PWSA | USA Bi-Weekly Pulse: June 7, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 100

June 7, 2024

www.pwsausa.org | 941.312.0400

Registration for the **United in Hope 2025 International PWS Conference is NOW OPEN!** As the first joint conference between PWSA | USA, FPWR, and IPWSO, it symbolizes a historic milestone in the PWS community. The power of working together and promoting our shared interests to benefit all those affected by PWS cannot be underestimated. Our theme “United in Hope” is a call to clinicians, scientists, parents, professional providers and caregivers, allied professionals and trainees, families, and most importantly, individuals with PWS.

Our aim is to bring your vision, your knowledge, your experience and your hopes, and to share and learn at this transformative gathering.

The conference will be held in **Phoenix, AZ, June 24-28, 2025,** and consists of thematic programs designed for the various roles of individuals in the PWS community. The Family Program and PWS and Sibling Camps will take place June 27th and 28th. PWSA | USA will also host a 50th birthday party to celebrate the five decades our organization has been supporting the PWS community!

Though this conference is a year away, there are limited spots in the camps so be sure to register soon! Learn more about the conference and the conference location, **The Arizona Grand Resort and Spa**, by clicking the button below. We look forward to spending an enriching and eventful time together, with people coming from around the world to gather in Phoenix, AZ!

VISIT THE CONFERENCE WEBSITE

PWS Adult, Youth, and Sibling Camps are Filling Up!

Little Tikes Camp (0 - 24 months) - **43% full**
Junior Adventure Camp (2 - 6 years old) - **43% full**
Sibling Camp (6 - 14 years old) - **52% full**
Adventure Camp (7+) - **26% full**

PWSA | USA'S

SPOTLIGHT ON HOPE

Sarah Kasaby, PWSA | USA's Information and Referral Specialist, was introduced to the world of PWS when her now 4-year-old son, Khaled, was diagnosed. In this video spotlight, she speaks about her experience as the mom to a child with PWS, and how the diagnosis does not define her son. She also talks about the impact of having a PWSA mentor in the beginning, why she enjoys working for PWSA, and how the organization helps families around the world. You can watch this video spotlight, filmed and edited by our Marketing Independent Contractor Nate Van Haute, by clicking below.

SPOTLIGHT ON HOPE VIDEO

EVENTS & FUNDRAISERS

Thank You for Helping Us Reach Our Goal!

HELP & HOPE

TOGETHER WE'VE GOT THIS

Prader-Willi Syndrome Association | USA

Thank you to all of the generous donors and dedicated fundraisers of the Help & Hope Family Support campaign for helping us reach our fundraising goal!

The funds raised in this campaign directly support our work in family support. We offer personal family support through our Package of Hope and mentoring program, assistance with the individualized education program (IEP) process, as well as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) claims, training for schools and residential providers, connections and information on PWS specific providers, informative webinars, community-engaging conferences, a blog that focuses on the variety of PWS experiences, and a 24-hour crisis hotline.

We are truly grateful for your dedication and support!

> ***"PWS is hard on everyone, and I'm grateful there are people like those on the Family Support team who pick us up and let us know we're not alone."***
>
> ***- Anonymous***

Registration for Residential Providers Conference

Residential providers and caregivers are integral to the health and well-being of those living with PWS and it is critical that they have access to the latest information. **PWSA | USA's 2024 Residential Providers Conference, *Empowerment Heroes: Reveal Your Superpowers***, will offer a variety of lectures and workshops in a collaborative space where professionals can exchange practice-driven knowledge and actively contribute their experiences. The Conference will take place **August 18-20, 2024**, both virtually via ZOOM and in-person at the Kimpton Brice Hotel in Savannah, GA. The goal of this event is to enhance the care provided to individuals and develop new methods of support on a range of topics like research, relationships, technology, the role of therapies, diagnostic instruments in behavior management, autonomy, aging, and more. Whether you have daily or occasional involvement as a professional caregiver of people with PWS, we invite you to join!

REGISTER HERE

Upcoming Fundraisers

DANCE SILLY for PRADER-WILLI

A FAMILY DANCE PARTY TO BENEFIT PWSA | USA

SATURDAY, OCTOBER 12TH
5:00PM (DOORS OPEN AT 4:30PM)
TRUMBULL CAREER & TECHNICAL CENTER
528 EDUCATIONAL HIGHWAY NW WARREN, OH 44483

INCLUDES:

- DJ FOR THE KIDS
- CRAFT TABLE
- DINNER FOR ALL
- RAFFLES
- A COSTUME CONTEST
- AND MORE!

In honor of Jayda Hampton

100% OF THE PROCEEDS WILL DIRECTLY BENEFIT PWSA | USA, AN ORGANIZATION THAT PROVIDES ADVOCACY, FAMILY SUPPORT AND LIFE-SAVING RESEARCH FOR INDIVIDUALS WITH PWS AND THEIR FAMILIES.

Prader-Willi SYNDROME ASSOCIATION | USA SAVING AND TRANSFORMING LIVES

The **Dance Silly for Prader-Willi** event, a fundraiser for PWSA | USA hosted by PWS mom Michele Hampton, will be a FUN, FAMILY, DANCE party for any family interested! The event will take place close to Halloween to help raise awareness on ways to include all individuals and show that holidays don’t need to be focused on food or candy, but instead fun experiences and time together! This event will include a DJ, dancing, costumes, games, crafts, a kid's basket for all families registered, kid and adult raffles, dinner/snacks for all, and a memorable time with some of your favorite people! Event registration, T-shirt information, and more will be shared at a later date. If you, or someone you know, would be interested in being a sponsor, donating a raffle basket, or being a volunteer, please feel free to reach out to Michele at mhampton0933@gmail.com.

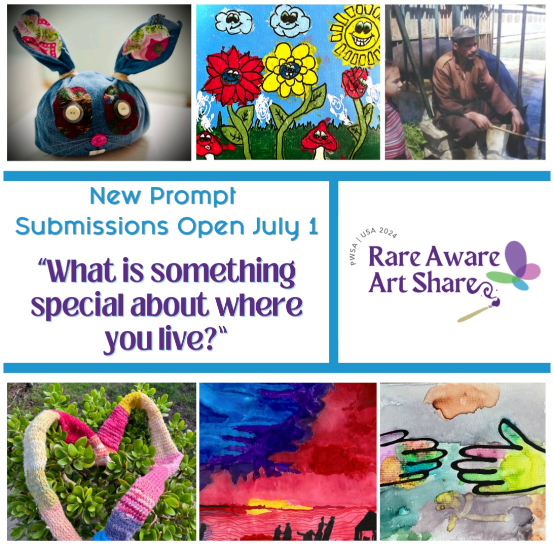
When: Saturday, October 12, 2024 at 4:30 p.m.
Where: Trumbull Career & Technical Center *(528 Educational Hwy NW, Warren, OH 44483)*

LEARN MORE & REGISTER TO ATTEND

PWSA | USA'S UPCOMING EVENTS

ADVOCACY

Rare Aware Art Share Continues

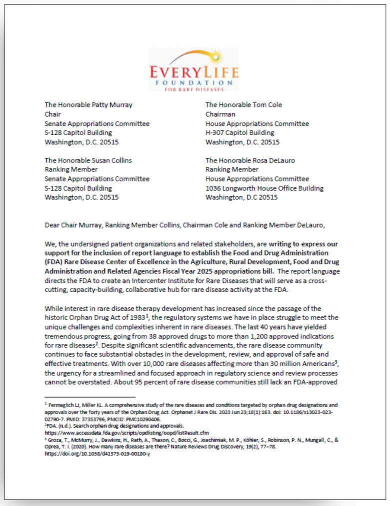


Theme #1 of our Rare Aware Art Share was "What is your superpower?" It introduced us to many talented and thoughtful artists in the PWS community. We greatly appreciated seeing the artistic voice and reading the insightful comments by the artists.

We are excited to prepare for a new round of submissions coming July 1! **Theme #2, "What is something special about where you live?"** intends to highlight the many places we will gather from at our 2025 International PWS Conference next June. Anyone with PWS, anywhere in the world, is welcome to submit, including those who submitted for theme #1. We are excited to see what is special and unique about where our PWS families live! Stay tuned for details on how to participate once we open our submissions for theme #2 on July 1st. Until then, check out the art gallery from theme #1 below.

VISIT ART SHARE GALLERY

Everylife Foundation Submits Letter to Congress Advocating for Rare Diseases



EVERYLIFE
FOUNDATION
FOR RARE DISEASES

The Honorable Patty Murray
Chair
Senate Appropriations Committee
S-128 Capitol Building
Washington, D.C. 20515

The Honorable Tom Cole
Chairman
House Appropriations Committee
H-307 Capitol Building
Washington, D.C. 20515

The Honorable Susan Collins
Ranking Member
Senate Appropriations Committee
S-128 Capitol Building
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Committee
1036 Longworth House Office Building
Washington, D.C 20515

Dear Chair Murray, Ranking Member Collins, Chairman Cole and Ranking Member DeLauro,

We, the undersigned patient organizations and related stakeholders, are **writing to express our support for the inclusion of report language to establish the Food and Drug Administration (FDA) Rare Disease Center of Excellence in the Agriculture, Rural Development, Food and Drug Administration and Related Agencies Fiscal Year 2025 appropriations bill.** The report language directs the FDA to create an Intercenter Institute for Rare Diseases that will serve as a cross-cutting, capacity-building, collaborative hub for rare disease activity at the FDA.

While interest in rare disease therapy development has increased since the passage of the historic Orphan Drug Act of 1983[1], the regulatory systems we have in place struggle to meet the unique challenges and complexities inherent in rare diseases. The last 40 years have yielded tremendous progress, going from 38 approved drugs to more than 1,200 approved indications for rare diseases[2]. Despite significant scientific advancements, the rare disease community continues to face substantial obstacles in the development, review, and approval of safe and effective treatments. With over 10,000 rare diseases affecting more than 30 million Americans[3], the urgency for a streamlined and focused approach in regulatory science and review processes cannot be overstated. About 95 percent of rare disease communities still lack an FDA-approved

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[1] Fermaglich LJ, Miller KL. A comprehensive study of the rare diseases and conditions targeted by orphan drug designations and approvals over the forty years of the Orphan Drug Act. Orphanet J Rare Dis. 2023 Jun 23;18(1):163. doi: 10.1186/s13023-023-02790-7. PMID: 37353796; PMCID: PMC10290406.
[2] FDA. (n.d.). Search orphan drug designations and approvals. https://www.accessdata.fda.gov/scripts/opdlisting/oopd/listResult.cfm
[3] Groza, T., McMurry, J., Dawkins, H., Rath, A., Thaxon, C., Bocci, G., Joachimiak, M. P., Köhler, S., Robinson, P. N., Mungall, C., & Oprea, T. I. (2020). How many rare diseases are there? Nature Reviews Drug Discovery, 19(2), 77–78. https://doi.org/10.1038/d41573-019-00180-y

The EveryLife Foundation has submitted its letter to Congress advocating for the inclusion of a Rare Disease Center of Excellence in the 2025 appropriations bill. PWSA | USA is proud to have been one of more than 100 organizations to sign on to this letter!

Click the button below to read more.

READ MORE HERE

FAMILY SUPPORT

PWS in Adulthood Blog Series

Are you prepared for your loved one with Prader-Willi syndrome's transition into adulthood? Most parents are not and many don't know where to begin. Thankfully, we can learn from the experiences of those who have already helped their loved ones through that transition. Jamie Prentice, mom to 31-year-old Logan, shares her advice and much-needed information on the steps toward adulthood and how early parents should start thinking about those decisions. She encourages connections and education and touches on the cautions of social media. With Jamie's insight and guidance, parents of loved ones with PWS transitioning into adulthood now have a clearer picture of their first or next steps. Read Jamie's blog below.

If you are the parent of an adult loved one with PWS and would like to share your advice, please email africke@pwsausa.org.

READ BLOG HERE

Post a Message for Father's Day

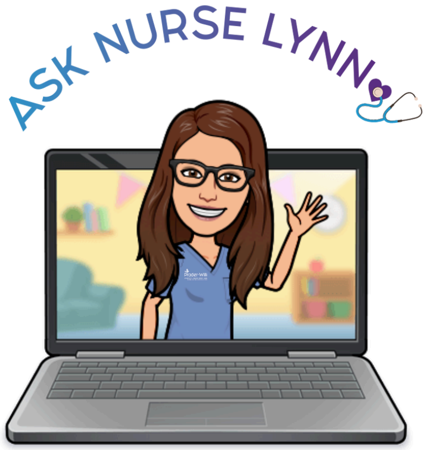
Ask Nurse Lynn

Question *(Male, 16, UPD):*

My son has had issues with bowel movements and constipation his entire life. He spends long amounts of time in the bathroom and tells me that he feels like there was more that needed to come out, but he can't get it out. A few times lately there has been blood on the stool. He has accidents sometimes when he passes gas and gets some tiny stool on his underwear. Should I take him to a doctor to be examined? What kind of doctor would I take him to and how do I help them to understand that this may be more serious than the usual answer to give him more Miralax. (Which seems to increase the frequency of the accidents).

Visit our blog to read Nurse Lynn's response about long-standing constipation.

READ NURSE LYNN'S RESPONSE



Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

Now you can **Ask Nurse Lynn,** PWSA | USA's very own PWS Nurse.

ASK YOUR QUESTION HERE

Family Support Webinars

To many, "exercise" seems to have become a bad word, often followed by sighs and groans of disgust at the mention of it. As caregivers of individuals with PWS, we know how important exercise is for our loved ones. We should also remember how important exercise is for ourselves, especially if we are hoping to avoid burnout. In this family support webinar, PWSA | USA Board Member Kathryn Lucero will discuss the benefits of exercise and the how and why of incorporating exercise into our daily lives. By changing the language we use around exercise, and what it means to us, we can promote and increase the likelihood of staying on an activity program that will benefit us. Join this webinar to learn, "What's the big deal about exercise?" Register below.

REGISTER HERE

Watch the recording of our May Family Support Webinar, **Romancing the PWS Parent: Strategies to Create a Strong and Healthy Marriage** with Lisa Graziano, MA, LMFT, at the button below.

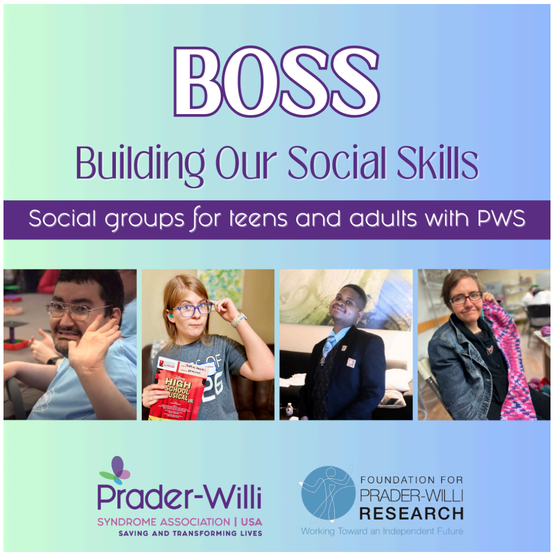
CLICK HERE TO WATCH

Building Social Skills for Teens and Adults with PWS

Does your teen or adult want the opportunity to build their social skills? PWSA | USA is thrilled to offer more sessions for the **Building Our Social Skills (BOSS) curriculum**, a highly effective social skills intervention program created at Vanderbilt University. The BOSS curriculum provides tailored social groups to teens and adults with PWS, empowering them to enhance their social interactions and build meaningful connections.

The BOSS curriculum will begin in July, and we will accept applications through June. These sessions will be held virtually via Zoom. All sessions are mandatory, and participants must be able to communicate vocally without assistance in order to participate in these virtual sessions. Please click the button below to find our application and send your completed application to info@pwsausa.org.

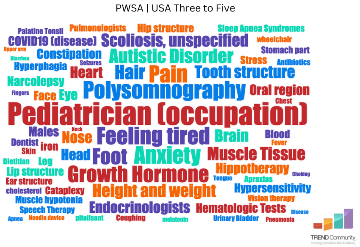
Thank you to The Foundation for Prader-Willi Research for funding the creation of the BOSS curriculum.

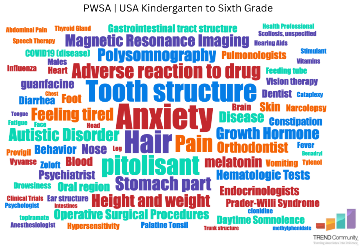


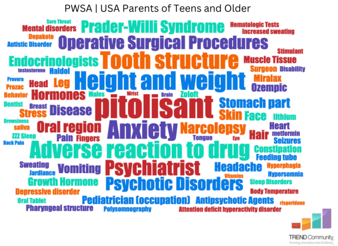
LEARN MORE HERE

RESEARCH

TREND Statistics from Facebook Groups







TREND Community is a “community-powered data analytics company, unlocking people’s conversations about living with rare and chronic diseases, delivering actionable, real-world insights, and driving progress in healthcare."

For 2.5 years PWSA | USA has been partnering with TREND Community to turn our online support groups into a source of real-world evidence. The above word cloud graphics represent the most frequently discussed terms in our Facebook group discussions. These insights have fueled critical research for our community by shedding light on under recognized symptoms and our community’s unmet needs. Our privacy is always protected. Only non-identifying data is used for research, with progress shared within the community.

Due to recent Facebook policy updates and limitations, TREND Community has shifted its research efforts to PWS Connect on Discord. Please check your inbox in the coming weeks for information on how you can participate.

Harmony Biosciences Opens New Trial Site and Launches Website

Harmony Biosciences has opened an additional trail site in Cincinnati, OH for their Pitolisant study. The Phase 3 Pitolisant clinical trial website for TEMPO is now live! Visit the website and learn more about this trial at the button below.

TEMPO WEBSITE

Help Needed: Caregivers of Children with Prader-Willi Syndrome and Repetitive Verbal Behavior

Kasey Bedard, PhD, and her team at The Chicago School are seeking caregivers of children diagnosed with Prader-Willi syndrome (PWS) who exhibit repetitive verbal behavior to participate in a research study. This study, part of a dissertation project, aims to test interventions that caregivers can implement at home.

If interested, please contact Dr. Bedard at Kbedard1@thechicagoschool.edu or Chante Dix, MA, BCBA, LBA at Cnr4994@ego.thechicagoschool.edu. Please share this information with anyone who might be interested.

Study Details:

- Duration: 2-3 weeks
- Frequency: 1-3 sessions per day
- All sessions will be recorded
- Caregivers will participate in training activities

Eligibility Criteria:

- Caregiver is 18 years or older
- Access to a computer or device with internet
- Proficient in English
- Child is 4-8 years old, diagnosed with PWS
- Child uses vocal communication
- No severe challenging behaviors in the child's history

DOWNLOAD THE FLYER

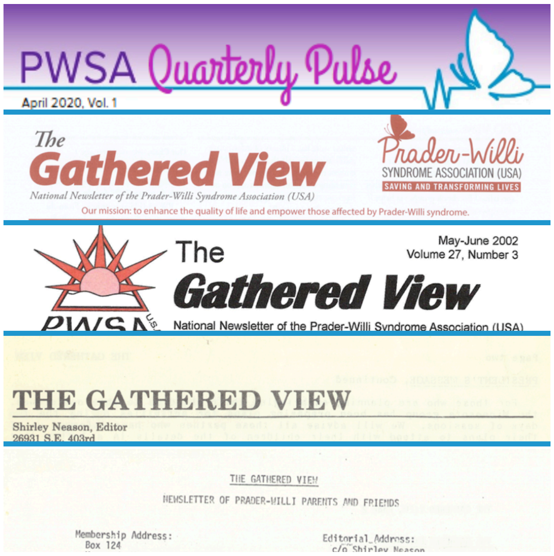
Request for Prader-Willi Syndrome Research and Mini-Fellowship Grant Applications

PWSA | USA is currently seeking research project applications with direct impacts on individuals and families affected by PWS. We are offering mini-fellowship grants to support providers in enhancing their understanding of PWS through clinical proctorships. Research priorities include expanding knowledge about PWS, applying therapies, and attracting new providers and investigators to the field. Funding opportunities include grants of up to $100,000 for 12 months, with potential renewal, smaller grants of up to $10,000, and mini-fellowships of up to $25,000. Applications and inquiries can be directed to Stacy Ward at sward@pwsausa.org or by calling (941) 312-0400. The deadline to submit a Letter of Intent is September 1, 2024, 5:00pm EDT. Click the button below to learn more and to read additional guidelines.

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight



PWSA Quarterly Pulse
April 2020, Vol. 1

The Gathered View
National Newsletter of the Prader-Willi Syndrome Association (USA)
Prader-Willi SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES
Our mission: to enhance the quality of life and empower those affected by Prader-Willi syndrome.

The Gathered View
May-June 2002
Volume 27, Number 3
National Newsletter of the Prader-Willi Syndrome Association (USA)

THE GATHERED VIEW
Shirley Neason, Editor

THE GATHERED VIEW
NEWSLETTER OF PRADER-WILLI PARENTS AND FRIENDS
Membership Address:
Box 124
Editorial Address:

This newsletter marks the **100th edition** of PWSA | USA's Pulse! In honor of this milestone, we wanted to direct people to our catalogue of past newsletters. Our organization has been around almost 50 years and we have been communicating via newsletter with the PWS community since the beginning. For the majority of our community-wide correspondence, our newsletter was called "The Gathered View" to symbolize the coming together of knowledge and support. While this newsletter is still a gathering of information and perspectives, the current name represents our organization's dedication, determination, and ability to stay on the **pulse** of what is happening in the world of PWS. Our staff and volunteers are diligent in following through with our mission, "To enhance the quality of life and empower those affected by Prader-Willi syndrome." If you're interested in a catalogue of PWS-related information throughout the decades, or simply want to check out any recent Pulse newsletters you may have missed, check out our "library" using the button below.

VISIT OUR LIBRARY

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: June 21, 2024

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 101

June 21, 2024

www.pwsausa.org | 941.312.0400

Do you want to be a part of imperative research for the PWS community from the comfort of your own home?

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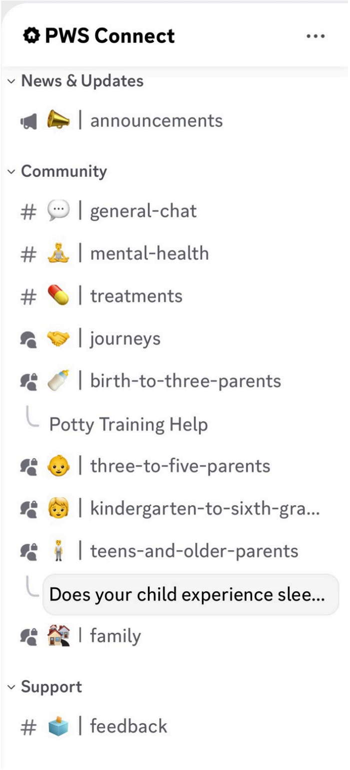
For 2.5 years PWSA | USA has been partnering with TREND Community to turn our online support groups into a source of real-world evidence. By collecting the most frequently discussed terms in the Facebook group discussions, TREND was able to gather insights that shed light on under-recognized symptoms and our community's unmet needs, fueling critical research for our community. Our privacy is always protected. Only non-identifying data is used for research, with progress shared within the community.

Due to recent Facebook policy updates and limitations, TREND Community has shifted its research efforts to PWS Connect on Discord. We are inviting the PWS community to join us there!

SIGN UP FOR PWS CONNECT ON DISCORD



PWS Connect ···

News & Updates
- 📣 | announcements

Community
- # 💬 | general-chat
- # 🧘 | mental-health
- # 💊 | treatments
- 🤝 | journeys
- 🍼 | birth-to-three-parents
  - Potty Training Help
- 👶 | three-to-five-parents
- 🧒 | kindergarten-to-sixth-gra...
- 🧍 | teens-and-older-parents
  - Does your child experience slee...
- 🏘 | family

Support
- # 🗳 | feedback

What You'll Find in PWS Connect

Everyone in the PWS community can join PWS Connect; parents, grandparents, siblings, caregivers, individuals with PWS, etc. There are multiple thematic discussions and groups to participate in. The age-specific groups are for parents only. Once your survey is filled out and processed, parents will automatically be added to appropriate age groups.

Once you join PWS Connect, please share your story under the “Journeys” channel so that everyone can get to know you.

Learn more about how TREND insights have helped further PWS research, accelerate drug development, and more by reading our blog below.

LEARN MORE HERE

PWSA | USA'S

SPOTLIGHT ON HOPE

Sarah Jane Clark is a 17-year-old living with PWS in Wheeler County, GA. This past April, she was honored by her classmates during their school prom. Sarah, along with a classmate with Down Syndrome, was crowned Prom Queen of her senior class. One of Sarah's classmates said that the two of them "let nothing limit them in life." Individuals with PWS often struggle socially in mainstream society and may be overlooked by their peers. Congratulations to Sarah for breaking down those barriers and attaining the role of royalty. You can watch the news story, "*A happy ending to a long battle: Wheeler County crowns beloved prom queen and king*," below.

SPOTLIGHT ON HOPE VIDEO

EVENTS & FUNDRAISERS

2025 United in Hope International PWS Conference

United in HOPE
2025 PWS CONFERENCE

Conference Details

June 24, 2025
PWS Clinical Workshop
Invitation Only

June 25-26, 2025
Clinical & Scientific Program
Professional Providers Program

June 26, 2025
Adults with PWS Program
1/2 Day

June 27-28, 2025
Family Program
PWS Camps

Registration for the 2025 International PWS Conference is well underway and camps are filling up! The Sibling Camp is now FULL and you can find the current capacities of the other Camps below.

The Conference will be held in **Phoenix, AZ, June 24-28, 2025,** and consists of thematic programs designed for the various roles of individuals in the PWS community. The Family Program and PWS and Sibling Camps will take place June 27th and 28th. PWSA | USA will also host a 50th birthday party to celebrate the five decades our organization has been supporting the PWS community!

Though this Conference is a year away, there are limited spots, especially in the Camps, so be sure to register soon! Learn more about the Conference and the Arizona Grand Resort and Spa by clicking the button below. We look forward to spending an incredibly enriching and eventful time together, with people coming from around the world to gather in Phoenix, AZ!

VISIT CONFERENCE WEBSITE

2025 Conference Camps:

Little Tikes Camp (0-24 months) - 43% capacity
Junior Adventure Camp (2-6 years) - 75% capacity
Sibling Camp (6-14 years) - FULL
Adventure Camp (7+) - 51% capacity

Registration for Residential Providers Conference

Residential providers and caregivers are integral to the health and well-being of those living with PWS and it is critical that they have access to the latest information. **PWSA | USA's 2024 Residential Providers Conference, *Empowerment Heroes: Reveal Your Superpowers***, will offer a variety of lectures and workshops in a collaborative space where professionals can exchange practice-driven knowledge and actively contribute their experiences. The Conference will take place **August 18-20, 2024**, both virtually via ZOOM and in-person at the Kimpton Brice Hotel in Savannah, GA. The goal of this event is to enhance the care provided to individuals and develop new methods of support on a range of topics like research, relationships, technology, the role of therapies, diagnostic instruments in behavior management, autonomy, aging, and more. Whether you have daily or occasional involvement as a professional caregiver of people with PWS, we invite you to join!

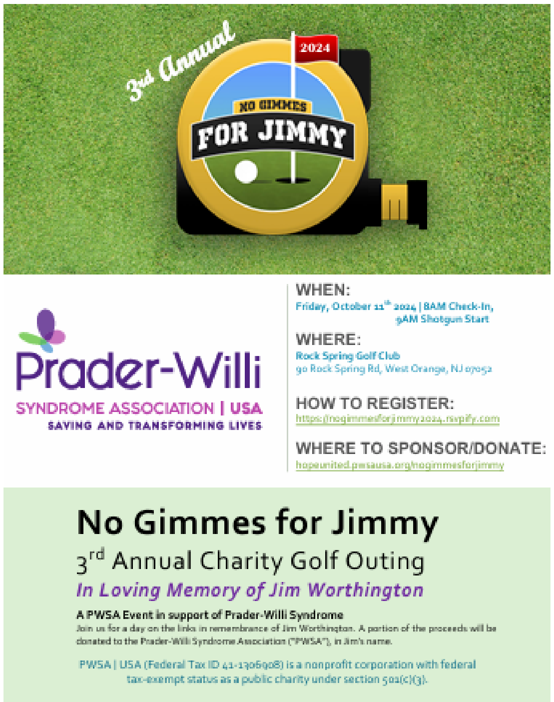
REGISTER HERE

Upcoming Fundraisers

Join us in remembrance of Jim Worthington. A portion of the proceeds will be donated to the PWSA, in Jim's name. This event is inclusive for golfers and non-golfers alike – all skill levels are welcome. While he survived being directly under Tower 1 on 9/11, Jim Worthington eventually lost his battle with leukemia on October 16, 2021. He loved to play golf when he could get out — which was not often. He loved his family even more, including his son with Prader-Willi Syndrome.

A “gimme” in golf is usually a short putt that is excused by one’s opponent for playing because it is considered too easy to miss. Jim was as generous on the golf course as he was in life, and his wish was that any “gimmes” go to helping those individuals and families with PWS.

When: Friday, October 11, 2024, Check-in at 8am
Where: Rock Spring Gold Club *(90 Rock Spring Rd, West Orange, NJ 07052)*



Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

WHEN:
Friday, October 11th 2024 | 8AM Check-In, 9AM Shotgun Start

WHERE:
Rock Spring Golf Club
90 Rock Spring Rd, West Orange, NJ 07052

HOW TO REGISTER:
https://nogimmesforjimmy2024.rsvpify.com

WHERE TO SPONSOR/DONATE:
hopeunited.pwsausa.org/nogimmesforjimmy

No Gimmes for Jimmy
3rd Annual Charity Golf Outing
In Loving Memory of Jim Worthington

A PWSA Event in support of Prader-Willi Syndrome
Join us for a day on the links in remembrance of Jim Worthington. A portion of the proceeds will be donated to the Prader-Willi Syndrome Association ("PWSA"), in Jim's name.

PWSA | USA (Federal Tax ID 41-1306908) is a nonprofit corporation with federal tax-exempt status as a public charity under section 501(c)(3).

LEARN MORE & REGISTER TO ATTEND

PWSA | USA'S UPCOMING EVENTS

Become a Hope United Champion and host an event in your community! Learn more below.

HOST A FUNDRAISER

Thank you, Hurdle Family

PWSA | USA would like to express our deep appreciation to Clint and Karla Hurdle for hosting another successful Hot Stove Dinner. This year, they raised $230,000 for PWSA | USA's family support programs and services. This includes our parent mentoring program, 24-hour crisis line, school and residential trainings, webinars, online support groups, downloadable and printable information, and more. You can find a recap of this year's event at the button below.

READ RECAP HERE

ADVOCACY

Congratulations Dorothea, Fierce Advocate!

Congratulations to our own Dorothea Lantz (PWSA | USA's Community Engagement Director) for winning the Patients Rising 2024 Fierce Advocate award! As many in our community know, this recognition is incredibly well-deserved. Dorothea is such an inspiration, constantly moving the needle in PWS and rare disease advocacy efforts. We are so proud of her for this achievement! Dorothea and other PWS advocates returned to D.C. for the 2024 We the Patients Week in D.C. You can watch a recording of the event's live stream below.

WATCH HERE

D.C. Fly-In Recap Video

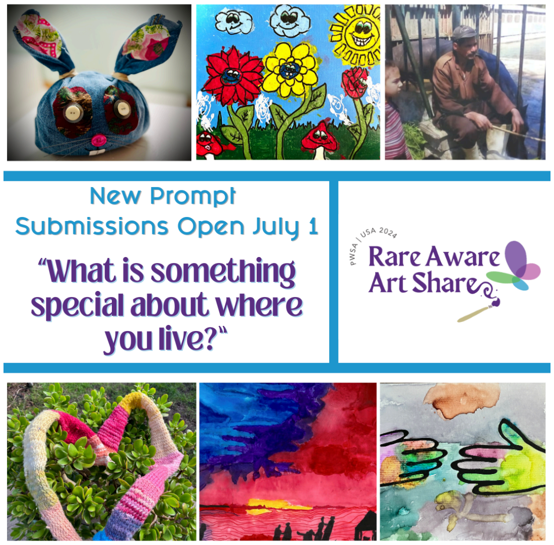
Thank you to everyone who made PWSA | USA's 2nd D.C. Fly-In event a success. This year's event was extra special with nearly 150 parents, siblings, and individuals living with PWS in attendance, sharing their stories in more than 130 Congressional meetings on National PWS Awareness Day (May 15th)! Find more information about this event below. Thank you to our incredible sponsors for all their support: Soleno Therapeutics, Harmony Biosciences, Aardvark Therapeutics, and Acadia Pharmaceuticals.

2024 D.C. FLY-IN

Rare Aware Art Share Continues

Theme #1 of our Rare Aware Art Share was "What is your superpower?" It introduced us to many talented and thoughtful artists in the PWS community. We greatly appreciated seeing the artistic voice and reading the insightful comments by the artists.

We are excited to prepare for a new round of submissions coming July 1! **Theme #2, "What is something special about where you live?"** intends to highlight the many places we will gather from at our 2025 International PWS Conference next June. Anyone with PWS, anywhere in the world, is welcome to submit, including those who submitted for theme #1. We are excited to see what is special and unique about where our PWS families live! Stay tuned for details on how to participate after we open our submissions for theme #2 on July 1st. Until then, check out the art gallery from theme #1 below.



VISIT ART SHARE GALLERY

FAMILY SUPPORT

Blog on Staying Safe in the Heat

Summer is well underway, and parts of the U.S. are experiencing extreme temperatures and high heat index warnings. While these conditions can pose a threat to anyone, they especially put our loved ones with PWS at risk for heat stroke and heat exhaustion. Due to the dysfunction of the hypothalamus, individuals with PWS struggle to regulate their body temperature. We must use serious caution with our loved ones in the heat, especially in the potentially dangerous conditions that parts of the country have been experiencing. To find tips on how to keep your loved one safe in the heat, please read our blog at the button below.

READ BLOG HERE

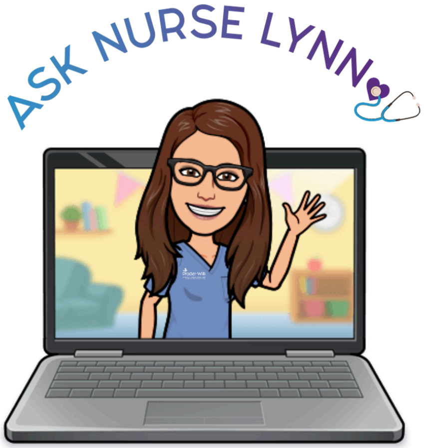
Ask Nurse Lynn

Question *(Male, 17, Deletion):*

How can I address my son's behavior? Lately he gets mad and starts throwing things around, the more I ask him to stop the angrier he gets. If I ground him, he does exactly the opposite of what I ask him to do. Also, at school, teachers have told me should spank him very hard for stealing food. I really don't think that is the right path to go. I really need your advice as I feel like nothing I do is working for him. Thank you in advance.

Visit our blog to read Nurse Lynn's response about behavior management and why spanking is never the answer.

READ NURSE LYNN'S RESPONSE



Do you have a non-emergency medical question about Prader-Willi syndrome? Do you have a non-urgent medical question that keeps coming up, but you forget to ask every time you're at the doctor? Perhaps your question applies to numerous families who will benefit from hearing the answer.

Now you can **Ask Nurse Lynn,** PWSA | USA's very own PWS Nurse.

ASK YOUR QUESTION HERE

Family Support Webinars

To many, "exercise" seems to have become a bad word, often followed by sighs and groans of disgust at the mention of it. As caregivers of individuals with PWS, we know how important exercise is for our loved ones. We should also remember how important exercise is for ourselves, especially if we are hoping to avoid burnout. In this family support webinar, PWSA | USA Board Member Kathryn Lucero will discuss the benefits of exercise and the how and why of incorporating exercise into our daily lives. By changing the language we use around exercise, and what it means to us, we can promote and increase the likelihood of staying on an activity program that will benefit us. Join this webinar to learn, "What's the big deal about exercise?" Register below.

REGISTER HERE

Watch the recording of our May Family Support Webinar, **Romancing the PWS Parent: Strategies to Create a Strong and Healthy Marriage** with Lisa Graziano, MA, LMFT, at the button below.

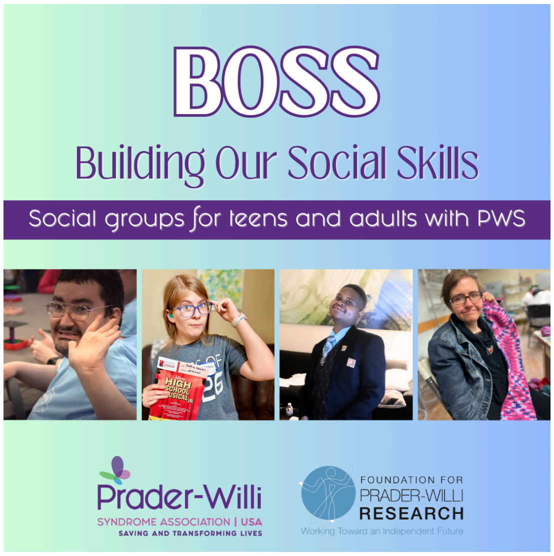
CLICK HERE TO WATCH

Building Social Skills for Teens and Adults with PWS

Does your teen or adult want the opportunity to build their social skills? PWSA | USA is thrilled to offer more sessions for the **Building Our Social Skills (BOSS) curriculum**, a highly effective social skills intervention program created at Vanderbilt University. The BOSS curriculum provides tailored social groups to teens and adults with PWS, empowering them to enhance their social interactions and build meaningful connections.

The BOSS curriculum will begin in July, and we will accept applications through June. These sessions will be held virtually via Zoom. All sessions are mandatory, and participants must be able to communicate vocally without assistance in order to participate in these virtual sessions. Please click the button below to find our application and send your completed application to info@pwsausa.org.

Thank you to The Foundation for Prader-Willi Research for funding the creation of the BOSS curriculum.



LEARN MORE HERE

RESEARCH

Help Needed: Caregivers of Children with Prader-Willi Syndrome and Repetitive Verbal Behavior

Kasey Bedard, PhD, and her team at The Chicago School are seeking caregivers of children diagnosed with Prader-Willi syndrome (PWS) who exhibit repetitive verbal behavior to participate in a research study. This study, part of a dissertation project, aims to test interventions that caregivers can implement at home.

If interested, please contact Dr. Bedard at Kbedard1@thechicagoschool.edu or Chante Dix, MA, BCBA, LBA at Cnr4994@ego.thechicagoschool.edu. Please share this information with anyone who might be interested.

Study Details:

- Duration: 2-3 weeks
- Frequency: 1-3 sessions per day
- All sessions will be recorded
- Caregivers will participate in training activities

Eligibility Criteria:

- Caregiver is 18 years or older
- Access to a computer or device with internet
- Proficient in English
- Child is 4-8 years old, diagnosed with PWS
- Child uses vocal communication
- No severe challenging behaviors in the child’s history

DOWNLOAD THE FLYER

Request for Prader-Willi Syndrome Research and Mini-Fellowship Grant Applications

PWSA | USA is currently seeking research project applications with direct impacts on individuals and families affected by PWS. We are offering mini-fellowship grants to support providers in enhancing their understanding of PWS through clinical proctorships. Research priorities include expanding knowledge about PWS, applying therapies, and attracting new providers and investigators to the field. Funding opportunities include grants of up to $100,000 for 12 months, with potential renewal, smaller grants of up to $10,000, and mini-fellowships of up to $25,000. Applications and inquiries can be directed to Stacy Ward at sward@pwsausa.org or by calling (941) 312-0400. The deadline to submit a Letter of Intent is September 1, 2024, 5:00pm EDT. Click the button below to learn more and to read additional guidelines.

LEARN MORE HERE

PWSA | USA ANNOUNCEMENTS

Empowering Diversity and Inclusion for the PWS Community

1:15,000 children are born with PWS.
How many children of color are diagnosed?
How are they and their families affected?

Want to meet more PWS families of color?

- Every person with PWS is different. We share our experiences and lessons learned. As caregivers, it's natural to seek out success stories that reflect our children.
- The purpose of this BIPOC Affinity group is to connect people of color, living with or affected by Prader-Willi Syndrome (PWS) to be empowered and live their best lives.
- If you are a person of color diagnosed with PWS or raise children of color, email BIPOCPWS@gmail.com to sign up for our email list and group chat on Signal.

Let's encourage a conversation that brings about a standard of care that considers all shades/cultures of people living with PWS.

In a significant step towards fostering equity and inclusion within our Prader-Willi syndrome (PWS) community, we are pleased to announce a collaborative initiative aimed at improving the standard of care and support for marginalized individuals living with PWS and their families. This initiative, undertaken with the active involvement of several community members, seeks to ensure that every person living with PWS, regardless of their background, can access better care and harbor hope for the future. As an initial measure, the community members established a BIPOC (Black, Indigenous, and People of Color) affinity group. This group is dedicated to people of color living with PWS and their caregivers, providing a platform to share experiences, offer mutual support, and develop necessary resources. We urge all PWS service providers to assist in spreading the word about this vital initiative to families of color within the PWS community. Your support is crucial in reaching those who will benefit most from these efforts. For any questions or further information, please contact the BIPOC organizer group - Charles Conway, Karine Kabundi, and Dini Rao - at bipocpws@gmail.com.

PWSA | USA Resource Spotlight

We have added a new webpage to the PWSA | USA website. **Welcome to Tech for Independence!** This is your go-to place for discovering innovative technology that helps support and enhance independence. Whether you're looking for tools to assist with daily tasks, mobility aids, or smart home devices, you'll find a range of ideas here. Many of these solutions may be covered under waivered services, making them more accessible. Please keep checking this webpage as we will continue to update it with more resources and tools.

[VISIT WEBPAGE]

PWS Community Tips for Summertime

Next week's Special Edition Pulse will focus on staying safe and enjoying summer. We will be covering various topics important to the PWS community and are looking for input from families and caregivers. Please check out the prompts and topics below. If you have something to share with the community, please email your responses to africke@pwsausa.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!

Donate

Privacy Policy | Unsubscribe

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

PWSA | USA Special Edition Pulse: June 28, 2024

www.pwsausa.org | 941.312.0400

Donate

For many families, summertime is an enjoyable break from the tediousness of scheduled living. There are backyard BBQs, ball games, kid camps, music festivals, vacations, campouts, swim parties, ice cream outings, and more. For families of individuals with PWS, summertime can be an incredibly challenging time of year. From the dangers of intense heat and sun exposure, to difficulties in finding safe summer camps, to creating a routine for your anxious loved one and getting them to drink enough water! As with most things on the PWS path, families must learn to adapt - their plans, their expectations, their lives. Thankfully, we are a resourceful community and have learned many ways to adapt to the challenges of PWS so that we may also have an enjoyable and pleasant summer. This issue is devoted to helping your family find ways to stay cool in the heat, create a routine, keep your loved one hydrated and active, along with some yummy recipes to bring a taste of summer to your home.

Staying Cool in the Heat

*Plan activities for cooler times of day (early morning or evening)

*Use umbrellas, hats, and portable fans

*Always wear sunscreen

*Keep frozen water bottles handy

*Stay hydrated

*Let the car cool down before getting in

*Wear light, loose-fitting clothing

*Take frequent breaks

*Find cool places to rest

*Use cooling vests, towels, and gel pads

READ MORE HERE

Keep Your Loved One Hydrated

It is well-known and documented that individuals with PWS typically do not like to drink plain water. While the mechanism behind this may not be completely understood, it should be thought of as another symptom of PWS that needs to be managed, especially during the hot days of summer. We asked some parents and staff members how they encourage individuals with PWS to drink water:

*Establish a schedule of water drinking throughout the day (e.g., drink a glass of water before each meal).

*Add lemon or lime, cucumber slices, fresh berries, mint leaves, or tea bags to the water to add a simple flavoring.

*Cirkul water bottles add flavor without sugar or calories.

*As dehydration can cause significant medical issues, it is sometimes more important to hydrate than to avoid sweet tastes. Electrolyte drinks like Liquid IV or Gatorade (they make a 0-calorie version) can be very helpful in these situations.

While water intoxication may not be something to fear, it is something to be aware of, especially if your loved one is on psychiatric medicine. Please click on the resources below to learn more.

WATER INTOXICATION ALERT

HYPONATRAEMIA ARTICLE

Get Moving

With most kids at home for the summer, and, in many places, the outside temperature is too hot for individuals with PWS, it can be more challenging to get our loved ones moving. We've asked volunteers, community members, and staff for ideas on getting your loved one moving during these summer months:

*Make use of indoor courts and pools.

*Create a mall scavenger hunt.

*Swimming is great but make it more active by playing pool games like basketball and diving for rings.

*Go to wooded areas and use the shady woods as your gym. Hike, climb over downed trees, or do a scavenger hunt to keep moving.

*Visit playgrounds in the morning.

*Use YouTube to find fun workout videos or learn a TikTok dance.

*Create a workout sticker chart to help motivate your loved one.

*Walk a dog (in the cooler parts of the day).

Watch our June Family Support Webinar, "*What's the BIG Deal about Exercise*" with speaker Kat Lucero, to learn more about the importance of exercise for the entire family.

WATCH WEBINAR HERE

Activities

Whether you're a parent working from home or have numerous free hours to spend with your loved one, it can be challenging to find entertaining and enriching activities for a full day. Hopefully, this list of ideas can help inspire activities your family will enjoy:

*Board games and puzzles.

*Age and skill-level-appropriate workbooks (these have the added bonus of keeping your loved one's academic skills active).

*Create scavenger hunts around the house.

*Curate a box of accessible, age-appropriate art supplies ("Dollar" stores often have fun, affordable art supplies).

*Visit the local bookstore and gather a stash of appropriate books for quiet afternoons.

> ***"Hop in your local town's mom Facebook group to find out what activities are happening regularly during the summer that may fit your kid's age and interests. I put all potential activities and events in a separate google calendar list so I can see what our options are but easily toggle it off as well."***
> - @raisinglazarusPWS on Instagram

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*Grab a stack of magazines from a local thrift store or recycling center and use those to create collages.

*Set up indoor obstacle courses or play "the floor is lava" with couch cushions.

*Get a backyard splashpad for fun, cooling play.

*YouTube has an assortment of videos teaching children how to draw various things.

*Set an amount of time your loved one "works" on the computer practicing academic skills. There are various websites that host age-related curricula. Khan Academy is a great option for multiple ages and skill levels.

*Visit local museums and discovery centers.

*Create submissions for PWSA | USA's Rare Aware Art Share, "What is something unique about where you live?"

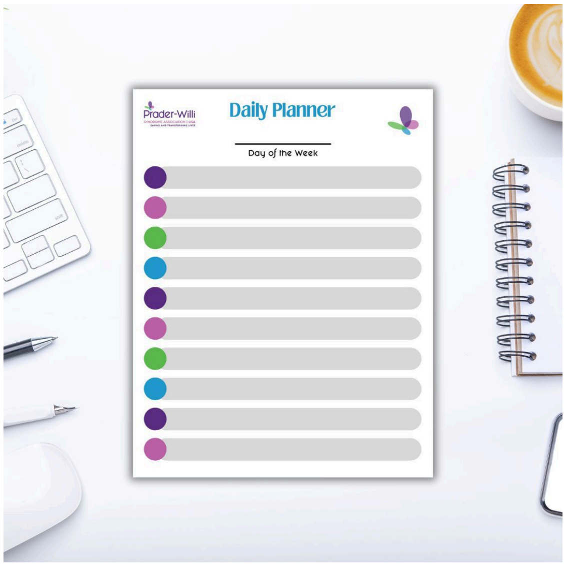
RARE AWARE ART SHARE

Creating Routine

A change in routine can be very challenging for our loved ones. Not knowing what to expect can cause anxiety and ultimately lead to behavior problems. Creating a routine, or crafting a visual schedule, can ease anxiety and help your loved one feel more secure and sure of what the day will bring.

Routines are little points in the day your loved one can rely on. Perhaps you start each day with a walk, or yoga exercises and spend 30 minutes reading or watching TV before bed. These are simple ways to include routine whether you are home or on vacation.

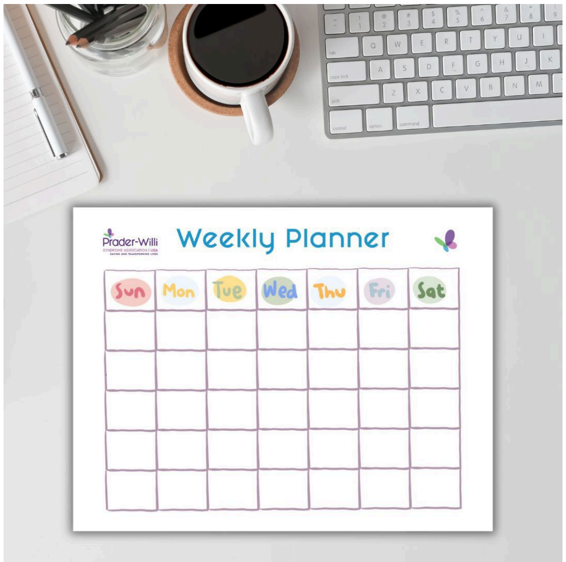
Schedules can be as simple as listing in order the events of the day (e.g., Breakfast, make bed, walk, play, lunch, computer time, snack, play, dinner, bed) or a more detailed schedule involving times and specific activities. A visual schedule can help lessen perseveration and "when are we...?" questions. We have created two printable schedules, a daily and a monthly resource document, as tools to help your family. **Click the images** to download and print.



Prader-Willi

Daily Planner

Day of the Week



Prader-Willi

Weekly Planner

Sun	Mon	Tue	Wed	Thu	Fri	Sat

Summertime Recipes

Summertime offers a wide array of fresh fruit and vegetables. Some families grow their own food which can be a bountiful blessing (and potentially another obstacle to navigate with PWS). Farmer's markets adorn many cities and towns through these months, and many grocery stores expand with the abundance of fresh fruit and vegetables. Summer can be a fun time to try new recipes. Below is a variety of recipes from the community and staff for delicious ways to enjoy that summer abundance. Please remember that these recipes are suggestions and possible ideas. They may not be a good option for your family. If you'd like to read more about nutrition choices and differences amongst families, please read our blog "Nutrition Discourse in the PWS Community".

READ BLOG HERE

Cabbage Steak Burgers (from @eisarosas on Instagram)

*Slice 1-inch thick cabbage

*season with olive oil, salt, pepper, onion powder, and garlic

*Roast in the oven

*Cook turkey burgers and place on top of cabbage steak

*Add onions, pickles, sugar-free ketchup, or barbecue sauce

Chicken Tzatziki Salad

"Chicken Tzatziki salad is an easy cold dish to use up leftover chicken. It's great served on a bed of shredded spinach, but works just as well in a wrap the next day." - Amy Voelker Watson

Recipe from *Nourished by Nic*.

GO TO RECIPE

Israeli Salad

"This is my favorite summer salad with veggies that we grow. It's great as a side dish for almost any meal and even tastes good in scrambled eggs." - Anne Fricke

Recipe from *The Forked Spoon*.

GO TO RECIPE

Almond Butter Popsicles

*1/2 Cup Almond Butter

*3/4-1 Cup Greek Yogurt (It's important to do the full fat because it has less sugar.)

*1 Tablespoon of maple syrup or honey

*Blend until smooth

*Pour into popsicle mold or lay on parchment with a stick and sprinkle nuts

*Freeze and enjoy!

Frozen Fruit Sorbet

*100% frozen fruit with nothing added

*You may want to add frozen Greek yogurt for protein

Click the button to view Yonanas Frozen Fruit soft serve maker on Amazon.

YONANAS MACHINE

Prader-Willi
SYNDROME ASSOCIATION | Ohio
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