

PWSA | USA Bi-Weekly Pulse: September 1, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



Vol. 82

September 1, 2023

www.pwsausa.org | 941.312.0400

Are You or Someone You Know a Current or Retired Federal Employee? You Can Make a Difference!

PWSA | USA PROVIDES
Help + Hope

CFC #10088



Between **NOW** and January 15, 2024, you can support PWSA | USA during this year's **Combined Federal Campaign (CFC)**! The CFC is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all." Please consider supporting PWSA | USA as we continue to provide help and hope to families around the world.

PWSA | USA's CFC ID # is 10088

[LEARN MORE HERE](#)

EVENTS

Community Conversations: Sibling Support Group



Siblings of loved ones living with PWS are invited to join PWSA | USA for our next Siblings Community Conversation on **September 13, 2023, at 8:00 p.m. EST**. These sibling community conversation webinars will take place the 2nd Wednesday of every month.

This discussion provides a safe space for dialogue between siblings of a person with PWS. All ages are welcome to attend! PWSA | USA team members will also be available to offer any insight and support. Register in advance at the button below.

14th Annual Hunter Lens Golf Tournament



Calling all New Englanders - Join the Lens family for a full afternoon of fun activities! The 14th Annual Hunter Lens Golf Tournament will take place Saturday, October 7, 2023, at 12:00 p.m. EST at the Back Nine Club (17 Heritage Hill Dr., Lakeville, MA 02347). Enjoy time with family and friends while participating in golf, a silent auction, prize drawings, and delicious dinner. Meet Hunter (24, living with PWS), learn more about PWS and how PWSA | USA is working to help families across the U.S, and enjoy a day on a beautiful course with great company!

REGISTER IN ADVANCE HERE

LEARN MORE HERE

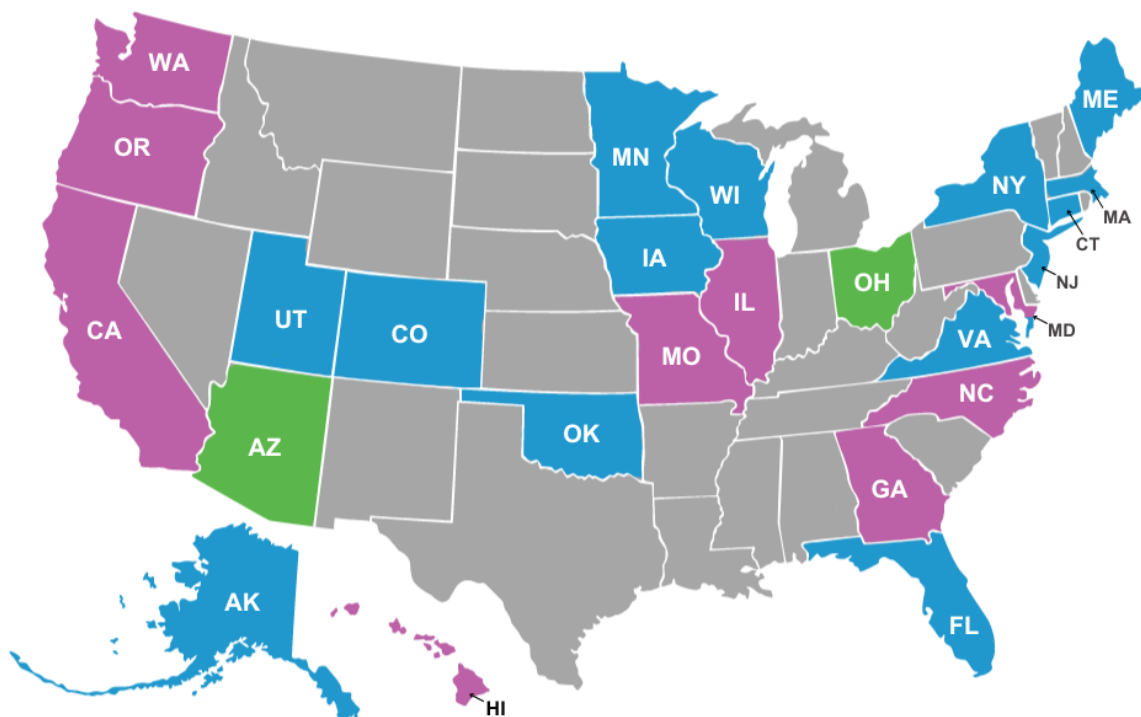


ADVOCACY

PWS State Qualifier Campaign Progress Update *Seven New States in the Beginning Stages of the Process!*

Right now, PWS is recognized in 14 states as an automatic qualifying condition, meaning the syndrome has been added to the state's list of developmental disabilities. We are excited to share that several **new** community members are in the beginning stages of having their states recognized. Currently, there are advocates in Ohio and Arizona working to make PWS a qualifying condition, and additional advocates in Georgia, Maryland, North Carolina, Oregon, California, Hawaii, Illinois, Washington and Missouri who are starting the process!

If you or someone you know is interested in leading the charge in your state, please email PWSA | USA at Advocacy@pwsausa.org.



States that recognize PWS States in the process of recognizing PWS States beginning to organize the recognition of PWS

WATCH: PWSA | USA's February Advocacy in Action webinar featured several PWSA Arizona Chapter leaders who discussed the Arizona State Qualifier Campaign. In this video, Crissy Burgstaler, Chelsee Loucks, Lisa Lamb and Tammie Penta walk through their Arizona campaign and help educate our community on the steps they've taken to make this happen.

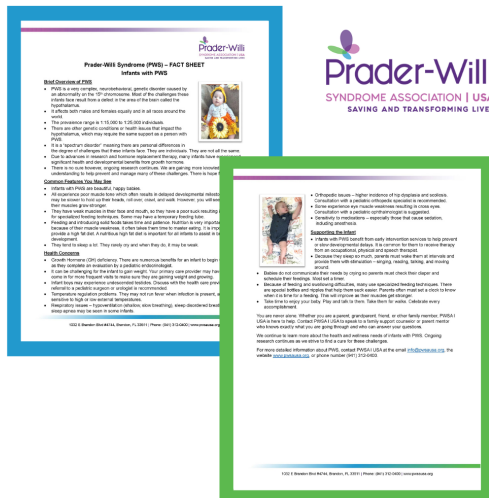
Advocacy in Action: Arizona State Qualifier Campaign





FAMILY SUPPORT

New Resource Available: PWS Infant Fact Sheet



PWSA | USA has a new resource available to help give an overview of how **infants** living with PWS are affected by the syndrome. Click the button below to download this fact sheet, which can be shared with family, friends, and other interested persons to offer insight.

We will also provide additional fact sheets for more age groups in the near future. You can find the PWS Adult Fact Sheet by [clicking here](#). A special thank you to volunteer Barb Dorn, RN, BSN, for working with the Family Support team to put these resources together.

[DOWNLOAD THE INFANT FACT SHEET HERE](#)

Show Some Love for the Grandparents in Your Loved One's Life!

Help us celebrate **National Grandparents Day** by sharing a photo and a quote at the button below! You can share a memory, how they support your loved one living with PWS and family, or simply a thank you message. We will share these submissions on PWSA | USA's social media pages on September 10th (Grandparents Day) and in our next Pulse newsletter!



SHARE YOUR MESSAGE HERE



RESEARCH

PWS Parents and Caregivers: Tell Your Healthcare Professionals About PWSA | USA's Next ECHO Webinar - Endocrinology 101

PWSA | USA's ECHO 4 PWS Healthcare Provider Series



Our next ECHO Webinar will take place
Tuesday, September 26, 2023 at 6:00PM EST

Topic - Endocrinology 101

Where - Virtual/Zoom Video

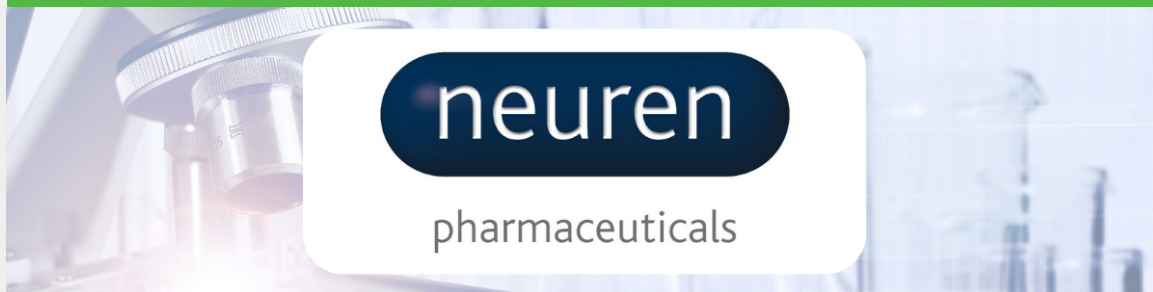
This series is for Healthcare Providers only

PWSA | USA's next **Healthcare Provider Project ECHO Series** webinar will take place September 26, 2023, at 6:00 p.m. EST. The topic discussed will be **"Endocrinology 101,"** presented by Jennifer Miller, MD, Professor of Pediatric Endocrinology at the University of Florida, followed by a 20-minute case study on PWS presented by Moris Angulo, MD, Pediatrics, Genetics, and Pediatric Endocrinologist at Catholic Health Physician Partners.

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 learn more details and find the registration link at the button below.

ECHO 4 PWS REGISTRATION LINK

Neuren Pharmaceuticals is Happy to Announce the First Site Participating in Their Phase II, Open Label, PWS Study (Neu-2591-PWS-001) is Now Open for Screening!



Important information regarding this exciting milestone:

- Rare Disease Research (RDR), located in Atlanta, GA, is now welcoming children with PWS and their families to their clinic for screening into this trial.
- The duration of active treatment in this study is 13 weeks. In a preclinical study in animals, physiological and behavioral symptoms were normalized within six weeks of dosing.
- Enrollment will begin in children diagnosed with PWS who are in the older age group (ages 8 through 12).
- After safety and tolerability data in the older group is independently reviewed, it will be announced when children in the younger group (ages 4 through 7) can start to be screened.
- As this is an open-label study, all children who participate on this trial will receive study drug.
- All travel and lodging for in-clinic visits (5 in total) can be reimbursed.
- If the study drug (NNZ-2591) development moves into Phase 3, all children who participate in this Phase II study may be eligible for an Open-label Extension study that would be opened in parallel to the NNZ-2591 Phase III trial in PWS.
- Study goals:
 - The overall goal of this first NNZ-2591 clinical trial in children with PWS is to assess safety and inform the design of subsequent

registration trials.

- The primary outcome measures in the study are safety and tolerability as well as measuring how the drug is used and distributed in the body.
- The secondary goal is to assess the potential benefit of NNZ-2591. The study looks at a range of outcomes that are functionally important to children with PWS: behavioral issues, anxiousness, social interaction, language, cognition/learning, hyperphagia/food behaviors, sleep, and activities of daily living.

For any questions in relation to study participation at Rare Disease Research, please reach out directly to the site at neu-2591-pws-001@rarediseasere search.com (please note that his email address is actively monitored for incoming emails in need of response). For any general questions, please reach out to Dorothea Lantz (dlantz@pwsausa.org).

Harmony Biosciences Issued a Statement Regarding its Confidence in Pitolisant Drug



Harmony Biosciences has reaffirmed its confidence in the strength of WAKIX® (Pitolisant) patents, after receiving a positive ruling from the U.S. Patent and Trademark Office (USPTO) rejecting the request for reexamination. WAKIX® is used to treat excessive daytime sleepiness (EDS) or cataplexy in adults with Narcolepsy. Read Harmony Biosciences' statement at the button below.

[LEARN MORE HERE](#)

Participate in Two New Surveys on the Global PWS Registry



**Help us understand the use of
GH Across Ages in PWS**

Complete your endocrinological history and medications-endocrinology surveys in the Global PWS Registry to let us know:

- Is your loved one with PWS currently prescribed GH?
- If not, were they ever prescribed GH? If they are no longer taking GH, why?

The Foundation for Prader-Willi Research is working to understand how growth hormone (GH) is prescribed and used in children and adults with PWS and we need your help!

Growth hormone is approved for children with PWS, and there is evidence that it can be beneficial for adults with PWS. We'd like to better understand GH use in the PWS population, including how GH use changes with the age, and why.

How can you help? By completing two specific surveys in the Global PWS Registry (www.pwsregistry.org) to share your child's experience with growth hormone use: 1. Endocrinological History and 2. Medications – Endocrinology. Take 5 minutes today and share your experience. Email lisa.matesevac@fpwr.org if you have questions or need assistance.

PARTICIPATE IN THE SURVEYS HERE

Are You the Caregiver of a Loved One Between 5-17 Living with PWS? This Survey is for You!



Alanna Morrissey MA, BCBA with The Chicago School of Professional Psychology is asking for help from our PWS community. She is recruiting for a research study evaluating the impact of a behavior analytic caregiver training program on teaching caregivers how to train self-care skills to improve their child's independence.

Participation is fully remote and will take place across 8 weeks, for 1-2 hours a week. If you are 18+, speak and read English fluently, a caregiver of a child with PWS aged **5-17** who needs help with self-care skills, and have access to the internet, you may

qualify. Please share the flyer at the button below with anyone who may be interested.

[LEARN MORE HERE](#)

PWSA | USA ANNOUNCEMENTS

PWS Families - We Need Your Help! *Share Your Holiday Tips*



Hope FOR THE Holidays



through a story, a photo, a tip, or recipe from a past Halloween, Thanksgiving, Hanukkah, Kwanzaa, Christmas, New Years, or another holiday you celebrate. We will share the information submitted in PWSA | USA's September Pulse Newsletter (9/29) and on our social media pages. You can also choose to submit anonymously. Thank you!

Summer is coming to an end and the holiday season is just around the corner! PWSA | USA is working to create a library of tips, stories, and recipes to help our community navigate this fun, but often, stressful time of year. You can help fellow parents, caregivers, and family members find inspiration and ideas by sharing what you have done for your loved one living with PWS as alternative options or unique traditions!

Click the button below to share your **Hope for the Holidays**, either

[SHARE YOUR HOPE FOR THE HOLIDAYS HERE](#)

PWSA | USA'S SPOTLIGHT ON HOPE



The Osterman family found themselves in the national spotlight as their heartwarming journey with their 13-year-old son, Max, who has Prader-Willi syndrome, was featured on **The Today Show**. Max, who recently celebrated his Bar Mitzvah, experienced a memorable moment when he visited The Today Show and had the opportunity to meet Hoda Kotb. Heather, Max's mom, shared that their initial hope was to simply greet Hoda and capture a photo, but Hoda went above and beyond, creating a truly magical day for their family.

By sharing Max's story and his uplifting encounter, Heather hopes to not only raise awareness about the challenges of Prader-Willi syndrome but also highlight the positive impact of human connections and understanding. Click the button below to read more.

[READ 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
1032 E Brandon Blvd #4744 Brandon, FL 33511

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Thank You to the Amazing Grandparents in our Loved Ones' Lives!

To celebrate National Grandparents Day (September 10th), we asked the PWS community to share messages to show their appreciation.



Declan's grandparents have been supportive from the very beginning, when Declan was born in 2012. They have helped in so many ways, from those early days in the hospital, all the way through now. They love and support and encourage Declan and us, and we couldn't do it without them!

- Allison Shelton

Thank you for loving our Jake as only a grandparent can and for supporting us all these years. Happy Grandparents' Day! We love



you!

- Laura Pawulak



We are so thankful to have you in our lives. Your love and support means so much to Lexi and I. You two have the most special bond. We love you Grammy Kathy.

- Jaynee Stoscup

EVENTS

14th Annual Hunter Lens
Golf Tournament

3rd Annual Answers for
Audrey Trivia Night



Calling all New Englanders - Join the Lens family for a full afternoon of fun activities! The 14th Annual Hunter Lens Golf Tournament will take place Saturday, October 7, 2023, at 12:00 p.m. EST at the Back Nine Club (17 Heritage Hill Dr., Lakeville, MA 02347). Enjoy time with family and friends while participating in golf, a silent auction, prize drawings, and delicious dinner. Meet Hunter (24, living with PWS), learn more about PWS and how PWSA | USA is working to help families across the U.S, and enjoy a day on a beautiful course with great company!

[LEARN MORE HERE](#)



Where: Incarnate Word Academy
2788 Normandy Avenue
St. Louis, MO 63121

When: Saturday October 21, 2023

Doors Open at 6:30pm & Trivia Begins at 7pm

"We want to continue to help fund research that will provide life changing treatments for PWS, which is why we are hosting our 3rd annual Trivia Night! We were blown away by the love and support of 2022's Trivia Night and cannot wait for October 21st!" - The Spring Family

[LEARN MORE HERE](#)



ADVOCACY

Dates Announced for PWSA | USA's 2nd D.C. Fly-In Event

We are excited to share the dates of PWSA | USA's 2nd D.C. Fly-In event - **May 13-15, 2024!** We will set up meetings with legislators to continue our advocacy

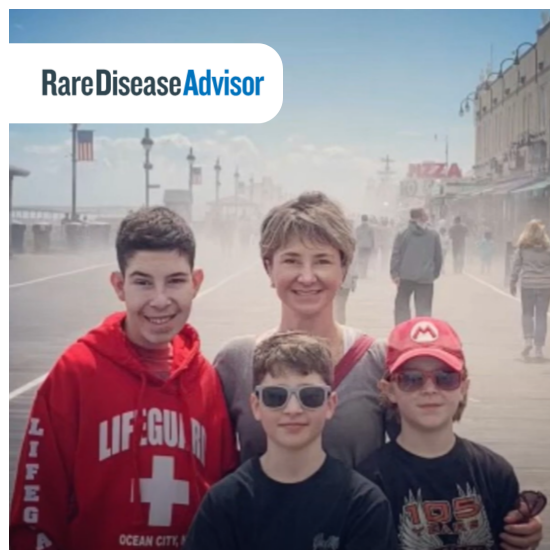
efforts in Washington, D.C., and come together on May 15th for a "Day on the Hill" to celebrate National PWS Awareness Day.

We will share more details about this opportunity soon. In the meantime, click the button below to check out highlights from our 2022 D.C. Fly-In!

[LEARN MORE HERE](#)



PWSA | USA Advocate Jenn Garzia and Son, Rocco, Featured in *Rare Disease Advisor* Article



Following her testimony and panel participation at PWSA | USA's Externally-Led Patient-Focused Drug Development Meeting in June, advocate Jenn Garzia and her son Rocco's journey with PWS was recently featured in *Rare Disease Advisor*. In the article, Jenn shares her experiences and challenges in managing Rocco's condition, and emphasizes the constant need to control food access to prevent explosive behavioral outbursts caused by Rocco's insatiable hunger. She highlights the difficulties her son

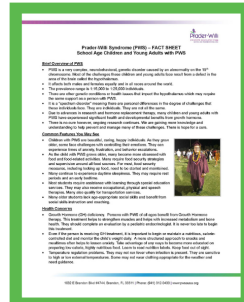
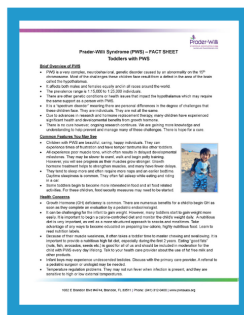
faces, including social isolation and the inability to attend school due to outbursts. This article also explores how current clinical trials are seeking new approaches to treatment for PWS. You can read the full story at the button below.

[READ MORE HERE](#)



FAMILY SUPPORT

New Resources Available: PWS Toddler Fact Sheet & PWS School Age/Young Adult Fact Sheet



PWSA | USA has two new resources available to help give an overview of how **toddlers and school age/young adults** living with PWS are affected by the syndrome. Click the buttons below to download these fact sheets, which can be shared with family, friends, school officials, and other interested persons to offer insight.

You can also find the PWS Adult Fact Sheet by [clicking here](#) and the PWS Infant Fact Sheet by [clicking here](#). A special thank you to volunteer Barb Dorn, RN, BSN, for working with the Family Support

team to put these resources together.

[DOWNLOAD THE TODDLER FACT SHEET HERE](#)

[DOWNLOAD THE SCHOOL AGE/YOUNG ADULT FACT SHEET HERE](#)

Transformative Tales: Empowering Families Dealing with Prader-Willi Syndrome Through Food Security



Living with PWS presents unique challenges, particularly in managing food-related behaviors. The experiences of families dealing with PWS takes on an extra layer of complexity, because of the significance of food control and security devices in their lives. In the excerpts you'll find at the button below, Christopher Rich with the Utah PWS Association dives into several experiences of families with PWS individuals and how the implementation of new food control devices have brought about remarkable changes.

[LEARN MORE HERE](#)

World Narcolepsy Day



September 22, 2023, is recognized as **World Narcolepsy Day**. Individuals with Prader-Willi syndrome often experience narcolepsy, a neurological sleep disorder characterized by excessive daytime sleepiness and sudden, uncontrollable episodes of falling asleep. This dual diagnosis can create unique challenges for those affected. Narcolepsy can exacerbate the already complex nature of PWS by making it even more challenging for individuals to manage their eating behaviors and maintain a healthy weight.

Moreover, the cognitive and emotional aspects of PWS, such as impulsivity and emotional dysregulation, can be further exacerbated by the disrupted sleep patterns associated with narcolepsy. This combination can create a more complex set of symptoms and demands on caregivers and healthcare providers. Dr. Amee Revana spoke at PWSA | USA's Sleep Summit last year and offered many helpful tips and an expert perspective on sleep issues and PWS. Click the

image to watch her presentation and click the button below to find more sleep-related resources.

[LEARN MORE HERE](#)



RESEARCH

PWS Parents and Caregivers: Tell Your Healthcare Professionals About PWSA | USA's Next ECHO Webinar - Endocrinology 101

PWSA | USA's ECHO 4 PWS Healthcare Provider Series



Our next ECHO Webinar will take place
Tuesday, September 26, 2023 at 6:00PM EST

Topic - Endocrinology 101

Where - Virtual/Zoom Video

This series is for Healthcare Providers only

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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 learn more details and find the registration link at the button below.

[ECHO 4 PWS REGISTRATION LINK](#)

ICYMI: Neuren Pharmaceuticals First Site in Phase II PWS

Study Now Open for Screening!

Exciting News: [Neuren Pharmaceuticals](#) is partnering with Rare Disease Research to enroll children aged 8 to 12 with PWS for a pioneering clinical trial, featuring a 13-week active treatment phase with the potential to significantly impact PWS symptoms. This open-label study offers all participants access to the investigational drug NNZ-2591. Additionally, travel and lodging for five in-clinic visits are reimbursable.

If you're interested in this groundbreaking opportunity and wish to learn more about the trial's goals, safety measures, and potential benefits, please click the link below for comprehensive details or contact RDR directly at neu-2591-pws-001@rarediseaseresearch.com with specific inquiries. Your participation could help pave the way for innovative PWS treatments!

[LEARN MORE HERE](#)



**Click Here to Visit
Neuren Pharmaceuticals'
New PWS Study
Website**

Research Opportunity: Play Skills & PWS

The Chicago School of Professional Psychology is seeking survey study participants to contribute to their research on the play skills of children with PWS. If you are 18 years or older, have a child aged 2 to 12 with PWS, are proficient in English, have internet access, and an internet-connected device, you're invited to participate.

By completing the survey, you will have the chance to win a \$25 Amazon gift card through a raffle. Please share the flyer at the button below with anyone



who might be interested in joining this study. If you have any questions, contact Kelly Krukowski, M.A., BCBA, at KKrukowski@ego.thechicagoschool.edu.

DOWNLOAD THE FLYER HERE

PWSA | USA ANNOUNCEMENTS

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



So many emotions, where do I even begin. If only I could tell myself the day I received Luna's diagnosis that this is how far we would come and that we continue to see the joy and beauty in her diagnosis.

I launched my first ebook "The Wholesome Child," which is PWS-friendly and inspired by Luna, who is now 19 months old. The word "wholesome" has so much meaning to her life; 10 months ago I started with the book and only managed to launch it now, we all know the juggle and struggle. I'm so passionate about creating a "normal" life for

Luna in the best and healthiest way possible, and that's why I started this book. Luna has pushed me to continue to advocate and achieve more than I ever thought was possible.

The book is a collaboration with pediatric dietitian Dr. Katherine Megaw, who is Luna's dietitian as well as the dietitian for other PWS children here in South Africa. She also consults with many overseas.

The book has breakfast, popsicle, smoothie, snacks, lunch, dinner and cake recipes all tailored to our kids' needs. It is personalized and has so much outpouring love to offer. It also has a notes section for any alterations you may want to make according to your other family needs or preferences.

- Author Savannah van der Walt, PWS mom living in South Africa

[LEARN MORE HERE](#)

PWS Families - We Need Your Help!

Share Your Holiday Tips



Hope FOR THE Holidays



recipe from a past Halloween, Thanksgiving, Hanukkah, Kwanzaa, Christmas, New Year's, or another holiday you celebrate. We will share the information submitted in PWSA | USA's September Pulse Newsletter (9/29) and on our social media pages. You can also choose to submit anonymously. Thank you!

Fall is in the air and the holiday season is just around the corner! PWSA | USA is working to create a library of tips, stories, and recipes to help our community navigate this fun, but often, stressful time of year. You can help fellow parents, caregivers, and family members find inspiration and ideas by sharing what you have done for your loved one living with PWS as alternative options or unique traditions!

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[SHARE YOUR HOPE FOR THE HOLIDAYS HERE](#)

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Learn more and donate at
[www.pwsausa.org/
combined-federal-campaign](http://www.pwsausa.org/combined-federal-campaign)

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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PWSA | USA's CFC ID # is 10088

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!

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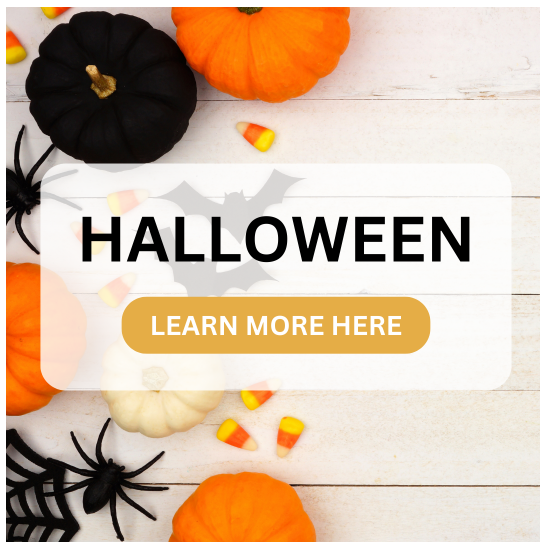
[Donate](#)



Holiday Safety for Your Loved One Living with PWS

With the holiday season just around the corner, we know it can be a fun, but often stressful time of year for our PWS community. PWSA | USA's Family Support Team and volunteers are here to offer helpful tips and tools to make trick-or-treating, holiday parties, and gift giving more manageable for your family and loved one living with PWS.

Click the images below to learn more!



HALLOWEEN

[LEARN MORE HERE](#)



THANKSGIVING

[LEARN MORE HERE](#)



WINTER HOLIDAYS

[LEARN MORE HERE](#)

Hope for the Holidays

Thank you to those who have participated in our **Hope for the Holidays** by sharing a story, tip, or recipe! Scroll below to learn some of the different ways PWS families have found success. YOU can help us continue to build a library of information that gives hope to families and helps them navigate the holidays.

[SHARE YOUR HOPE FOR THE HOLIDAYS](#)



"Thanks to the advice of more seasoned PWS parents, we have found a way to be successful at Halloween pretty early on. We make sure to have friendly snack options for Emily during trick-or-treat time. Naturally, our other children snack on their candy from trick or treat, location to location. If anyone has food, Emily must have something too. We make sure to have Emily-approved snack options with us."

We typically stick to a small bag of Skinny Girl popcorn and a small pack of raisins. We ration out portion sizes to make them last for the trick-or-treat time duration. Emily collects candy and we try our best to choose non-food options when presented with them. We also keep some non-food item treats that we can sneak into her bucket, such as a slinky, pop tubes, bubbles, etc. That way, she gets the experience of pulling from her bucket to enjoy "treats" too. Then, once trick or treat time is over, we head to Wal-Mart to pick a toy. The candy in the bucket is then exchanged for the new toy. We heard this from other families who do the "Switch Witch" method. Emily is now 5 and so far this system has worked great."

- Mary Howard, Mom to Emily, 6 (KY)

"Miah has an Elf on the Shelf named Butterfly. Miah is always very happy and enthusiastic each holiday season when Butterfly comes! Miah's elf comes the day after Thanksgiving. Miah loves to leave Butterfly notes to bring back to Santa! Elf on the Shelf has many different outfits and scenes to make this holiday season very exciting! Butterfly has a few different outfits she comes back to our house wearing. It's always fun to look around for Butterfly to see where she is hiding. I love to see the smile on Miah's face when she does locate where Butterfly is!"

- Lisa Cole, Mom to Miah, 19 (NY)



"Planning and having an itinerary. He loves knowing what's going to be happening for the day!"

- Roselynn Palaita, Mom to Atticus, 7 (UT)

"We leave 'treats' for Santa rather than cookies. We make a small plate of veggies. He loves a break from the sweets at our house!"

- Anonymous



"At Halloween, we put more emphasis on the way we are dressed. It's so exciting to get dressed up! We participate in a local trunk-or-treat before Halloween, where the environment is more controlled and they have all non-food items. On Halloween, we trick-or-treat with family members and friends who offer non-food items (coloring book, playdoh, crazy straw, pencil, etc). We also look at the Teal Pumpkin Project map near us but may follow that map when she's a bit older. Next year, we might add the

spooky cat wash on our way home."

- Anonymous

"We participate in a local Turkey Trot before going to a family's home for a Thanksgiving meal."

- Anonymous



"At Thanksgiving, we bring a veggie tray with our favorite vegetables. We try to sort the vegetables in the shape of a turkey (a quick Google search gives lots of ideas). It's fun for everyone and ensures some good snacks for everyone."

- Anonymous

"Before Christmas, we purchase 25 books (new and used), wrap them individually, and open one each night leading up to Christmas rather than using an advent calendar. It increases our home library and is a fun surprise for everyone."

- Anonymous

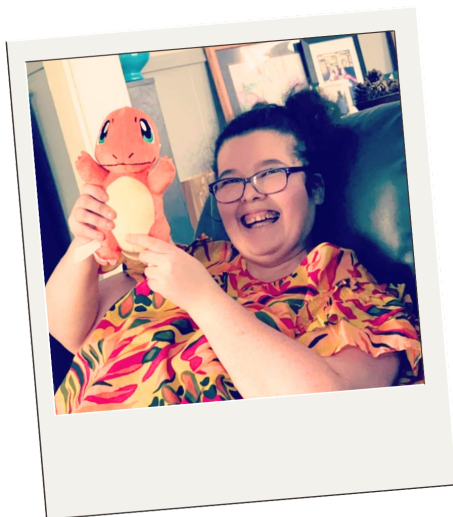


"Plan ahead! Zoey does really well through the holidays when we plan ahead and can fill her in on those plans. She likes knowing what to expect so planning ahead and discussing it with her helps to soothe a lot of her anxiety."

- Jamie Cox, Mom to Zoey, 13 (KS)

"My son loves spooky things! On Halloween, he wears his costume to eat dinner in a restaurant. We used to come home after and play a spooky game or watch a spooky movie, but now a car wash near us does a haunted car wash!"

- Cindy Szapacs, Mom to Daschel, 16 (PA)



"My daughter Chassidy, 29, was diagnosed with PWS at 18-months-old. We don't do Halloween because of the candy and temptation. Thanksgiving is with family members who support our guidelines on food security. Christmas is the same. I bring dessert that is sugar free.

I make sure that Chassidy is supervised and has something to do while getting together with our loved ones."

- Rhonda Williams, Mom to Chassidy, 30 (IN)

"The holidays tend to be a busy time. Instead of trying to fit more in, I try to look at what I can remove from our list of activities and obligations. I also try to take extra time off work and build in spaces for down-time. This helps relieve stress and gives us more space to deal with whatever challenges come up, because they always do!"

- Emily Felt, Mom to Olivia, 11 (CA)



Cameron Graziano, now 24 (pictured at age 9) with many Halloween celebrations behind him, shares the following in hopes it will be helpful to families:

“Halloween doesn’t have to mean ‘candy’. Halloween can feature ghoulishly fun and healthy veggies and fruits! Host a Halloween Party at your home so your family can better manage supervision. Invite guests to wear costumes, have a dance party, and serve some of the healthy options below. Switch things up

every year to make treats exciting and fun year after year!”

- Lisa Graziano, Mom to Cameron, 24 (CA)

Holiday Recipes

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