Prader-Willi syndrome (PWS).

The 2022-2023 school year may have just ended for most students but now is the time to start scheduling for the 2023-2024 school year. Encourage your school district to contact PWSA | USA to schedule their annual training by emailing [info@pwsausa.org](mailto:info@pwsausa.org) or calling 941-312-0400.





## RESEARCH

### Request for Caregivers of Children with PWS (ages 7-17) to Participate in Focus Group



Primary caretakers of children with PWS (between 7-17 years of age) who will be attending the 2023 PWSA | USA 2023 National Convention are needed to provide feedback on wearable devices during 90-minute focus groups, tentatively planned for Friday, June 23, 2023.

Families interested should contact either Dr. Ann Scheimann ([ascheim1@jhmi.edu](mailto:ascheim1@jhmi.edu)) or Dr. Jessica Duis ([Jessica.Duis@childrenscolorado.org](mailto:Jessica.Duis@childrenscolorado.org)) **no later than June 19, 2023**, for further information. Thank you!

**DEADLINE EXTENDED: Submit a Letter of Intent by July 1, 2023 to Receive Research Funding from PWSA | USA**



PWSA | USA is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with PWS. PWSA | USA is seeking to fund two projects that will each receive **\$25,000** for a one-year grant support.

Letters of Intent (LOI) submissions can be submitted to Paige Rivard at [privard@pwsausa.org](mailto:privard@pwsausa.org) through **Saturday, July 1, 2023 at 12:00 p.m. EST**. Learn more by clicking the button below.

[LEARN MORE HERE](#)

## Acadia Pharmaceuticals Announces Next Phase for ACP-101 (Intranasal Carbetocin) After Meeting With FDA



announcement by reading Acadia Pharmaceuticals' full press release at the button below.

This week, Acadia Pharmaceuticals made the announcement the drug company plans to begin Phase 3 of ACP-101, intranasal carbetocin, later this year after a recent meeting with the U.S. Food and Drug Administration (FDA). ACP-101 is currently being studied to treat hyperphagia in Prader-Willi syndrome.

Learn more about this

[READ MORE HERE](#)

## Calling All PWS Medical Providers!



The PWS clinic at Children's Mercy Kansas City is seeking input from medical providers who treat infants less than 1 year of age with PWS, related to sleep assessments and management of growth hormone therapy.

Please consider completing the REDCap Survey by clicking the button below.

[TAKE SURVEY HERE](#)

*Details about the REDCap Survey on behalf of Children's Mercy Kansas City:*

### **Sleep Assessments and Management of Growth Hormone Therapy in Infants with Prader-Willi Syndrome**

#### **Background**

Current consensus guidelines encourage polysomnogram (PSG, sleep study) prior to growth hormone (GH) start in individuals with PWS. While the exact ideal age of GH start in children with PWS is not known, some experts and caretakers are advocating for GH start as soon as possible in infancy. However, there are challenges with obtaining and interpreting PSG early in infancy. Therefore, alternative assessments of sleep related breathing disorders may be necessary.

#### **Purpose**

To gather expert opinion on current clinical practices as they relate to baseline sleep assessment and GH start/management in infants younger than 1 year of age with PWS.

### Intended audience

Medical providers of infants < 1 year of age with PWS.

### Time commitment

5-10 minutes

## PWSA | USA ANNOUNCEMENTS

### PWSA | USA'S **SPOTLIGHT ON HOPE**



We want to share a BIG congratulations to Robin, who is living with PWS, for graduating from an online program through Southern University of New Orleans (SUNO) and finishing in five semesters!

If you'd like to share a Spotlight on Hope with us, click the button below.

**SHARE YOUR STORY!**

## Foster Care Needed for 9-Year-Old Boy Living with PWS

Kyle (not his real name) is a delightful, and very social, 9-year-old boy with PWS and related conditions – including hypothyroidism, obstructive sleep apnea, morbid obesity and albinism – who is in need of a loving foster family. He currently resides in a group setting outside of Philadelphia, PA where, with the benefit of structure, close supervision and very restricted access to food, he is



doing well and losing weight. While he will take food when the opportunity presents itself or engage in skin picking, at his current placement these behaviors have been infrequent.

Kyle benefits from behavioral health treatment at his placement and enjoys participating in this. At times, Kyle struggles with following directions and may get upset when he does not get his way and has difficulty making choices. Many of Kyle's behaviors can be attributed to his PWS diagnosis. But Kyle is also

a very active and inquisitive child who enjoys reading and being read to, watching scary movies, singing in sing-a-longs, going for walks and swimming. He attends the local public school where he is in a special education classroom. Kyle's teacher reports that she is pleased with his behavior, as well as his academic progress. Because food is inaccessible to Kyle in this setting, his teacher reports no problems in this regard.

A foster family with experience caring for individuals with PWS is being sought for Kyle. If you are interested in learning more about Kyle – who has a great personality and enjoys talking to people and interacting with his peers – please contact his child advocate attorney Shannon Sherwood at [ssherwood@sccalaw.org](mailto:ssherwood@sccalaw.org) or his child advocate social worker Cathy Behar at [cbehar@sccalaw.org](mailto:cbehar@sccalaw.org).

**Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope they so desperately need. Thank you!**

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



# PWSA | USA Special Edition Pulse: June 30, 2023

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PWSA | USA 2023  
NATIONAL CONVENTION



Rare Disease Advisors: Photo by Terri Airov

**THANK YOU** to everyone who attended PWSA | USA's 2023 National Convention, and to those who presented, volunteered, and sponsored this unforgettable event! We sincerely appreciate you making the trip to Orlando and participating in our Medical and Scientific Conference, Professional Providers Conference, Family Conference, PWS Camps, FDA Externally-Led Patient-Focused Drug Development Meeting, and Hope United Gala. We are inspired by our community's unwavering commitment to improving the lives of our loved

ones.

*The impact of this Convention will extend far beyond the walls of our session rooms. It will ripple through our homes, schools, workplaces, and communities,*

*influencing change and fostering a more inclusive society. **Together, we are United in Hope!***

*Paige Rivard*

Paige Rivard, MBA | CEO  
Mom to Jake (13) living with PWS

## What PWSA | USA Attendees are Saying About the 2023 National Convention

*We are so grateful for the outstanding Conference! All who participated were impressed by the thoughtful program, the informative sessions, and the special bond created among us all. Importantly, the powerful interactions did not stop when the meetings were over: the event gave rise to new collaborations united in the Hope to bring safe and effective drugs to those with PWS!*

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*The event was a tremendous success, and having the opportunity to attend the Gala was a real honor. Listening to the accounts of those with PWS and their families was powerful and moving, but equally powerful was seeing the PWS community come together so warmly at the Gala. I briefly saw the kids' Gala set-up before I came over, and it looked like the kids were going to have an amazing time as well.*

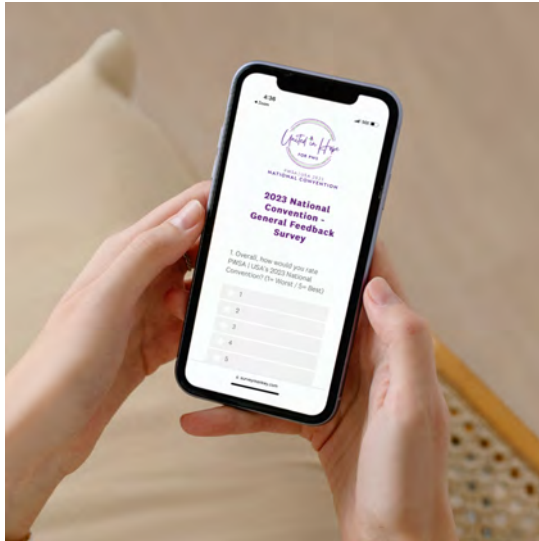
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*I have attended numerous medical conferences, family conferences, EL-PFDD meetings, and galas across a vast range of therapeutic areas (although never all in the same week), and this surpassed them all. The details of the conference were also very inclusive and accessible, including the clinical trial panel, siblings panel, the siblings camp, Dad's Den, and ASL translator. Numerous families that I met were so thankful for the opportunity to be connected with their "second family."*

---

*Congratulations on an amazing meeting! The sessions were both informative and impactful. I honestly cannot think of anything that should have been thought of that was not addressed. The Gala was outstanding and so much fun! Thank you for a wonderful meeting.*

## Don't Forget to Participate in our 37th National Convention Surveys



For those who attended, we encourage you to click the buttons below to participate in our general Convention and PWS Camp surveys (if you haven't done so already). Your feedback will help us prepare for future Conventions!

[General Feedback Survey](#)

[PWS Camp Feedback Survey](#)

## Send in Your Convention Photos to PWSA | USA!



We are excited to share pictures taken at our 37th National Convention, many of which have been provided by those who joined us in-person! Click the button below to view the gallery.



If you would like to submit your own images, please email them to [communications@pwsausa.org](mailto:communications@pwsausa.org).

[VISIT THE GALLERY HERE](#)



## Convention Session Recordings will be Available Soon

Be on the lookout for an email with a link to view these recordings. We appreciate everyone's patience as we work to make them available!



## Congratulations to PWSA | USA's 2023 Volunteer Award Recipients!

[CLICK HERE TO READ MORE](#)



## There's Still Time to Submit a Testimonial for our Voice of the Patient Report



Thank you to those who attended our FDA Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting, both in-person and virtually. A special thank you to our panelists and those who shared their PWS journey - the ups, downs, and everything in-between. A recording of the EL-PFDD meeting will be available for viewing soon.

The testimonials shared during the meeting and those collected via PWSA | USA's website will be used to create a *Voice of the Patient Report*. The report will be publicly accessible, meaning pharmaceutical companies can utilize it to develop protocols that best fit our community's needs. With this report, **WE** can assist with the development of drugs to help our entire community. You can share your personal story, the struggles your family and loved one living with the syndrome have faced, or anything else you want others to consider at the button below.



Submit a Testimonial for the  
"Voice of the Patient" Report

[CLICK HERE](#)

## PWS Word Cloud

During the EL-PFDD meeting, attendees were asked to share what significant symptoms of PWS impact their lives aside from hyperphagia. The below word cloud was created with the answers provided. Click the button below to view a larger version of this word cloud. We appreciate everyone who participated in this exercise, which will be included in our Voice of the Patient Report.



[VIEW THE WORD CLOUD HERE](#)

## Special 2nd Chance Offer to Purchase Hope United Gala AmFund Trips!

If you're still interested in purchasing one of the many amazing auction trips from our Hope United Gala, there's now a second chance to do so. A portion of the proceeds will benefit PWSA | USA's many programs. To claim your trip, call Barbara with AmFund at (407) 761-3012 or email [Belyea@amfund.org](mailto:Belyea@amfund.org).

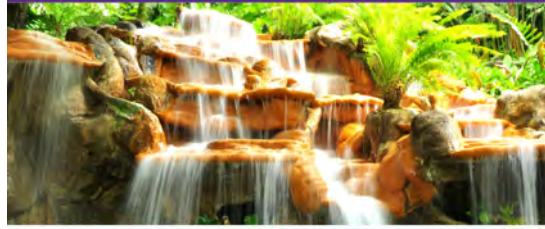
**Offer expires July 1, 2023!**

[LEARN MORE HERE](#)

9-day/8-night Greece and Greek Island Odyssey



7-day/6-night Costa Rica



7-day/6-night Alaska Cruise "Call of the Wild"



7-day/6-night Sun-Splashed Adventure in Spain





7-day/6-night Fire and Ice – Iceland



4-day/3-night I Love New York



4-day/3-night San Francisco/Napa



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