PWSA | USA Bi-Weekly Pulse: May 5, 2023

Enhancing the Quality of Life and Empowering those Affected by PWS

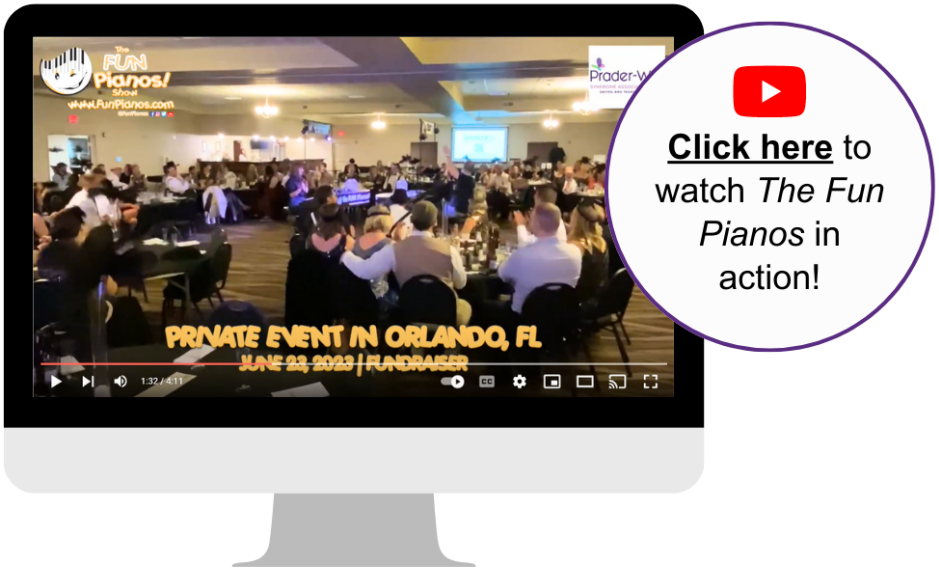
PWSA | USA PULSE

Vol. 74

May 5, 2023

www.pwsausa.org | 941.312.0400

Get Your Tickets TODAY for PWSA | USA's Hope United Gala - Dueling Pianos for PWS



Click here to watch *The Fun Pianos* in action!

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**.

Attendees will enjoy a buffet-style dinner and drinks. You will also have the chance to bid on must-have items in our silent and live auction. Your loved ones living with PWS and their siblings are welcome to attend, or they can enjoy the Night Under the Stars Gala, which will run concurrent to the Hope United Adult Gala. We will also offer childcare for those who prefer that option.

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!

Hope United Gala Attire: Business Casual

LEARN MORE HERE

PWS Families in Michigan!

The Prader-Willi Association of Michigan is offering scholarships for YOU to attend the 37th National Convention

The Michigan chapter of PWSA | USA has scholarships available for Michigan residents interested in attending the 2023 PWSA National Convention.
If you would like more information about this opportunity and are interested in receiving the scholarship forms, please email Judy Mulder at jmulder122@gmail.com.
Don't delay, the scholarship application deadline is next week - Wednesday, May 10th!

Important Upcoming 37th National Convention Deadlines

37th National Convention Hotel Room Block Deadline: **May 16, 2023**

Place your 37th National Convention Merchandise Orders by: **May 21, 2023**

PWS Camps (for children/adults living with PWS and their siblings) Registration Deadline: **May 31, 2023**

Early Bird Registration Pricing Ends: **June 1, 2023**

37th National Convention Conference Registration Deadline: **June 9, 2023**

Hope United Gala Ticket Purchase Deadline: **June 9, 2023**

In-Person EL-PFDD Meeting Registration Deadline: **June 9, 2023**

Reminder: Submit your story for the EL-PFDD Voice of the Patient Report

Reserve your hotel room for the 37th National Convention by May 16, 2023 to get a spot in our group room block!

BOOK NOW

Thank You Sponsors!

If you are interested in sponsoring PWSA | USA's 2023 National Convention, contact Paige Rivard at privard@pwsausa.org.

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The Steele Family
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PWSA CHAPTER SPONSORS

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Minnesota Prader-Willi Syndrome Association
Prader-Willi Syndrome Association of New England
PWSA of Ohio
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Utah Prader-Willi Syndrome Association

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HOPE UNITED GALA SPONSORS

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Hope Partner
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Gedeon Richter
Mainstay Life Services
OT4B
Sir Speedy

Family Support Campaign Update

When you join other members of our community and make a tax-deductible donation to PWSA |

SAVE THE DATE

Upcoming Events >>>

ECHO 4 PWS - Heathcare Provider Series

USA's 2023 **Family Support Campaign** through May 31st, YOUR IMPACT WILL BE DOUBLED up to our first $20,000, thanks to a match from a generous PWS parent.

As we work together to ensure every member of our Prader-Willi syndrome community has access to the support, expertise, and resources needed to help our loved ones thrive, we need your help. Whether you have just begun your PWS journey or are well along your way, join us to help ensure PWSA | USA's responsive and ever-evolving services and resources are always available to all.

Did you know you can DOUBLE your donation to PWSA | USA through our employer matching donation program?

See if your employer will match your donation!

Search company name...

First name | Last name

Many employers sponsor matching gift programs to match charitable contributions made by their employees to deserving nonprofit organizations. When you donate to our 2023 Family Support Campaign, check to see if your employer has a matching gift program!

"Genetics in PWS 101"

When: May 16, 2023

Learn More Here

PWS Jeopardy!

When: May 15, 2023
Games at 7:30 pm EST and 9:00 pm EST

Register Here

37th National Convention

When: June 21 - 24, 2023

Register Here

Hope United Family Support Challenge: Current Leaderboard

Sujeiri Colon	$5,000
Jane Rosen	$3,018
Laurie Skinner	$965
Stacy Ward	$850
Nancy Behringer	$760
Jennifer Hill	$485
Sarah Kasaby	$405
Amy McDougall	$250
Anne Fricke	$155

Thanks to our amazing **Hope United Family Support Challenge** fundraisers and their supporters, we are more than 80% of the way to reaching our fundraising goal for this challenge! These donations will directly benefit PWSA | USA's lifesaving family support programs.

There's still time to join the effort! Click the button below to be directed to our PWS Hope United website. You can then select "Get Started" to create your Family Support Challenge page today! If you have questions, please contact us at hopeunited@pwsausa.org.

JOIN THE FAMILY SUPPORT CHALLENGE HERE

ADVOCACY

Request a Proclamation or Resolution for PWS Awareness Month (May)

One great way to help raise awareness for PWS during the month of May is by requesting a proclamation or resolution from your local and/or state government.

PWSA | USA's Director of Community Engagement Dorothea Lantz shares what steps need to be taken to have May recognized as PWS Awareness Month in your area.

Click the button below to get the full details and make sure you share your proclamation journey with us at advocacy@pwsausa.org!

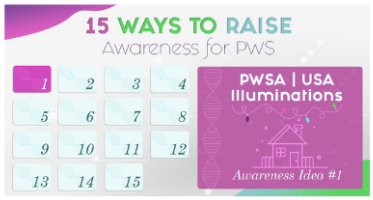
LEARN MORE HERE

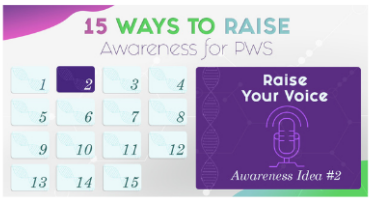
15 Ways to Raise Awareness for PWS in May

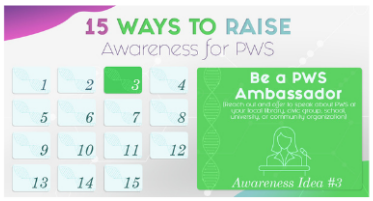
There are many additional ways you can help raise awareness for Prader-Willi syndrome in May and all year long! We have highlighted 15 easy ways to take action, including thanking your healthcare providers, becoming a volunteer or family mentor, and hosting your own Wear Jeans for Rare Genes fundraiser!

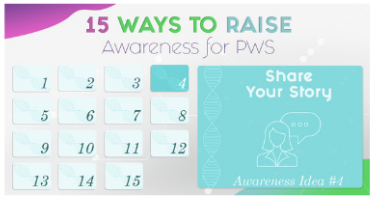
Click on the button below to learn more.

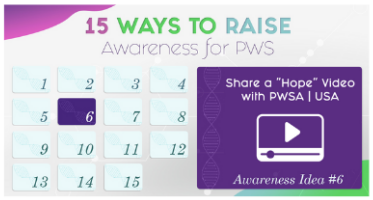
LEARN MORE HERE











FAMILY SUPPORT

PWS Jeopardy

To celebrate and raise awareness for PWS Awareness Month, bring your family, friends, and brain power for a fun night of PWS Jeopardy.

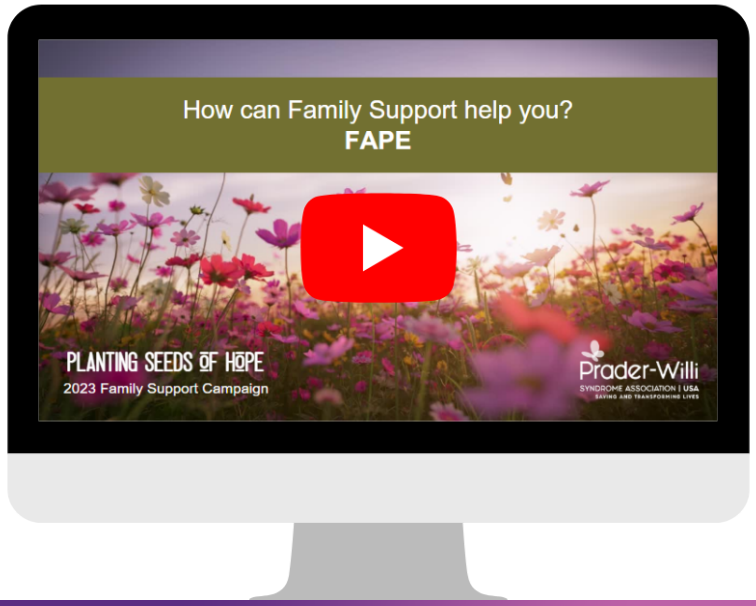
FREE for all to attend!

When: Monday, May 15, 2023
Games at 7:30 pm EST and 9:00 pm EST
Where: Zoom

Click Here to Register & Learn More

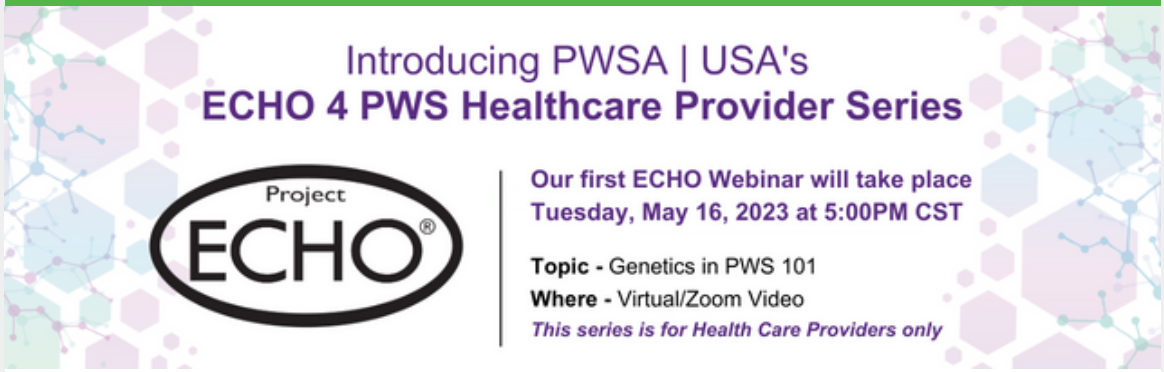
How Can Family Support Help You?

Throughout PWSA | USA's Family Support Campaign, Director of Family Support Stacy Ward, MS, will share several ways our team can help YOU, families and individuals in our community affected by PWS. Click the image below to view the next video in this series, *FAPE (Free and Appropriate Public Education)*, and visit our Family Support resource video library **HERE**.



RESEARCH

PWS Parents and Caregivers: Tell Your Healthcare Professionals About PWSA | USA's New ECHO Series



PWSA | USA's first **Healthcare Provider Project ECHO Series** webinar will take place May 16, 2023 at 5:00 p.m. CST. The topic discussed will be

“Genetics in PWS 101” presented by Jessica Duis, MD, Associate Professor of Pediatrics and Genetics at Children’s Hospital Colorado, University of Colorado, followed by a 20-minute case study on PWS presented by Shawn McCandless, MD, Chair of the Department of Genetics and Metabolism at Children’s Hospital Colorado.

While this ECHO series is only for healthcare providers to attend, recordings of the webinars will be made available for our PWS families on our website. We encourage you to share this opportunity with the healthcare professionals in your life! You can download our ECHO 4 PWS flyer at the button below.

DOWNLOAD THE FLYER HERE

REGISTRATION LINK

PWSA | USA ANNOUNCEMENTS

Spread HOPE This PWS Awareness Month

Calling all PWS families! 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 on our social media pages throughout PWS Awareness Month to inspire others AND in a special video at our 37th National Convention.

Click here to upload your video and contact communications@pwsausa.org with any questions.

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

PWSA | USA Bi-Weekly Pulse: May 19, 2023

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
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Vol. 75

May 19, 2023

www.pwsausa.org | 941.312.0400

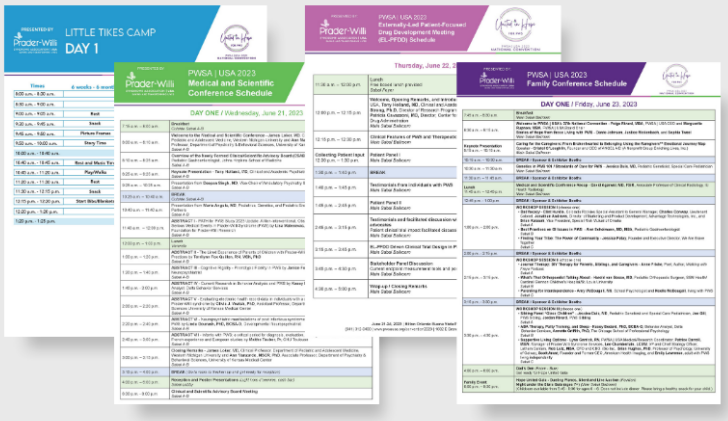
Countdown to Convention

32

DAYS TO GO!

Register for the 2023
National Convention **HERE!**

PWSA | USA's 37th National Convention Detailed Schedules are Now Available for Download!



CLICK HERE TO VIEW AND DOWNLOAD THE 2023 CONVENTION SCHEDULES

With about one month left until we're back together in-person, we are excited to share our **2023 National Convention detailed schedules**! By clicking the image above, you will find the Medical and Scientific Conference, Professional Providers Conference, Family Conference, Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting, and PWS Camp schedules.

Each gives an in-depth look into the daily opportunities you'll be able to experience throughout Convention, breaking down our amazing speakers and sessions, as well as the exciting new additions to this year's event.

Have Your Voice Heard by Members of the FDA!

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!

CLICK HERE TO ATTEND THE EL-PFDD MEETING VIRTUALLY

This Sunday, May 21st, is the LAST DAY to Order 2023 Convention Merchandise in Time for the Event!

Show your PWS Pride at the June 21-24, 2023 Convention with United in Hope and PWSA | USA swag, including shirts, sweatshirts, coffee mugs, hats, onesies, and more!

Place your orders by **this Sunday, May 21, 2023** to receive your items by June 15th - in time for the 2023 Convention. Shop our merchandise by clicking the button below.

CLICK HERE TO SHOP!

Convention & PWSA | USA Short and Long Sleeve Shirts

Convention & PWSA | USA Coffee Mugs

Convention & PWSA | USA Hats

Convention & PWSA | USA Sweatshirts

Convention & PWSA | USA Onesies

Convention & PWSA | USA Tote Bags

And so much more!

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Thank You Sponsors!

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OT4B
Prader-Willi Homes

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The Steele Family
Jamie and Tiffany

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Prader-Willi Syndrome Association of Colorado

Prader-Willi Syndrome Association of Colorado
PWSA of New Jersey

Partner in Hope Sponsors
Prader-Willi California Foundation
Prader-Willi Florida Association
Georgia Association for Prader-Willi Syndrome
Minnesota Prader-Willi Syndrome Association
Prader-Willi Syndrome Association of New England
PWSA of Ohio
Texas Prader-Willi Association
Utah Prader-Willi Syndrome Association

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Gedeon Richter
Mainstay Life Services
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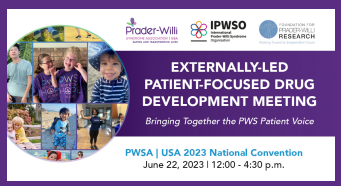
Sir Speedy

Family Support Campaign Update

Time is running out to make your tax deductible donation to PWSA | USA's 2023 Family Support

SAVE THE DATE

Upcoming Events >>>



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

Campaign!

When you join other members of our community and make a tax-deductible donation to PWSA | USA's 2023 **Family Support Campaign** through **May 31st**, YOUR IMPACT WILL BE DOUBLED up to our first $20,000, thanks to a match from a generous PWS parent.

As we work together to ensure every member of our Prader-Willi syndrome community has access to the support, expertise, and resources needed to help our loved ones thrive, we need your help. Whether you have just begun your PWS journey or are well along your way, join us to help ensure PWSA | USA's responsive and ever-evolving services and resources are always available to all.

DONATE HERE

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

Learn More Here

Register to Attend the Meeting Virtually Here

United in Hope FOR PWS
PWSA | USA 2023 NATIONAL CONVENTION

37th National Convention

When: June 21 - 24, 2023

Register Here

Hope United Family Support Challenge: Current Leaderboard

Sujeiri Colon	**$5,000**
Jane Rosen	**$3,018**
Jennifer Hill	**$1,685**
Laurie Skinner	**$965**
Stacy Ward	**$850**
Nancy Behringer	**$760**
Sarah Kasaby	**$405**
Teresa Kellerman	**$400**
Amy McDougall	**$250**

hope united
BUILDING BRIGHT FUTURES FOR PWS FAMILIES

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fundraising goal for this challenge! These donations will directly benefit PWSA | USA's lifesaving family support programs.

There's still time to join the effort! Click the button below to be directed to our PWS Hope United website. You can then select "Get Started" to create your Family Support Challenge page today! If you have questions, please contact us at hopeunited@pwsausa.org.

JOIN THE FAMILY SUPPORT CHALLENGE HERE

EVENTS

We are excited to share the upcoming fundraiser in New Mexico, benefitting PWSA | USA, **AXES FOR HOPE**! This great event, hosted by PWS parents Maggie and Jonathan Andrews, will take place Sunday, May 28, 2023, from 12:00 - 5:00 p.m. at ABQ Ax (5505 Osuna Road NE, Albuquerque, NM 87109).

AXES FOR HOPE will combine both competitive and social axe throwing to create an event where people with any level of experience can enjoy the experience and raise money to provide HOPE to families living with PWS. AXES FOR HOPE will feature Social AXE Throwing, an IATF Marathon League, a Silent Auction, Raffles and other exciting events throughout the day.

A special thank you to the Andrews family for their work in making this event happen!

"Jonathan and I have wanted to hold a fundraiser that would engage the community and excite people for quite some time. When the idea for AXES

FOR HOPE occurred to us, we knew we had a great opportunity to plan an annual event that would raise awareness and funds for PWS, while creating a fun and novel atmosphere for all involved. We are thrilled to get this event up and running for the first time at the end of the month."
- Maggie Andrews, mom to Chris (6) living with PWS

LEARN MORE HERE AND REGISTER HERE

READ THE AXES FOR HOPE FUNDRAISING SPOTLIGHT

PWS hope united
BUILDING **BRIGHT** FUTURES FOR PWS FAMILIES

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

VISIT THE **PWS HOPE UNITED** WEBSITE HERE

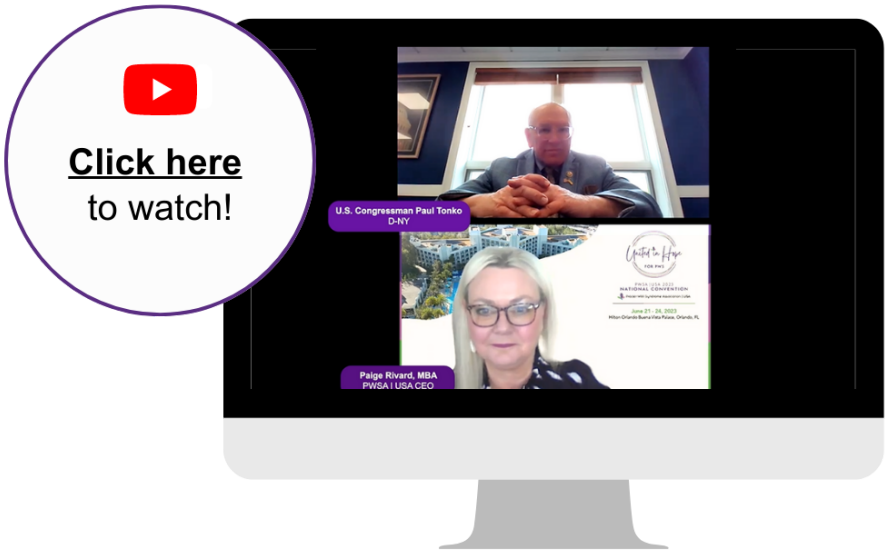
ADVOCACY

ICYMI: May 15th is OFFICIALLY PWS Awareness Day in the United States

On Monday, May 15th, PWSA | USA announced a historic milestone for our PWS community! U.S. Congressman Paul D. Tonko (D-NY) and Congresswoman Maria Elvira Salazar (R-FL) filed a joint resolution declaring **May 15, 2023, and every May 15th thereafter, Prader-Willi Syndrome (PWS) Awareness Day** in the United States of America!

Thank you to our advocates, especially those who shared our PWS Awareness Day ask on Capitol Hill last September, for working hard to make this milestone happen. We are hopeful this additional spotlight on our rare disease community will help further and open new doors for the advancement of treatments.

Watch PWSA | USA's PWS Awareness Day announcement video below, featuring Congressman Tonko and CEO Paige Rivard.



LEARN MORE HERE

Two PWSA | USA Advocates Received PWS Awareness Proclamations

After submitting a resolution request, PWSA | USA advocate Valerie Selinger received the exciting news that New Mexico's Governor Michelle Lujan Grisham declared May 15th as PWS Awareness Day across the state. Valerie shared the below quote on her Facebook page.

"When New Mexico Governor Michelle Lujan Grisham officially proclaims that May 15th is Prader-Willi Syndrome Awareness Day in New Mexico, you shout it from the rooftops!! Happy first official PWS Day to my fellow New Mexicans, and thank you Governor Michelle Lujan Grisham and Secretary of State Maggie Toulouse Oliver!"

- Valerie Selinger, mom to Isla living with PWS

PWSA | USA advocate Elaine Towle also received a proclamation from New Hampshire's Governor Chris Sununu declaring May as PWS Awareness Month across the state.

"As a member of PWSA | USA's Advocacy Workgroup, I am always inspired by the work of others. I decided to follow their examples and try to get a Proclamation for PWS Awareness Month from the Governor's office in New Hampshire. An acquaintance of mine with another rare disease guided me through the process, and happily, it was incredibly easy. Our state has a staff person in the Governor's office that handles all Proclamations, and there is even a webpage to make your request. The hardest part is the language for the Proclamation but fortunately, there are others in the PWS community who have done this and can help. You can also get language from PWSA | USA directly – that is what I did and it worked perfectly. Once I made my request, I waited several weeks and then followed up with an email – the Proclamation was ready several days later.

I am pleased to shine a little more light on the PWS community here in New Hampshire. My son is an adult so we don't have things like school events or even IEP meetings to talk about PWS. This is a great opportunity to raise awareness."
- Elaine Towle, mom to James living with PWS

Congratulations, Valerie and Elaine! Learn how YOU can request a proclamation or resolution with your local and state officials by clicking the button below.

LEARN MORE HERE

FAMILY SUPPORT

May is Better Speech and Hearing Month

Many of our loved ones living with PWS are impacted by speech and language barriers including reduced articulation, hypernasality or hypo nasality, slow rate

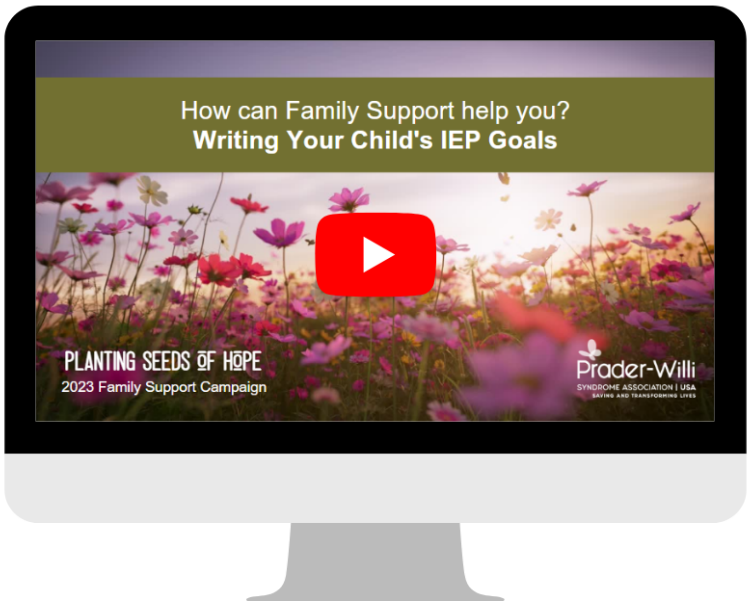
of speech, delayed receptive / expressive language, poor pragmatic skills, and imprecise articulation.

While parents can help stimulate language development and growth, a trained Speech and Language Pathologist (SLP) is needed to help individuals achieve their full potential. Since yesterday, May 18th, was nationally recognized as SLP Appreciation Day, we encourage our community members to show your appreciation to the SLPs on your team!

LEARN MORE HERE

How Can Family Support Help You?

Throughout PWSA | USA's Family Support Campaign, Director of Family Support Stacy Ward, MS, is sharing several ways our team can help YOU, families and individuals in our community affected by PWS. Click the image below to view the next video in this series, *Writing Your Child's IEP Goals*, and visit our Family Support resource video library **HERE**.

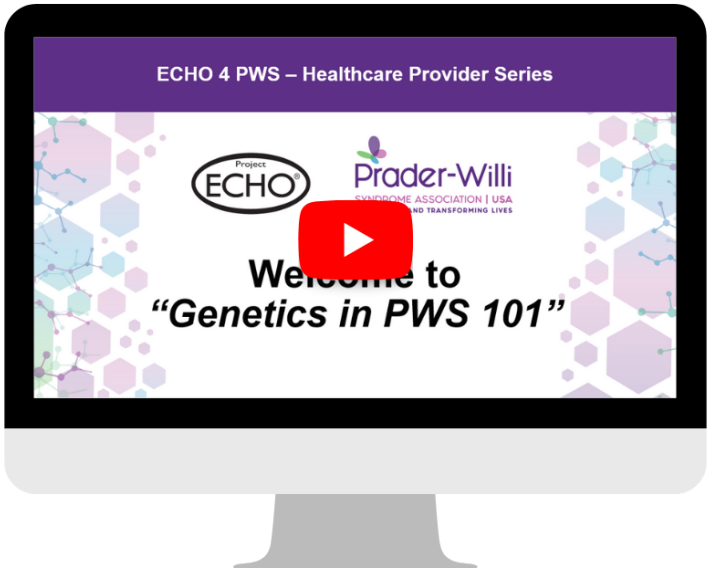


RESEARCH

PWSA | USA's ECHO 4 PWS "Genetics in PWS 101" Webinar Recording Now Available

We held our first **Healthcare Provider Project ECHO** webinar this week, which focused on “Genetics in PWS 101." The recording is now available for our community to view and features speakers Jessica Duis, MD, Associate Professor of Pediatrics and Genetics at Children’s Hospital Colorado, University of Colorado and Shawn McCandless, MD, Chair of the Department of Genetics and Metabolism at Children’s Hospital Colorado.

Thank you to Dr. Duis and Dr. McCandless for taking the time to educate healthcare professionals in the PWS space! Learn more about PWSA | USA's ECHO 4 PWS series by clicking the button below.



LEARN MORE HERE

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

Attention primary caretakers of children with PWS, between 7-17 years of age, who will be attending the 2023 PWSA | USA National Convention! You are asked to participate in a 90-minute focus group, tentatively planned for Friday, June 23, 2023, to provide feedback on wearable devices. The location and time is still being determined.

Families interested should contact either Dr. Ann Scheimann (ascheim1@jhmi.edu) or Dr. Jessica Duis (Jessica.Duis@childrenscolorado.org) no later than June 7, 2023, for further information. Thank you!

PWSA | USA ANNOUNCEMENTS

Spread HOPE This PWS Awareness Month

Calling all PWS families! 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 on our social media pages throughout PWS Awareness Month to inspire others AND in a special video at our 37th National Convention.

Click here to upload your video and contact communications@pwsausa.org with any questions.

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

PWSA | USA May Special Edition Pulse

www.pwsausa.org | (941) 312-0400

Donate

PWSA | USA Special Edition

PULSE

MAY 26, 2023

Have Your Voice be HEARD by Members of the FDA!

Prader-Willi SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

IPWSO International Prader-Willi Syndrome Organisation

FOUNDATION FOR PRADER-WILLI RESEARCH
Working Toward an Independent Future

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

You have the opportunity to share your PWS journey, the ups, downs, and everything in-between, with several U.S. Food and Drug Administration (FDA) representatives at PWSA | USA's 37th National Convention! The **Externally-Led Patient-Focused Drug Development (EL-PFDD)** meeting is **FREE** for **ALL** to attend, and will take place Thursday, June 22, 2023, from 12:00 - 4:30 p.m. EST both in-person at the Hilton Orlando Buena Vista Palace and virtually via Zoom. It will offer an opportunity for our families, healthcare professionals, and other PWS stakeholders to come together and **advocate** for our loved ones living with PWS.

YOU have the chance to
be part of history.

This is the **FIRST TIME** an FDA EL-PFDD meeting will take place specifically for the PWS community. It is an incredible opportunity to get our message across to those who can enact real change.

YOU have the chance to
make a real impact.

Our loved ones living with PWS need us to step up and show up when advocacy opportunities arise. THIS IS A BIG ONE! The testimonials shared during the meeting and those collected in advance 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.

Learn more about the EL-PFDD meeting by clicking the image below.

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.

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 or (941) 312-0400.

Register for the 37th National Convention Here

Additional Item

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

Free

Select

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.

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.*

How to Register to Attend the Meeting Virtually

In an effort to have as many people as possible join this historic conversation, we have added the option to allow our community to attend the EL-PFDD meeting virtually via Zoom. Click the button below to be directed to our virtual registration form. Once you fill out your information and select "Register," you will receive a calendar invitation. Make sure you save this invite as it will remind you to remotely join the meeting on Thursday, June 22, 2023 from 12:00 - 4:30 p.m. EST. We hope to see you online!

Register to Attend the EL-PFDD Meeting Virtually Here

Childcare will be 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 with the child's name and age.

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

CLICK HERE

As stated above, we are collecting testimonials from our PWS community ahead of the 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. These testimonials will be included in our ***Voice of the Patient Report***, which becomes published papers.

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

Beginning next Friday, June 2nd, PWSA | USA's Community Engagement Director Dorothea Lantz will host open office hours 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.

EL-FDD Open Office Hours Link

Introducing Our EL-PFDD Meeting Panelists

Andrea Warren

Charles Conway

Jamie Cox

Jennifer Garzia

Brian Kalasek

Lisa Matesevac

Sue Colon

Amy McDougall

Vonnie Sheadel

Justice Rickenbach

Victor Penta

Thank You

to our EL-PFDD Meeting Sponsors

EVERYLIFE FOUNDATION FOR RARE DISEASES

HARMONY BIOSCIENCES

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The Steele Family
Jamie and Tiffany

Prader-Willi SYNDROME ASSOCIATION | USA
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