

Enhancing the Quality of Life and Empowering Those Affected by PWS



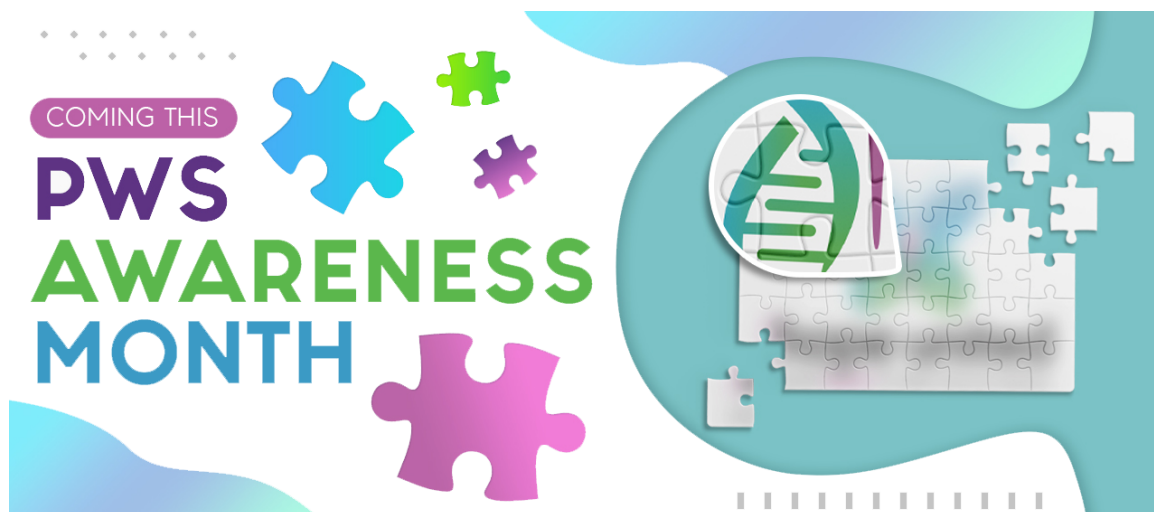
Vol. 48

April 1, 2022

www.pwsausa.org

[Donate](#)

941.312.0400



PWS Awareness Month begins in May, and with it, PWSA | USA will unveil an exciting surprise for our community on our social media pages! Make sure you follow us (@PWSAUSA) to see all of the puzzle pieces in the above graphic revealed. We can't WAIT to show you what we have in store!

Show Your PWS Pride!

NEW MERCH NOW LIVE!



With PWS Awareness Month just around the corner, PWSA | USA has added new merchandise to our online store! Show your PWS Pride during the month of May, and all year long, with our **Hope defined** and **PWS is RARE but HOPE is NOT** items, including shirts, sweatshirts, water bottles, coffee mugs, hats, onesies, and so much more. Get yours TODAY in time for PWS Awareness Month by clicking the button below!

[SHOP HERE!](#)

SAVE THE DATE

[Upcoming Events >>>](#)



"No Gimmes for Jimmy" Annual Charity Golf Outing

When: Friday, May 6, 2022

[Learn More Here >>](#)



PWANY 30th Annual Conference

When: May 20 - May 21, 2022

[Learn More Here >>](#)



11th Annual IPWSO Conference 2022

When: July 6 - 10, 2022

[Learn More Here >>](#)

PWS AWARENESS Spotlight

Do you know someone who deserves recognition for spreading PWS awareness? Throughout May, we want to spotlight those in our community for the efforts they are making and the strides they are taking to help inform others about our rare disease community.

If you know someone who regularly shares their story through social media or a blog, hosts an inspirational podcast, organizes events to support the PWS community - we want to shine a light on them! Simply fill out the form at the button below and submit an image if you have one to share.

For any questions, please reach out to us at communications@pwsausa.org. Thank you!

[SHARE YOUR SPOTLIGHT STORY HERE](#)

EVENTS



The **8th Annual Clint Hurdle Hot Stove Dinner** was a major success because of YOU, our PWS community! Thank you to those who sponsored the event,

joined us on the island, tuned in virtually, placed bids in our auction, and participated in the Coconut Helicopter Drop and raffle.

We want to give a special shout out to Clint and Karla Hurdle. It's because of their hard work and dedication to PWSA | USA this amazing event is even possible and raises necessary funds for our Family Support programs. We would also like to say a special thanks to our event partner, Leaving Legacies Foundation. We are sincerely grateful!



Find Your Voice: Advocating for PWS Health Care Webinar Series

Today at 2:30 p.m. EST, PWSA | USA hosted the first webinar of our four-part series - **"Find Your Voice: Advocating for PWS Health Care."** If you were not able to join, we will share the recorded presentation on our YouTube channel early next week. This webinar series provides helpful tools and resources on health care advocacy for our PWS community.

Our next webinar will take place on Friday, April 8, 2022 at 2:30 p.m. EST. The presentation will be led by PWSA | USA's Medical and Research Coordinator Lynn Garrick, who will discuss key advocacy points and common urgent health topics, including GI problems, fragile bones, skin picking, food seeking and weight management.

Learn more and register in advance by clicking the button below.

**LEARN MORE AND
REGISTER HERE**

Gavin's Sweet 16 Run Against PWS

**Thank you to everyone who
helped Joe reach his goal of
\$26,200! Can you help him get
to his new goal of \$32,000?**

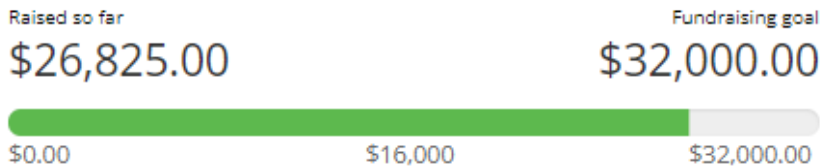
"When I began this special project to honor my brother Gavin just a few short months ago, it was my greatest hope to raise at least \$16,000 in



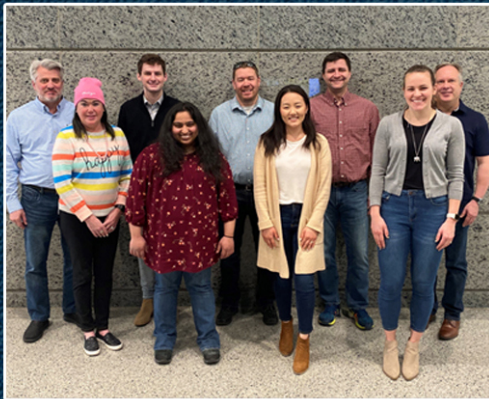
honor of his 16th birthday. I can't begin to thank everyone who helped us to get there AND blew our whole family away by helping us to reach our second goal (\$26,200) to reflect the 26.2 miles that make up the Boston Marathon's length. I am so inspired by the support and so grateful for the donations, the encouragement, and the momentum of this effort. With the marathon less than one month away, I am increasing my goal to **\$32,000** - double my original goal. If you have already donated.... THANK YOU! If you have not, join me in raising

awareness and much-needed funds in my *Race Against PWS!*"

[SHOW YOUR SUPPORT HERE](#)



Looking for a Fun and Easy way to Raise Money and Awareness
for PWS at your School or Workplace?



Thank You, Denison Parking!

We want to give a BIG thank you to Denison Parking for hosting a Wear Jeans for Rare Genes fundraiser at their workplace last Friday, in support of PWSA | USA. Their CEO even MATCHED the funds raised dollar for dollar!!

Wear JEANS FOR RARE GENES!

Download our customizable flyer and start planning your "Wear Jeans for Rare Genes" fundraiser today!

Wear jeans for rare genes **ALL YEAR LONG!** You can help PWSA | USA provide care for families in our community by simply wearing your jeans and donating a few dollars. Pick a date to host a "Wear Jeans for Rare Genes" event with your school, community group, coworkers, church, etc. to help raise money for PWSA | USA!

Find all of the information you need to start your own "Wear Jeans for Rare Genes" event, including a customizable letter and flyer, by clicking the button below. If you have

any questions, please reach out to us at events@pwsausa.org.

[LEARN MORE](#)



Save the Date | April 27, 2022

PWSA | USA's April Advocacy in Action Webinar will Feature Guest Speakers from the FDA

As our community continues down the ever-evolving road of drug trials to enhance the lives of those who have PWS, PWSA | USA would like you to join us as we bring you a live webinar featuring two speakers direct from the U.S. Food and Drug Administration (FDA)!

A registration link will be available soon. Learn more about this exciting opportunity by clicking the button below.

[LEARN MORE HERE](#)



PWS Emergency Preparedness Checklist

The weather seems to be getting wilder and fiercer. From devastating hurricanes to raging wildfires, natural disasters destroy lives and property. Disaster often happens with little to no warning, leaving you cut off from



the world for days.

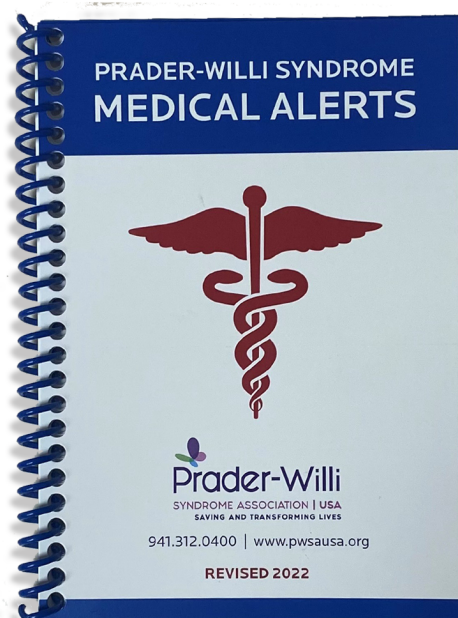
Being prepared is important to surviving and recovering from a disaster. PWSA | USA has put together an emergency checklist to help in your preparation to best support your loved one with PWS.

[DOWNLOAD THE EMERGENCY PREPAREDNESS CHECKLIST HERE](#)



RESEARCH

PWSA | USA's Updated Medical Alert Booklets Now Available for Download and Hard Copy Purchase!



PWSA | USA's newly updated Medical Alert Booklet is now available! This handy guide is a valuable resource for medical providers, family members, and caregivers worldwide.

The Medical Alert Booklet was developed by physicians and medical experts with expertise in Prader-Willi Syndrome (PWS). It alerts medical practitioners and guides treatment relating to complications that can develop in individuals with PWS. The booklet also includes a life-saving gastrointestinal (GI) chart, postoperative monitoring, and so much more.

By utilizing the information in the Medical Alert Booklet, families and

caregivers can better understand and advocate for the health needs of individuals living with PWS.

The Medical Alert Booklet is now available for download in a PDF format. Hard copies will be available in PWSA | USA's online store soon.

[DOWNLOAD THE MEDICAL ALERT BOOKLET](#)

What Type of Research Matters to You?



We want to know what PWS research matters to you most! Please take a moment to help inform our next phase of research efforts and related programming by taking a brief five-minute survey to share your thoughts and preferences for the type(s) of research PWSA | USA should support moving forward.

Find the survey link by clicking the button below.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

Join Our Team!

PWSA | USA is currently looking for an Executive Assistant to the CEO. We are headquartered in Sarasota, FL, but this will be a remote position.

The Executive Assistant to the CEO will provide a broad range of highly skilled administrative services, and must be effective, timely, efficient,



and proactive to ensure organizational objectives are accomplished. The Executive Assistant will also provide administrative services on occasion to other Directors within the organization as needed.

Read the full job description and find out how you can apply by clicking the button below.

[LEARN MORE 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](#)

8588 Potter Park Drive, Suite 500 Sarasota, FL 34238

Enhancing the Quality of Life and Empowering Those Affected by PWS



www.pwsausa.org

941.312.0400

Vol. 49

April 15, 2022

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We are excited to share another hint about PWSA | USA's upcoming special announcement, which will be revealed during **PWS Awareness Month**, specifically on May 15, 2022 - PWS Awareness Day! If you haven't done so already, make sure you follow us on Facebook (@PWSAUSA) to see all of the puzzle pieces and details about this brand new initiative. We can't WAIT to show you what we have in store!

SAVE THE DATE

[Upcoming Events >>>](#)

Show Your PWS Pride!

NEW MERCH NOW LIVE!



With PWS Awareness Month just around the corner, PWSA | USA has added new merchandise to our online store! Show your PWS pride during the month of May, and all year long, with our **NEW Ask Me... About PWS, Hope defined, PWS is RARE but HOPE is NOT** items, including shirts, sweatshirts, water bottles, coffee mugs, hats, onesies, and so much more. Get yours **TODAY** by clicking on the button below!



Find Your Voice: Advocating for PWS Health Care Webinar Series

When: Friday, April 22, 2022
& Friday, April 29, 2022

[Learn More Here >>](#)



"No Gimmes for Jimmy" Annual Charity Golf Outing

When: Friday, May 6, 2022

[Learn More Here >>](#)



PWANY 30th Annual Conference

When: May 20 - May 21, 2022

[Learn More Here >>](#)

SPECIAL UPDATE: PWSA | USA will have even more special items for sale next week! On Monday, we will share a link to purchase our "PWSA | USA All Star" baseball style t-shirts. These will be customizable, allowing you to print the name of your loved one or any text you choose on the back!



11th Annual IPWSO
Conference 2022

When: July 6 - 10, 2022

[Learn More Here >>](#)



Do you know someone who deserves recognition for spreading PWS awareness? Throughout May, we want to spotlight those in our community for the efforts they are making and the strides they are taking to help inform others about our rare disease community.

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inspirational podcast, organizes events to support the PWS community - we want to shine a light on them! Simply fill out the form at the button below and submit an image if you have one to share.

For any questions, please reach out to us at communications@pwsausa.org. Thank you!

[SHARE YOUR SPOTLIGHT STORY HERE](#)

EVENTS



We are less than two weeks away from the **2022 Sarasota Giving Challenge**! Make sure to mark your calendars for noon to noon on April 26 - 27, 2022.

Join the celebration by giving to your favorite nonprofit organization (which we know is us!). Click on the button below to find out more details.

[LEARN MORE](#)



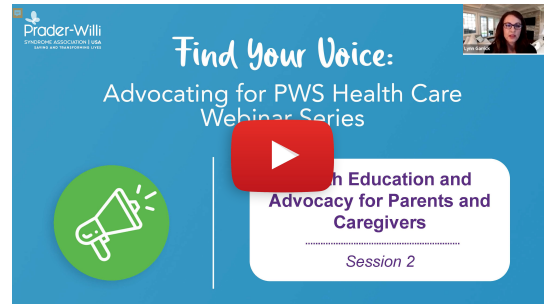
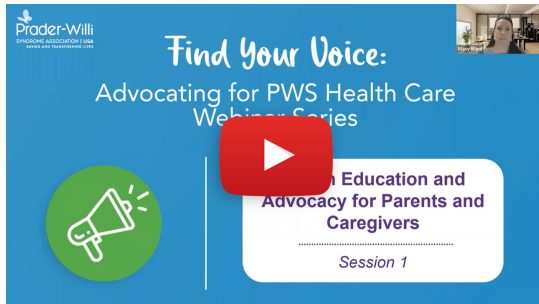
Join us April 22, 2022 and April 29, 2022 for valuable information around PWS health care advocacy! The **Find Your Voice: Advocating for PWS Health Care** webinar series provides helpful tools and resources on health care advocacy for our PWS community. You can find recordings of the first two webinars in this series by clicking on the images below.

Our next webinar will take place on Friday, April 22, 2022 at 2:30 p.m. EST. The presentation will be led by Barb Dorn, RN, BSN, who will discuss concerns for the hospitalized person with PWS (ER information, anesthesia, post-op monitoring, medication sensitivity, and food security).

Learn more and register in advance by clicking the button below.

**LEARN MORE AND
REGISTER HERE**

**Watch the April 1, 2022 and April 8, 2022 Find Your Voice Webinar
Recordings Below**



Gavin's Sweet 16 Run Against PWS



**Joe has reached his goal
\$32,000! Can you help him get
to \$35,000 before his race on
Monday?**

"When I began this special project to honor my brother Gavin just a few short months ago, it was my greatest hope to raise at least \$16,000 in honor of his 16th birthday. I can't begin to thank everyone who helped us to get there AND blew our whole family away by helping us to reach our second goal (\$26,200) to reflect the 26.2 miles that make up the Boston Marathon's length. I am so

inspired by the support and so grateful for the donations, the encouragement, and the momentum of this effort. With the marathon only a few days away, I am increasing my goal to **\$35,000**. If you have already donated.... THANK YOU! If you have not, join me in raising awareness and much-needed funds in my *Race Against PWS!*"

[SHOW YOUR SUPPORT HERE](#)

Raised so far
\$32,175.00

Fundraising goal
\$35,000.00

\$0.00

\$17,500

\$35,000.00

Looking for a Fun and Easy way to Raise Money and Awareness
for PWS at your School or Workplace?



Wear jeans for rare genes **ALL YEAR LONG!** You can help PWSA | USA provide care for families in our community by simply wearing your jeans and donating a few dollars. Pick a date to host a "Wear Jeans for Rare Genes" event with your school, community group, coworkers, church, etc. to help raise money for PWSA | USA!

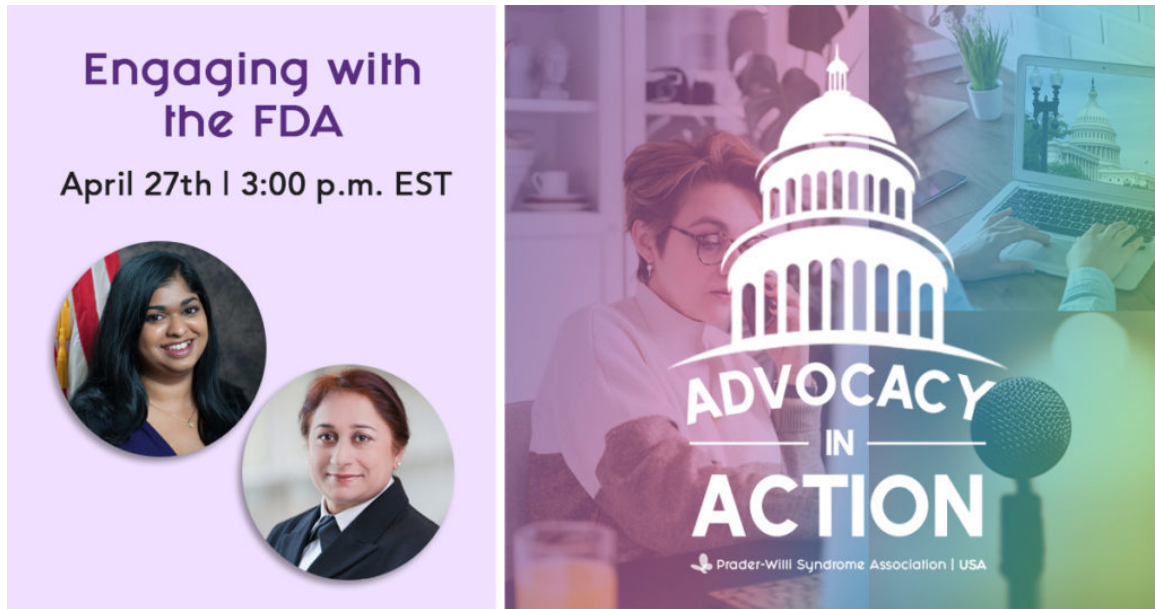
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any questions, please reach out to us at events@pwsausa.org.

[LEARN MORE](#)



ADVOCACY



FDA Advocacy in Action Webinar Registration is Now Available!

PWSA | USA's Advocacy in Action "Engaging with the FDA" registration link is now available! Join us April 27, 2022 at 3:00 p.m. EST to hear from two members of the U.S. Food and Drug Administration (FDA) as they share information about opportunities and boundaries when engaging with the FDA.

Learn more about this exciting opportunity and register in advance by clicking the button below.

[LEARN MORE HERE](#)

You can help PWSA | USA by sending in photos or videos of your loved one living with PWS



PWSA | USA is in need of pictures and videos of your loved one living with PWS. We constantly like to refresh our stories with new and diverse faces and would like to create a library of photos and videos shared by parents. If you have any pictures and/or videos of your child (young or older) that fit this criteria below, please [click here to upload](#). We would love to share your experiences with our community and create awareness.

We are in search of pictures and videos that evoke emotion and **show us how hard your children work!**

- Kids in action
- Working out
- During therapy
- Meeting milestones
- At a doctor's appointment (non-revealing)
- Achievements
- Family photos
- PWS Friendships
- Media should be as high resolution as possible
- Closeups and distance shots
- Inspiring quotes that carry you through the journey
- A quick line of what you would like the world to know about your child and PWS
- Your child's name

For the protection of your child, please do not use pictures of children that are not completely clothed or that can appear to be revealing in nature.

[SUBMIT YOUR PICTURES/VIDEOS HERE](#)



FAMILY SUPPORT



COMMUNITY CONVERSATIONS

Prader-Willi Syndrome Association | USA

Join us for a discussion on
PWS Awareness Month

Tuesday, April 19, 2022
8:00 p.m. EST

Join PWSA | USA's Family Support team on Tuesday, April 19, 2022 at 8:00 p.m. EST for our next Community Conversation! CEO Paige Rivard, Director of Family Support Stacy Ward, Parent Support Coordinator Kristi Rickenbach and Alterman Family Support Counselor Kim Tula will host a discussion focused on PWS Awareness Month. Click the button below to register in advance.

[REGISTER HERE](#)

Hyperphagia and How it Affects Learning



PWSA | USA's Director of Family Support Stacy Ward and Medical/Research Coordinator Lynn Garrick combined efforts to share information about hyperphagia and how it affects learning for those living with PWS. This article explores hyperphagic behaviors, hyperphagic drive, and hyperphagic severity. It also dives into helpful details about food security. Learn more by clicking the button below.

[LEARN MORE HERE](#)

Residential Living Survey

You can help PWSA | USA by



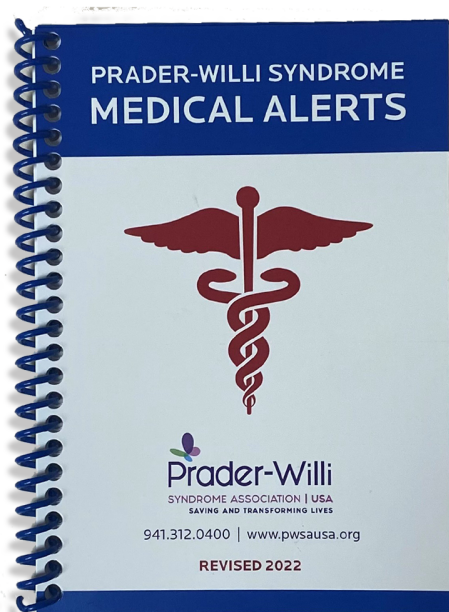
sharing where your loved one with PWS lives! Our Professional Provider work group is collecting data to find out where most people with PWS are living: at home, in traditional group homes, or other non-traditional settings. This survey only takes a couple minutes to complete. You can find the survey link by clicking the button below. Thank you!

[TAKE SURVEY HERE](#)



RESEARCH

PWSA | USA's Updated Medical Alerts Booklets Now Available for Download and Hard Copy Purchase!



PWSA | USA's newly updated Medical Alerts Booklet is now available! This handy guide is a valuable resource for medical providers, family members, and caregivers worldwide.

The Medical Alerts Booklet was developed by physicians and medical experts with expertise in Prader-Willi Syndrome (PWS). It alerts medical practitioners and guides treatment relating to complications that can develop in individuals with PWS. The booklet also includes a lifesaving gastrointestinal (GI) chart, postoperative monitoring, and so much more.

By utilizing the information in the Medical Alerts Booklet, families and caregivers can better understand and advocate for the health needs of individuals living with PWS.

The Medical Alerts Booklet is now available for hard copy sale AND as a downloadable PDF.

[DOWNLOAD THE MEDICAL
ALERTS BOOKLET](#)

[PURCHASE THE MEDICAL
ALERTS BOOKLET](#)

Feeding Tube Survey



NEW SURVEY

Complete your
**FEEDING TUBE
SURVEY**
in the Global PWS Registry

This survey only takes a few minutes to complete and provides invaluable insight into the use of feeding tubes in our loved ones with PWS.

- What type(s) of feeding tubes were used?
- How long was the feeding tube used?
- Why was the feeding tube put in place?
- Did you experience any complications related to the feeding tube?

www.pwsregistry.org

We know feeding tubes are often used in infancy for our loved ones with PWS who have difficulty feeding in the early months after birth. If your child used a feeding tube, we are asking you to spend 10 minutes today completing the new '**Feeding Tube Use and Complications**' survey.

This survey will help PWS experts in the newly formed PWS-CLIC (PWS **C**linical **I**nvestigation **C**ollaborative) learn more about how often feeding tubes are used in the PWS population, complications from

feeding tube use, and duration of use. The mission of the PWS-CLIC is to improve the quality of clinical research and medical care for people with Prader-Willi syndrome (PWS) across the lifespan through collaborative investigation and research to support evidence-based care. This project on feeding tubes is the first of several new projects to be launched.

You can contribute to this research easily from the comfort of your home. Simply login to your account in the Global PWS Registry www.pwsregistry.org. To complete this survey, you must have first completed the 'Diagnosis' and 'Birth History' surveys. If you have already done this and indicated your loved one has a history of using a feeding tube, you are ready to complete the new '**Feeding Tube Use and Complications**' survey.

If you need help setting up or reactivating your account, or if you have any questions, email us: info@pwsregistry.org or info@pathforpws.com

PWSA | USA ANNOUNCEMENTS



PWSA | USA's First-Ever Volunteer Summit is Coming Up!

Our staff is busy getting ready for our first annual Volunteer Summit, which will take place April 29, 2022 - May 1, 2022 in Dallas, TX. Spots are already filled for this year's event, but be on the lookout for a recap and photos from this year's event. If you are interested in becoming a PWSA | USA volunteer, please click [here](#)!

Learn more about the exciting activities and guest speakers who

will attend this year's Volunteer Summit by clicking the button below.

[LEARN MORE HERE](#)

IN MEMORY OF



We are deeply saddened to share the passing of Shaun Kopietz who was living with PWS. Shaun was born on 5/10/1987 and passed away on 3/24/2022.

Shaun wrote a beautiful poem that his family asked to be shared with our community. You can read it by clicking on the button below.

[READ SHAUN'S POEM
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](#)

8588 Potter Park Drive, Suite 500 Sarasota, FL 34238