

PWSA | USA Bi-Weekly Pulse: July 7, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS

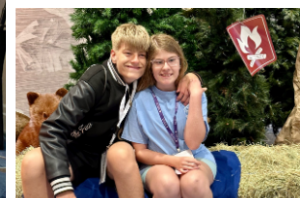


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July 7, 2023

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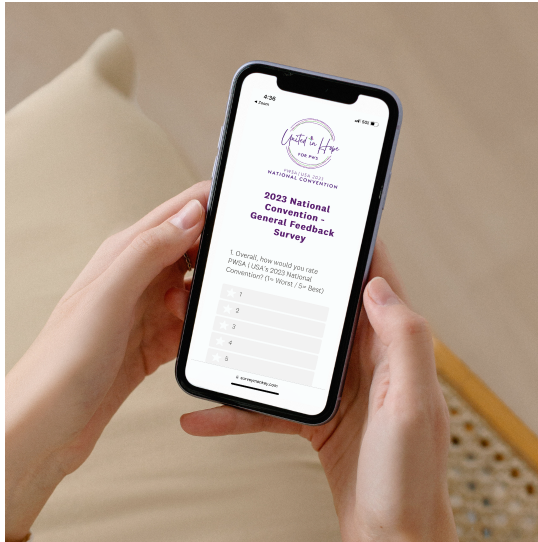
Thank You for Sending in Your Convention Photos!



[CLICK HERE TO VISIT THE GALLERY](#)

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 CAMPS SURVEY](#)

PWS Custom Shoes Now Available for Purchase!



Show off your PWS pride with amazing customizable shoes! We want to thank the Marx family, their daughter Brooklyn living with PWS, Denver Broncos player Caden Sterns, and *Custom Creations by JMART* (the shoe creator) for their help in bringing this vision of PWS customizable shoes to life.

Shop these shoes by clicking the buttons below!

[**Customizable Nike Tennis Shoes**](#)



[Shop Boy's \(Youth\) Nike's](#)

[Shop Men's \(Adult\) Nike's](#)



[Shop Girl's \(Youth\) Nike's](#)

[Shop Women's \(Adult\) Nike's](#)

Customizable Vans



[Shop Youth Customizable Vans](#)

Nike Slides



**Not available for customization*

[Shop Adult/Youth Nike Slides](#)

[Shop Adult Customizable Vans](#)



CONVENTION SESSION RECORDINGS WILL BE AVAILABLE AT THE END OF JULY

Be on the lookout for an email with a link to view these recordings, including the Externally-Led Patient-Focused Drug Development Meeting. We appreciate everyone's patience as we work to make them available!

Congratulations to PWSA | USA's 2023 Volunteer Award Recipients

On June 24, 2023, the last day of PWSA | USA's 37th National Convention, seven individuals who have gone above and beyond to not only spread the mission of PWSA | USA, but who work on behalf of the entire PWS community, were recognized with PWSA | USA's 2023 Volunteer Awards.

Research Star Award | **Ann Manzardo, MSCR, PhD**

Legislative Champion Award | **Congressman Paul D. Tonko (D-NY)**

Family Support Volunteer Award | **Lieutenant Colonel (R) Charles Conway**

Advocacy in Action Award | **Chrissy Burgstaler**

Hope United Fundraising Star Award | **John & Lori Lens**

Volunteer of the Year Award | **Barb Dorn, RN, BSN**



[READ MORE HERE](#)

EVENTS

MOM'S RETREAT

OCTOBER 12 - 15, 2023 | PALM SPRINGS, CALIFORNIA

More details coming soon!

 **Prader-Willi**
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES



ADVOCACY

Spotlight on Advocacy: PWS Advocate Erin Cooper Carter, PhD Continues to Fight for our Ohio Families!



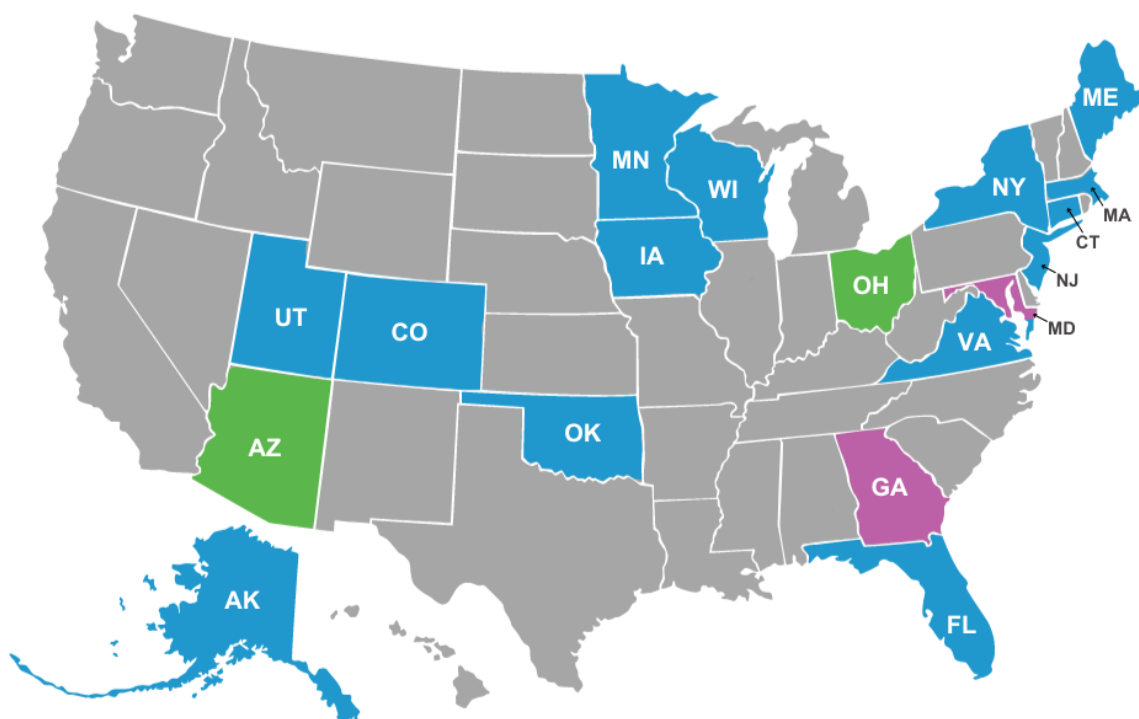
Erin Cooper Carter, PhD (mom to Victoria, age 6 living with PWS) is leading the effort to have PWS added to the state's list of developmental disabilities in Ohio! This important piece of legislation is being filed by Representative Bride Rose Sweeney (D-16) and will likely be co-sponsored by Representative Nick Santucci (R-64).

When asked about the bill and what inspired her to undertake this challenge, Erin said *"Before I had Victoria, I assumed, like many people do, that disabled children are guaranteed the services they need to*

*live full lives. I assumed the financial burden was not placed at the family's feet – because that's what I think a civilized society should do. At the bare minimum, we should take care of our most vulnerable children. Unfortunately, that is not the case for far too many families, in far too many states, including Ohio. I've always loved a good challenge, and this is one that needs to be addressed. We **MUST** continue to move the needle for families of children living with PWS. If our community doesn't do it, who will? I'm honored to leverage my skillset to help not just my family, but hundreds of other families in Ohio like mine. And I'm incredibly thankful for Representative Sweeney's unwavering support. Let's do this!"*

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

PWS State Qualifier Map



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



FAMILY SUPPORT

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 July 12, 2023, at 2:00 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.

In an effort to ensure attendees feel comfortable to share openly, this opportunity is just for siblings. We appreciate your understanding!



[REGISTER IN ADVANCE HERE](#)



RESEARCH

Pharmacogenomics and You



Jessica Duis, MD and her team at the University of Colorado Anschutz Medical Campus are now recruiting individuals with PWS ages 5-21 to learn about how they metabolize medications.

This study is fully remote, will be a survey collection, and participants will receive their results. To learn more, call Mindy at (720) 777-6249 or email melinda.taylor@cuanschutz.edu.

Thank you for your consideration!

[DOWNLOAD THE FLYER HERE](#)

Are You a Caregiver of a Child 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

10-17 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.

[CLICK HERE TO SEE IF YOU QUALIFY](#)

[DOWNLOAD THE FLYER HERE](#)

PWSA | USA ANNOUNCEMENTS

 PWSA | USA'S
SPOTLIGHT ON HOPE



"My son, Liam Gibney (living with PWS) is in the final stages of completing his Eagle Scout project for Troop 36 in Oradell, NJ. He collected 80 boxes filled with school, hygiene, gym, sensory, and art supplies for Latham Centers and raised over \$6,000 to go towards the new facility they are building."

- Kate Gibney, mom to Liam

To help the Gibney's share their story with local media outlets, we are working to find others in our PWS community who have completed their Eagle Scout service project. If you or your loved one living with PWS has achieved an Eagle Scout rank, please let us know at info@pwsausa.org.

SHARE YOUR SPOTLIGHT ON HOPE!

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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1032 E Brandon Blvd #4744 Brandon, FL 33511

PWSA | USA Bi-Weekly Pulse: July 21, 2023

Enhancing the Quality of Life and Empowering Those Affected by PWS



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July 21, 2023

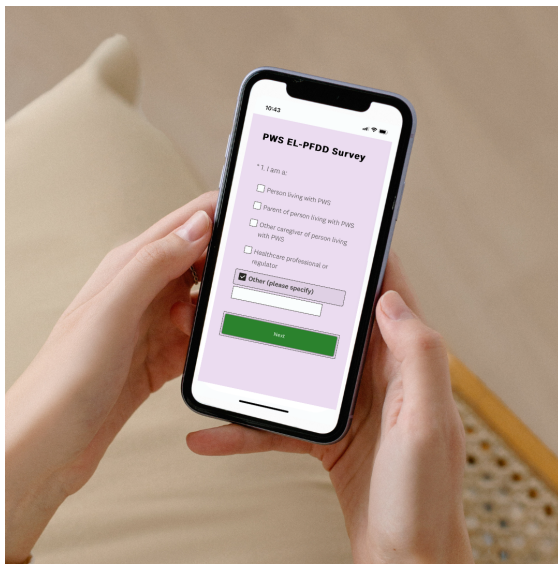
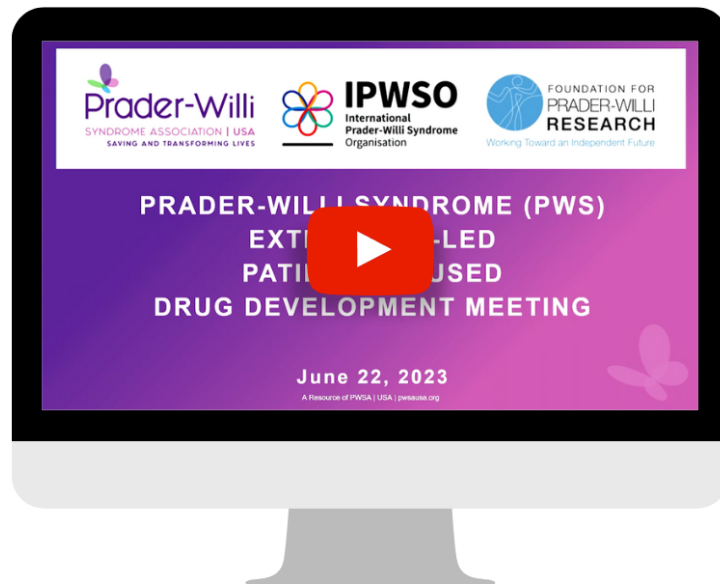
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Thank You for Sharing Your Voice!

Find next steps for the FDA Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting and a link to the recording below

Thank you to everyone who shared their voice in-person and virtually at the FDA Externally-Led Patient-Focused Drug Development Meeting. Your time and commitment to our loved ones living with PWS is truly incredible. **You can now view the EL-PFDD meeting recording by clicking the image below.**

As for next steps, we are working to build a "Voice of the Patient Report" based on the testimonials shared both during the EL-PFDD, and those collected [HERE](#) on our website. Please submit your testimonial before Tuesday, August 1, 2023.



During the EL-PFDD meeting, we used a survey to collect critical patient information from the PWS community. This information will be used to assist the FDA in determining our patient experiences, while evaluating therapies to treat different symptoms of PWS, and will be published data in our "Voice of the Patient Report." You DID NOT have to attend or participate in the EL-PFDD to take this survey, and it is imperative that we capture as much data as possible for the FDA. Don't delay, fill out the survey today.

[TAKE THE EL-PFDD SURVEY HERE](#)



**SEVERAL FAMILY
CONFERENCE SESSION
RECORDINGS WILL BE
AVAILABLE AT THE END
OF THIS MONTH**

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!

EVENTS

PWSA | USA 2023 Moms' Retreat Application Now Available!



To give the amazing moms and full-time female caregivers in our PWS community some much-deserved “me-time,” PWSA | USA will host its first-ever Moms’ Retreat October 12-15, 2023 in Palm Springs, CA with facilitator Jessica Patay, founder and executive director of *We Are Brave Together*.

Since this is the association's first Moms' Retreat event and to provide an intimate atmosphere, 30 people will be selected to attend at random from the applications submitted. Applications are due by August 14, 2023. Learn more about the event and apply at the button below.

[LEARN MORE HERE](#)

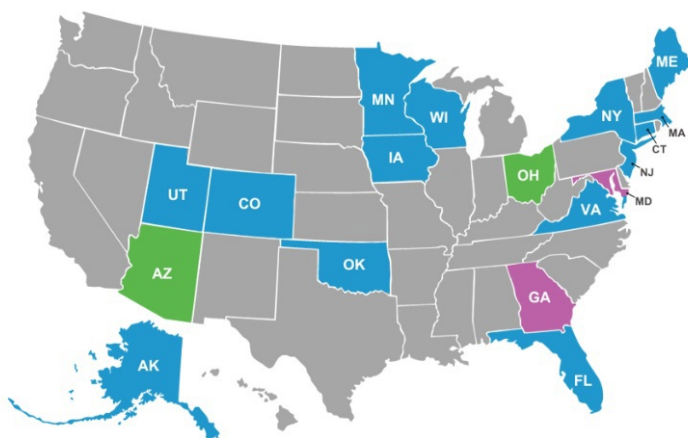


ADVOCACY

Calling all PWS Advocates! Help Get PWS Added as a Qualifying Condition in Your State

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. Currently, there are advocates in Ohio and Arizona working to make PWS a qualifying condition, and additional advocates in Georgia and Maryland 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



PWS State Qualifier Map

States that recognize PWS as a qualifying condition: **14**

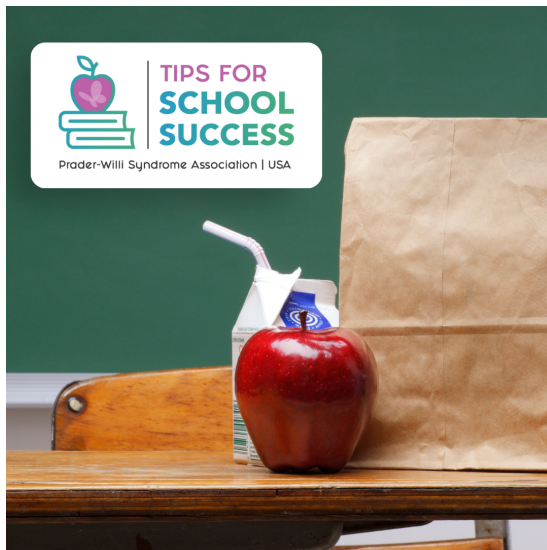
States in the process of recognizing PWS as a qualifying condition: **2**

States beginning to organize the recognition of PWS as a qualifying condition: **2**



FAMILY SUPPORT

Share Your School Lunch Tips



Next Friday, PWSA | USA's Special Edition Pulse will focus on back-to-school and offer helpful tips from our Family Support team as well as how to best utilize our School Success resources. We also want to hear from YOU, our PWS community, on what has worked for you / your loved one living with PWS when it comes to packed lunches. Click the button below to share your packed lunch recipes and any advice you have for other families navigating school lunches.

Thank you in advance and we look forward to sharing your answers in next week's Pulse!

[SHARE YOUR TIPS HERE](#)

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 **August 9, 2023, at 2:00 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.

In an effort to ensure attendees feel comfortable to share openly, this opportunity is just for siblings. We appreciate your understanding!

[REGISTER IN ADVANCE HERE](#)



RESEARCH

Gedeon Richter Now Recruiting for KITE-PWS Clinical Trial



You or someone you love could be part of developing new therapies for PWS. Learn about [Gedeon Richter's](#) research study KITE-PWS, also known as RGH-706-003, to evaluate an experimental drug for hyperphagia in people with Prader-Willi syndrome.

Learn more and find out how you can get involved at the button below.

[LEARN MORE HERE](#)

Harmony Biosciences Announces Plan to Begin Phase 3 Trial for Pitolisant Following Meeting with FDA

This week, Harmony Biosciences announced the company is working on a plan to begin their Phase 3 clinical trial for pitolisant, also known as WAKIX, following a positive End-of-Phase 2 meeting with the U.S. Food and Drug Administration.

Find Harmony Biosciences' full press release announcement at the button below, which includes more details from their meeting with the FDA and next steps for the Phase 3 study.



[LEARN MORE HERE](#)

Behavioral Training for Caregivers of Children with Prader-Willi Syndrome



The Chicago School of Professional Psychology is looking for research study participants! Help researchers learn about the effects of a behavioral caregiver training program for caregivers of children with PWS.

All participants will be compensated with a \$250 gift card following the completion of the study.

Click the buttons below to learn more.

[DOWNLOAD THE FLYER HERE](#)

[CLICK HERE TO SEE IF YOU QUALIFY](#)

Parents of Older Teens/Young Adults Living with PWS Invited to Participate in Smart-Start Program



This Smart-Start Program is a free training group for parents of older teens and young adults living with PWS that covers a variety of behavior-analytic strategies specified to the needs of people with PWS.



Facilitated by Stacy Ward, MS, and Kasey Bedard, PhD, BCBA-D, this training includes a weekly live meeting, and at times, a weekly video to watch. Participants are requested to complete a variety of "homework" assignments that include collecting data and implementing a variety of strategies.

Learn more and find the link to sign up by clicking the button below.

[DOWNLOAD THE FLYER HERE](#)

PWSA | USA ANNOUNCEMENTS

ICYMI: PWSA | USA Announces the Resignation of CEO Paige Rivard and Appointment of Interim CEO Stacy Ward

Last week, PWSA | USA announced the resignation of its CEO, Paige Rivard, MBA. Paige held the CEO position for the past three years and has led many efforts to advance awareness, research opportunities, and provide support for families in the PWS community. The association extends its heartfelt appreciation to Paige for her leadership and dedication during her tenure.

PWSA | USA will commence a search for a new CEO. In the meantime, Stacy Ward, MS, will serve as the Interim CEO. Under Stacy's guidance, the organization looks forward to continuing its vital work, expanding its reach, and providing essential support to individuals with PWS and their families. Find the full announcement at the button below.

IMPORTANT ANNOUNCEMENT



[READ MORE HERE](#)

Show Off Your PWS Pride with Amazing Customizable Shoes!



Created by  JMART

PWS 2023 CUSTOM SHOE LINE



Inspired by **Brooklyn Marx** living with PWS and **Caden Sterns** from the Denver Broncos.



Get your very own PWS customizable Nikes and Vans! We want to thank the Marx family, their daughter Brooklyn living with PWS, Denver Broncos player Caden Sterns, and *Custom Creations by JMART* (the shoe creator) for their help in bringing this vision of PWS customizable shoes to life. Shop these shoes by clicking the button below!

[SHOP HERE](#)

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 or his child advocate social worker Cathy Behar at 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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PWSA | USA Special Edition Pulse: July 28, 2023

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Get Ready for Back-to-School!

The end of summer is just around the corner and once again, it will be time to grab the backpacks and schoolbooks!

Whether it is in the classroom or at home, school can come with many challenges for our rare disease community. As you start preparing for your loved one's return to learning, PWSA | USA is here to offer helpful tips and reminders about the education-focused resources available for our PWS families.



**TIPS FOR
SCHOOL
SUCCESS**

Prader-Willi Syndrome Association | USA

We encourage our PWS families to utilize PWSA | USA's Tips for School Success Toolkits! Explore six school success toolkits that share how your child can be successful while navigating learning - whether it's at home or in the classroom.

Get to know the School Success Toolkits

PWS Challenges and Solutions



This toolkit includes videos and resources that outline the unique educational and environmental needs of students with PWS.

[**ENTER HERE**](#)

Individualized Education Program (IEP)



This toolkit includes videos to aid in preparing your child's IEP at every transition period, sample IEPs and supporting documentation.

[**ENTER HERE**](#)

Homeschooling



Thinking about homeschooling? This toolkit is for you. It includes a video by two veteran homeschool parents as well as several resources.

[**ENTER HERE**](#)

Behavior Challenges



This toolkit includes videos and resources that outline the school's legal responsibility when responding to behavioral challenges in the school district.

[**ENTER HERE**](#)

Effective Advocacy



This toolkit includes videos that teach parents how to be effective advocates while building a positive relationship with their child's school, sample letters to use when communicating with the school, as well as templates to share information regarding your child.

[ENTER HERE](#)

Special Education Law



This toolkit includes videos that explain special education law, IDEA and FAPE in laymen's terms. You can also find a copy of IDEA 2004 here.

[ENTER HERE](#)



Interested in learning more? Visit our School Success blog feed for additional resources.

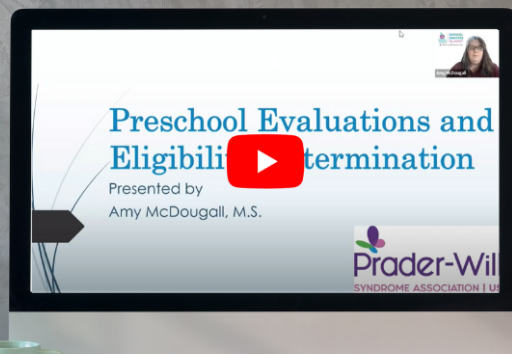
[CLICK HERE](#)

[Share Your School Lunch Tips](#)

[Creating a Parent Input Statement for Your Child's IEP](#)

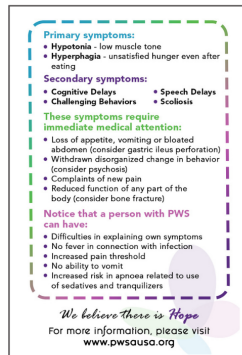
[Creating Your Child's Education File](#)

[How to Develop Positive Relationships with Your School District](#)



Watch PWSA | USA's 2023 School Success Summit recordings to learn many helpful tips and gather information from education experts.

[CLICK HERE](#)



Download PWSA | USA's Customizable PWS Health Identification Card

To help our communities better understand Prader-Willi syndrome, how it affects those diagnosed, and what symptoms require immediate medical attention, PWSA | USA has created a customizable PWS Health Identification Card. This Health ID card can be printed and shared with anyone in your community, e.g. school officials, medical providers, family members, etc.

Learn more and download your customizable card at the button below.

[DOWNLOAD OUR CUSTOMIZABLE CARD HERE](#)

School Lunch Tips from the PWS Community



While I know a lot of parents worry about providing a variety of food options so that meals don't become boring, I never had a concern about this. Day after day, when given the choice between a peanut butter and jelly sandwich and anything else, Cameron chose the peanut butter and jelly sandwich. From Kindergarten through the end of High School, Cameron's school lunches consisted of some type of protein (almost always peanut butter!) on 40-45 calorie bread, raw veggies in a baggie such as carrots and/or celery sticks, some type of fruit in a baggie such as strawberries and/or blueberries, and a 100-calorie pack of some type of chips. Easy, healthy, and delicious -- for twelve years!

- Lisa, mom to Cameron, 24, living with PWS (CA)



We purchased a PlanetBox lunchbox. It was very expensive, but it has lasted 4 years already. It is great for portion control and also for visual appeal. We heat up Sandy Kay's protein option in the morning and then put it in the round covered container. She likes all types of beans. So I will do beans and beef or chicken in that portion. We then add some type of berries in the top portion, and for the 3rd area we put a vegetable with a dip. Something like cucumbers or peppers with peanut butter or hummus. She

really enjoys dipping her veggies. We also include at least 10 oz of water and even wrote that up in her IEP to help improve her water consumption during the day. Sometimes I will put a lemon packet in the water or even a tsp of vinegar! She likes her water to have a bite.

- Winnie, mom to Sandy Kay, 8, living with PWS (NC)

I always packed my son a healthy lunch when he went to school. As he became older, he realized that he could eat it on the bus going to school, and then tell staff that I forgot to make him lunch or that he lost it. He was very cute and very convincing! When I realized what was happening, I made a handout with his photo, a description of PWS and how it affected him, and my contact information. I also stated that he was not to be given a lunch until I was contacted first. I shared it with the bus driver and monitor, school secretary, clerks, and nurse, the teachers and paras. Anyone who had contact with him throughout the day. I did this until he graduated from high school. It worked for the most part. The only glitch was when the middle and some high school kids thought it was hysterical to provide him with food just to laugh at how much and what he ate. That was addressed as well.

- Sharon, mom to a 33-year-old living with PWS (RI)