PWSA | USA Pulse Newsletter: June 6, 2025

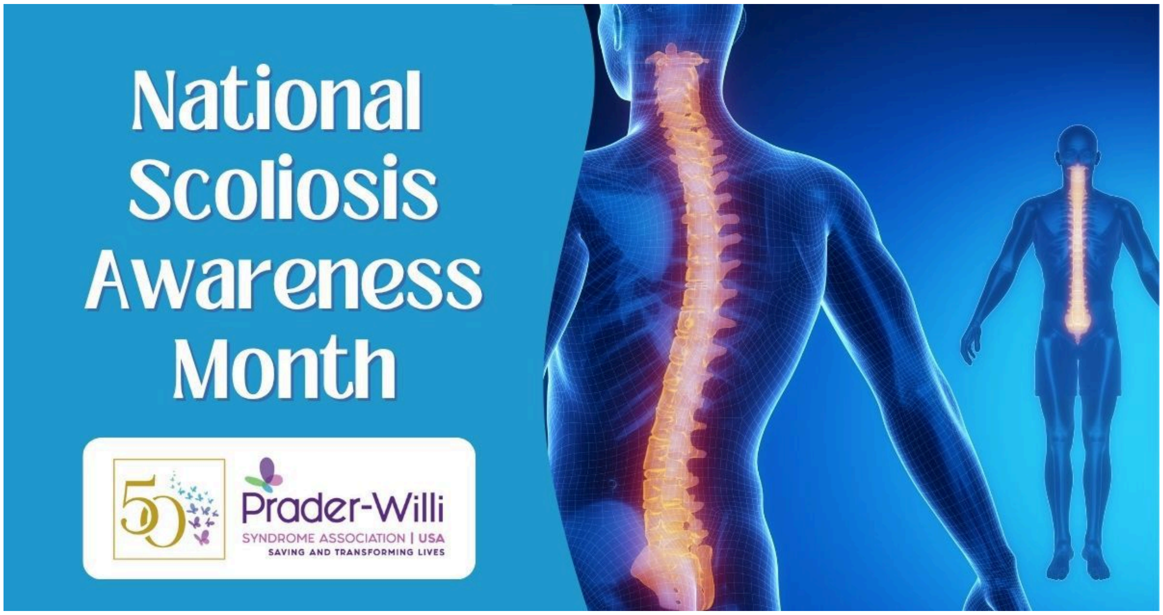
Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA PULSE

Vol. 124

June 6, 2025

www.pwsausa.org | 941-312-0400

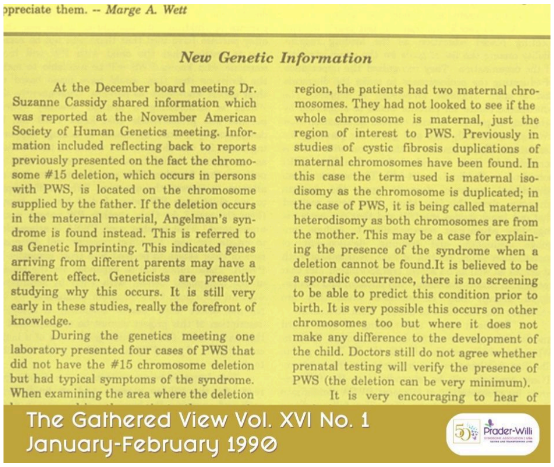


With less than 3 weeks to go, the upcoming International PWS United in Hope conference is a hot topic in the PWS community. As we enter into June with conference on our minds, we are also reminded of a common diagnosis with our loved ones with PWS: scoliosis. June is Scoliosis Awareness Month, a time to remind our community of the prevalence of scoliosis, the necessity of early testing, and intervention and treatment options. With diagnoses ranging from mild scoliosis to curves requiring surgical care, understanding the risk of scoliosis for our loved ones and how to support them in prevention and treatment is very important. To help you better understand potential risk factors, signs of scoliosis, and next steps, click the button below.

SCOLIOSIS RESOURCE

PWSA MEMORIES

At the American Society of Human Genetics meeting in November 1989, "one laboratory presented 4 cases of PWS that did not have the #15 chromosome deletion but had typical symptoms of the chromosome. When examining the area where the deletions occurred in other patients, these geneticists found that instead of having one maternal and one paternal chromosome in that region, the patients had two maternal chromosomes...it is being called maternal heterodisomy as both chromosomes are from the mother."



ppreciate them. -- *Marge A. Wett*

New Genetic Information

At the December board meeting Dr. Suzanne Cassidy shared information which was reported at the November American Society of Human Genetics meeting. Information included reflecting back to reports previously presented on the fact the chromosome #15 deletion, which occurs in persons with PWS, is located on the chromosome supplied by the father. If the deletion occurs in the maternal material, Angelman's syndrome is found instead. This is referred to as Genetic Imprinting. This indicated genes arriving from different parents may have a different effect. Geneticists are presently studying why this occurs. It is still very early in these studies, really the forefront of knowledge.

During the genetics meeting one laboratory presented four cases of PWS that did not have the #15 chromosome deletion but had typical symptoms of the syndrome. When examining the area where the deletion

region, the patients had two maternal chromosomes. They had not looked to see if the whole chromosome is maternal, just the region of interest to PWS. Previously in studies of cystic fibrosis duplications of maternal chromosomes have been found. In this case the term used is maternal isodisomy as the chromosome is duplicated; in the case of PWS, it is being called maternal heterodisomy as both chromosomes are from the mother. This may be a case for explaining the presence of the syndrome when a deletion cannot be found.It is believed to be a sporadic occurrence, there is no screening to be able to predict this condition prior to birth. It is very possible this occurs on other chromosomes too but where it does not make any difference to the development of the child. Doctors still do not agree whether prenatal testing will verify the presence of PWS (the deletion can be very minimum).

It is very encouraging to hear of

The Gathered View Vol. XVI No. 1
January-February 1990

When PWS was first discovered genetically in 1981, it was seen as being caused solely by a deletion on the 15th chromosome. At the American Society of Human Genetics meeting in late 1989, the geneticists and PWS community were officially introduced to other causes of PWS, leading to what we now know are three subtypes: Deletion, maternal Uniparental Disomy or UPD, and Imprinting Mutation.

At the time of this article in The Gathered View, testing for PWS was minimal and doctors did not agree whether or not prenatal testing would "verify the presence of PWS." We have come a long way from those early days of understanding the genetics of PWS and are incredibly grateful to all of the doctors, researchers, specialists, and advocates who have helped pave the way for a deeper understanding of this syndrome.

Read this article in The Gathered View by clicking the button below.

READ HERE

SHARE YOUR MEMORY

PWSA | USA'S

SPOTLIGHT ON HOPE

Ada was diagnosed with Prader-Willi syndrome at 1 month old, and today is thriving and shining. Like most parents in this community, receiving the diagnosis turned their world upside down. The first year was challenging, but her mom proudly reports that Ada, "continues to show us every day how strong and resilient she is..."

This Spotlight on Hope was submitted by Caitlin Heckman, mom to Ada (1, living with PWS). Read Caitlin's submission in our Spotlight on Hope blog series by clicking the button below.

READ HERE

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

Countdown to Conference: 17 Days to Go!

In just 17 days, the PWS community will come together in Phoenix, AZ, for the [2025 International PWS Conference: United in Hope](), a powerful gathering of families, professionals, and researchers from around the world.

We're excited to announce that the detailed program agendas, conference mobile app, and conference attendee welcome packet are all live and available for viewing and download! Scroll below to learn more and to find these links.

As a reminder: The Family Program and PWS/Sibling Camps are now at full capacity, and we are no longer accepting registrations for those portions of the conference. However, registration remains open for the Clinical & Scientific and Professional Providers Programs, and spots are still available!

The 2025 United in Hope PWS Conference Mobile App is Now Live!

We created an app for the 2025 International PWS Conference! Conference attendees are encouraged to use this app throughout the event to stay up-to-date on the latest news and announcements, manage their personal schedules, add sessions to their agendas, and create event profiles. Click the buttons below to download our "how to use" mobile app flyer and to log in to the app.

The mobile app is for conference attendees' use only.

DOWNLOAD FLYER

LOG IN TO THE APP

2025 Conference Welcome Packet

Our 2025 United in Hope PWS Conference Attendee Welcome Packet contains important information about the conference, including details about the schedule, how to download and utilize the conference mobile app, how to get to the conference center, and more. It shares important details about your stay (on and off the Arizona Grand Resort & Spa property), including dining options, what to pack, getting around the resort, and how to make the most of your time at the Arizona Grand Resort & Spa.
It also includes helpful reminders and answers to some of the most frequently asked questions.

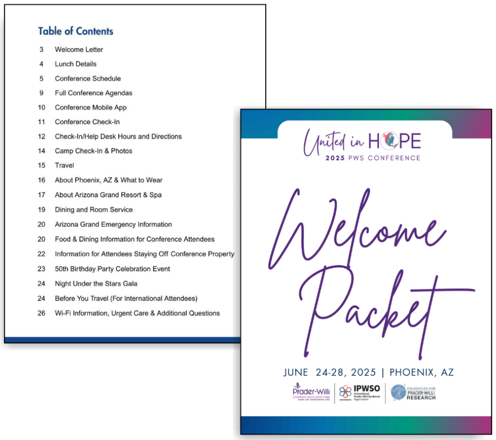


Table of Contents

United in HOPE
2025 PWS CONFERENCE

Welcome Packet

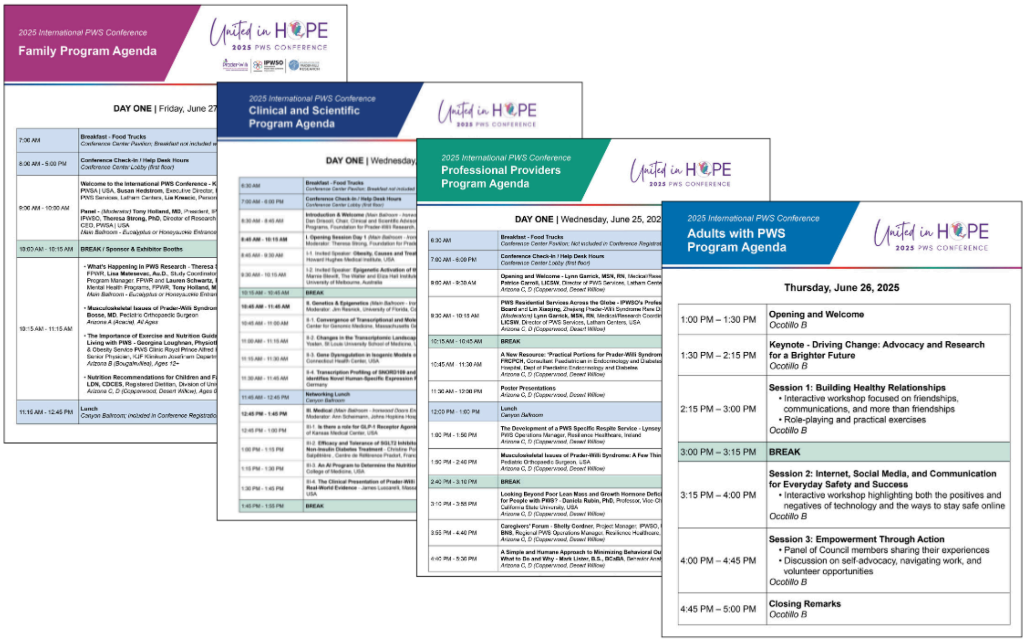
JUNE 24-28, 2025 | PHOENIX, AZ

Please take time to read through this packet before you arrive. It will help you avoid last-minute surprises and allow you to fully focus on what really matters - connecting with the PWS community and experiencing everything this week has to offer.

DOWNLOAD WELCOME PACKET

Detailed Conference Agendas Now Available for Download

We’re excited to share the final, detailed agendas for the 2025 International PWS Conference!
Explore the full schedules for our Clinical & Scientific, Professional Providers, Family, and Adults with PWS programs by clicking the buttons below. Each agenda includes session titles, times, locations, and speaker information to help you plan your conference experience.



2025 International PWS Conference

Adults with PWS Program Agenda

United in HOPE 2025 PWS CONFERENCE

Thursday, June 26, 2025

1:00 PM – 1:30 PM	**Opening and Welcome** *Ocotillo B*
1:30 PM – 2:15 PM	**Keynote - Driving Change: Advocacy and Research for a Brighter Future** *Ocotillo B*
2:15 PM – 3:00 PM	**Session 1: Building Healthy Relationships** • Interactive workshop focused on friendships, communications, and more than friendships • Role-playing and practical exercises *Ocotillo B*
3:00 PM – 3:15 PM	**BREAK**
3:15 PM – 4:00 PM	**Session 2: Internet, Social Media, and Communication for Everyday Safety and Success** • Interactive workshop highlighting both the positives and negatives of technology and the ways to stay safe online *Ocotillo B*
4:00 PM – 4:45 PM	**Session 3: Empowerment Through Action** • Panel of Council members sharing their experiences • Discussion on self-advocacy, navigating work, and volunteer opportunities *Ocotillo B*
4:45 PM – 5:00 PM	**Closing Remarks** *Ocotillo B*

FAMILY PROGRAM

CLINICAL & SCIENTIFIC PROGRAM

PROFESSIONAL PROVIDERS PROGRAM

ADULTS WITH PWS PROGRAM

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Calling All New England Families! Join us for the 16th Annual Hunter Lens Golf Tournament

Join the Lens family for a day of golf, good spirits, and great friends as you golf and dine at Heritage Hills Golf Club in Lakeville, MA. The **Hunter Lens Golf Tournament** is celebrating its *16th year* raising critical funding for PWSA | USA.

"Hunter Lens is 27 years old and has Prader-Willi syndrome. He leads a happy, active life despite his daily challenges. He has friends, a loving family and his weight is under control. Supporting PWSA | USA, a non-profit, will open more doors for Hunter and others who live with PWS, which ultimately means a better life. Hunter deserves a better life." Please join the Lens family on this special day in honor of Hunter to benefit PWSA | USA's mission. Find more details and purchase tickets at the button below. We hope to see you there!

HUNTER LENS GOLF TOURNAMENT

United We Brunch: Awareness in Every State

Hummus and Tahini in Nebraska

Sarah Kasaby, mom to Khaled (living with PWS) and PWSA | USA's Information and Referral Specialist, hosted a successful United We Brunch for PWS Awareness Month in Nebraska. "*This weekend's United We Brunch was more than I could have imagined — full of warmth, support, connection, and purpose. As we gathered around delicious and healthy homemade dishes (yes, the hummus and tahini were a hit!), we shared stories, laughter, and tears. I opened up about our family's journey —*

how we found out about the diagnosis, what it meant, and how it's shaped our lives ever since. Thank you to everyone who came out, asked questions, donated, shared, and simply showed up with open hearts."
Read her full recap and see photos by clicking the button below.

HUMMUS AND TAHINI

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

Between June 24-28, 2025, families and providers in the PWS community from around the world will be gathering in Phoenix, AZ, for the 2025 United in Hope International PWS Conference. This is the first ever joint conference between PWSA | USA, The Foundation for Prader-Willi Research (FPWR) and the International Prader-Willi Syndrome Organisation (IPWSO), which symbolizes a historic milestone in the PWS community. This groundbreaking event will shape the future of PWS research and care!

In our latest episode of PWS United, we have a conversation between the three organization leaders, Susan Hedstrom, Marguerite Hughes, and of course, our own Stacy Ward. They spoke about what this conference collaboration means for the PWS community and the families we support. How conference is a place to find community, explore the experience of rarity, and share commonality amongst people who you may have thought were worlds apart. With a combined 100 years of dedication and work in the PWS community, this conference collaboration is a momentous event.

If you're looking for information on conference details, listen to last week's episode, "Ep 43: All Things Conference." Click here to listen.

Find the latest episode of PWS United on your preferred podcast app or by clicking the button below.

LISTEN ON PODBEAN

ADVOCACY

Call to Action! Share your Story to Help Expand Medicaid

Calling All PWS Families!

We need your voice to help make a difference! Currently, only 14 states recognize PWS as an intellectual/ developmental disability (IDD), which limits

access to crucial services and supports for individuals with PWS.

Your personal story could help change that.

We invite you to take part in an important advocacy effort by sharing your experience with qualifying for Medicaid waiver programs and other state-funded IDD services. By filling out the form at the button below, you'll contribute to our collective efforts to improve access to critical services for individuals with PWS across the country.

Your story has the power to make an impact! Together, we can push for change for the PWS community in your state and beyond.

SHARE YOUR STORY

Thank You for Helping to Spread PWS Awareness!

As PWS Awareness Month fades in the rearview mirror and we turn our high beams onto conference, we'd like to extend a robust thank you to our community for all of your actions to spread PWS awareness. From navigating legislation to creating state proclamations, to hosting United We Brunch fundraisers, to those who shared our daily fact graphics with your online community, all of your efforts help advance awareness of PWS in our communities, schools, medical offices, and government buildings. Be proud of your actions and know that you have helped better the lives of families and individuals living with PWS.

FAMILY SUPPORT

Adults with PWS Advisory Board Spotlight

Abbott Philson is 41 years old and lives with Prader-Willi syndrome. He resides in Maine and has been an advisory board member for PWSA | USA for 25 years. In an effort to learn more about our adults with PWS, and to shine a light on their lives and experiences, we asked our Adults with PWS Advisory Board members some questions. Here is one of Abbott's heartfelt responses:

"It (PWS) brings out a better understanding of other people's difficulties." - Abbott Philson

Visit the blog article at the button below to learn more about Abbott.

READ MORE

We Need Your Voice: Help Shape a New Family Resource Program

PWSA | USA is partnering with the Behavioral Innovations for Rare Diagnosis (BIRD) Lab at The Chicago School to develop a new *Family Resource Program* - and we want to hear from you!

Through upcoming focus groups, PWS caregivers will have the chance to share real-life insights about the challenges, needs, and supports that matter most. Your input will directly guide the creation of a resource designed to support families like yours at every stage of life.

Topics will include:

- Key knowledge and information needs
- Daily caregiving challenges and successes
- Emotional, behavioral, and medical support priorities

- Navigating education, healthcare, and social systems
- Preferred formats for receiving support

Your experience matters. For information on joining our focus groups, please visit the links at the buttons below.

PARENTS AND CAREGIVERS

SIBLINGS OF INDIVIDUALS WITH PWS

DOWNLOAD THE FLYER

New Bilingual Sibling Support Opportunity

A new, bilingual sibling support app

Does your child with a disability or health concern have a sibling, aged 3-6?

You may be eligible to use the SibTime app in an 8-week pilot study.

Participating families receive $200.

Space is Limited. Learn more at sibtime@influentsin.com | 541-434-1577

Do you have a child with disabilities, and a typically-developing child ages 3-to-6? Check out the new SibTime app from the Sibling Support Project.

SibTime app features stories and activities for typically developing preschool siblings and their caregivers. SibTime includes videos, animated stories, podcasts, and mindfulness exercises to promote bonding, understanding, and fun!

This project is seeking 160 English and Spanish-speaking families to help us test the app! Families who participate in this research study receive $200 for trying out the app and completing two surveys.

Learn more by clicking the button below.

¿Tienes un niño con discapacidad, y un niño con un desarrollo normal de 3 a 6 años? ¡Nuestra nueva app SibTime es para usted!

La app SibTime incluye historias y actividades para hermanos preescolares con un desarrollo normal y sus cuidadores. SibTime incluye videos, historias animadas, podcasts y ejercicios de atención plena para fomentar la conexión, la comprensión y la diversión.

¡Necesitamos 160 familias que hablen inglés y español para ayudarnos a probar la app! Las familias que participen en este estudio de investigación recibirán $200 por probar la app y completar dos encuestas.

Aprende más abajo.

LEARN MORE

APRENDE MAS

Ask Nurse Lynn

Female, 42 years old, UPD subtype

My question is about treatment for osteoporosis. My sister, to my knowledge, has never had any hormone replacement. She is obese, BMI 38, and the only abnormal lab done by her gynecologist was testosterone, which was "below the technical range of the assay." Her vitamin D levels are normal, and she takes supplements. She does not appear to take calcium supplements- her PCP says her calcium and Vit D levels are in normal range. Her DEXA scan shows that she's progressed from osteopenia to osteoporosis (-4.2). She currently does not have an endocrinologist, as none will accept her referrals. Her PCP wants to go straight to a yearly infusion of zoledronic acid.

I’m concerned about side effects, safety in PWS, alternatives like hormones or supplements. Can you help with any guidance?

Visit our blog to read Nurse Lynn's response and find links to connected resources.

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

RESEARCH

Webinar Recording Now Available to Learn More About Aardvark's HERO PWS Study

Missed the webinar? Watch the recording below!

On Tuesday, May 20th, many of you joined us for an informational and important webinar featuring Dr. Tien Lee, CEO of Aardvark Therapeutics, and Dr. Manasi Jaiman, Chief Medical Officer, to learn more about the HERO clinical trial for ARD-101 - a potential treatment for hyperphagia in individuals with Prader-Willi syndrome.

In this session, attendees:

- Learned about the HERO Phase 3 clinical trial of ARD-101
- Heard where trial sites are located and which are actively enrolling participants
- Had the opportunity to ask questions directly to the Aardvark team

aardvark therapeutics

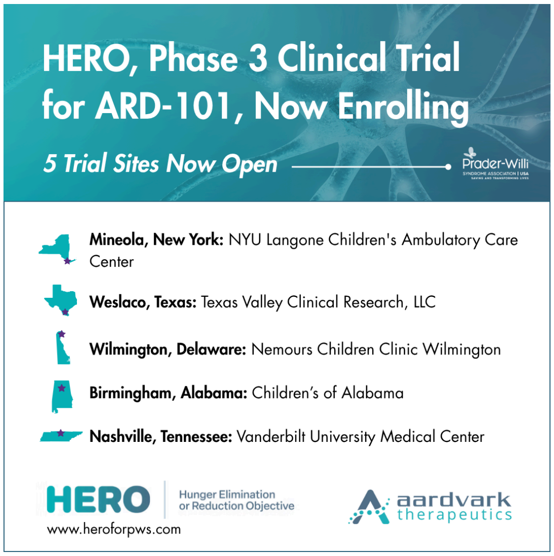
ARD-101 and the HERO Trial

May 2025

With the support of our community, this groundbreaking treatment is one step closer to FDA approval - bringing hope and new options to those who need it most.

To learn more about the HERO Study, visit www.heroforpws.com. Click the button below to watch the full webinar recording.

WATCH HERE



HERO, Phase 3 Clinical Trial for ARD-101, Now Enrolling

5 Trial Sites Now Open

- **Mineola, New York:** NYU Langone Children's Ambulatory Care Center
- **Weslaco, Texas:** Texas Valley Clinical Research, LLC
- **Wilmington, Delaware:** Nemours Children Clinic Wilmington
- **Birmingham, Alabama:** Children's of Alabama
- **Nashville, Tennessee:** Vanderbilt University Medical Center

HERO Hunger Elimination or Reduction Objective
www.heroforpws.com

aardvark therapeutics

Aardvark Therapeutics' HERO Phase 3 clinical trial is now enrolling participants at sites across the United States to investigate a potential new treatment (ARD-101) designed to reduce excessive hunger in individuals with Prader-Willi syndrome.

You can learn more about these open trial sites and how to participate in the HERO study by clicking the button below. You can also visit https://www.heroforpws.com/ for the most up-to-date information.

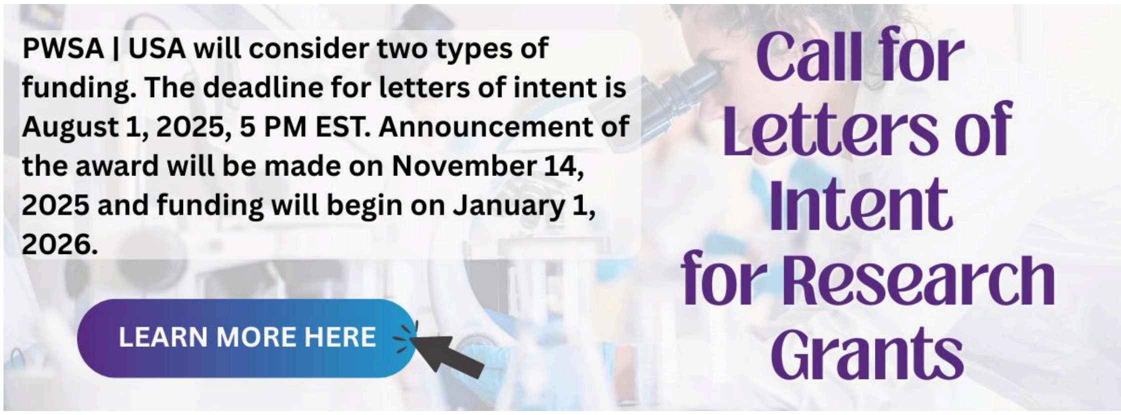
Additional trial sites are expected to begin enrolling soon. PWSA | USA will continue to share trial sites as they become available.

HERO TRIAL SITES

Supporting PWS Research

Prader-Willi Syndrome Clinical Scholarships Available

$25,000 USD to support providers in enhancing their understanding of PWS through clinical proctorships with experts in the field. Available to providers currently in practice in the US and who presently care or plan to care for patients with PWS.



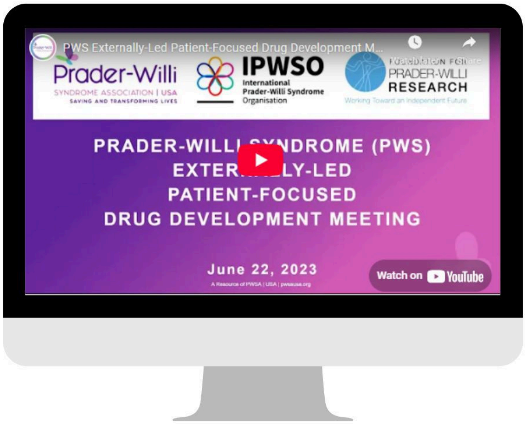
PWSA | USA will consider two types of funding. The deadline for letters of intent is August 1, 2025, 5 PM EST. Announcement of the award will be made on November 14, 2025 and funding will begin on January 1, 2026.

LEARN MORE HERE

Call for Letters of Intent for Research Grants

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight



Two years ago, at the 2023 United in Hope PWS Convention, individuals with PWS shared their experiences of living with this diagnosis in Prader-Willi Syndrome's First Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting. These stories were compiled into the "Voice of the Patient Report," which has helped create a comprehensive picture of what living with PWS looks like and the sincere need for treatment options. Click on the photo to watch the testimonials from the 2023 EL-PFDD meeting. Click the button below to read the "Voice of the Patient Report."

VOICE OF THE PATIENT REPORT

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 Pulse Newsletter: June 20, 2025

Enhancing the Quality of Life and Empowering those Affected by PWS

PWSA | USA
PULSE

Vol. 125

June 20, 2025

www.pwsausa.org | 941-312-0400

We are very excited to gather together as a community - and very soon! In just a few days, we will come together to share stories, knowledge, and support. We'll probably shed some tears and certainly have some laughs. Whether you're a new parent or well-versed in raising someone with PWS, a grandparent or a sibling, a researcher, a provider, a PWS specialist, someone living with PWS, or a friend - we are honored that you chose to spend your time with us in Phoenix. Thank you for joining us for this incredible moment in PWS history - let's make some memories! For those unable to attend, please know that we will spread what we create to the larger PWS community. Whether you are in attendance or not, we are all in this together.

If you are a conference attendee and are looking for resources, (like the Welcome Packet, details for joining the app, conference schedules, food options, etc.) please visit our conference site at 2025 United in Hope Conference - Prader-Willi Syndrome Association | USA.

Bringing Conference to Non-Attendees

For those unable to attend this conference, we will be sharing some of the sessions with the larger PWS community. Every session being held in the main ballroom during the Family Program will be recorded on video and available at a later date on our PWSA | USA YouTube channel.

PWS United, our podcast, will be attending conference for the first time! We will record two of the smaller conference sessions to be shared as episodes at a later date. We will also have a chance for you to join the conference in real time with our first ever PWS United LIVESTREAM! This livestream will be on Saturday, June 28, at 2:15 PM PT | 5:15 PM ET for the session “Teaching Emotional Regulation in Individuals with Prader-Willi Syndrome: ABA Strategies for Lasting Success,” presented by Kasey Bedard, PhD, BCBA-D. If you join during this time, you will be able to listen to Kasey's presentation in real time, as well as participate in an online text chat with other livestream attendees. To learn more about joining our livestream, read How To Join a PWS United Livestream on Podbean - Prader-Willi Syndrome Association | USA.

Be a Part of Our Conference Media

If you are attending conference and would like to share your voice, your experiences, or your story with the PWS community, please look for Anne or Carrie from PWSA | USA, or a sign-up sheet at PWSA | USA's exhibitor table. We will be looking for people to feature on our podcast and social media platforms (Facebook and Instagram), and to be interviewed for our Spotlight on Hope videos. If you and your family are willing and interested in being interviewed, please email communications@pwsausa.org to add your name to the sign-up sheet.

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PWSA MEMORIES


National Prader-Willi Syndrome Workshop
Maple Valley, Washington, 1979

Between June 13-15, 1979, the National Prader-Willi Syndrome Workshop was held at the Lake Wilderness Conference Center in Maple Valley, Washington. The keynote speakers for the event were Gerald LaVeck, MD, and Gene Deterling, the founder and former president of PWSA | USA. The workshop was sponsored by the then named Child Development and Mental Retardation Center of the University of Washington. Papers presented involved the medical, nutritional, behavioral, and social aspects of PWS.

SHARE YOUR MEMORY

PWSA | USA'S SPOTLIGHT ON HOPE

Our **Spotlight on Hope** series strives to share and celebrate the successes of our loved ones. No success is too small! Whether your child took a first step, had a great time at the school dance, made a shot in a basketball game, or is working toward a goal, we want to celebrate it all.

There are many challenges with PWS, and much of our focus is toward mitigating the effects of these challenges. So, PWSA | USA has created a space to share the other stories. The wins, the smiles, the milestones.

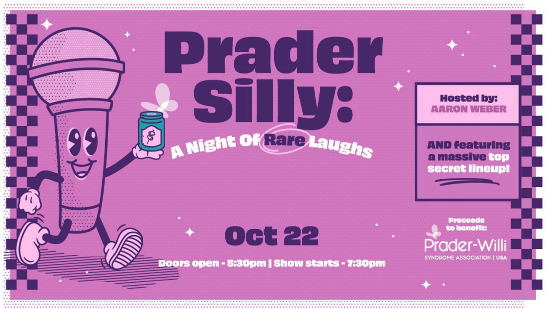
The moments that bring joy and hope, a relaxing of the shoulders, and a momentary reprieve from the struggles of PWS.

If you’d like to honor your loved one and share their success story with the PWS community, please fill out our Spotlight on Hope form using the button below. We’re looking forward to celebrating with you!

SHARE YOUR SPOTLIGHT ON HOPE

EVENTS & FUNDRAISERS

Get Your Tickets Now for Prader Silly: A Night of Rare Laughs!



When: **October, 22, 2025 | Doors Open at 5:30 PM CT**
Where: **Zanie's Comedy Club, Nashville, TN**

Join us for an incredible night of PWS awareness, laughs, enjoyment, and fundraising!

Comedian and new PWS father Aaron Weber and a (**TOP SECRET**) celebrity lineup of nationally acclaimed comics are hosting an evening of laughs for a cause! This is more than a comedy show. It’s a night of gathering, giving, and gut-busting laughter — featuring a powerhouse lineup of top-tier comedians, a silent auction packed with unforgettable prizes, and several surprise guest performers we’re keeping tucked in our back pocket (Shhh...). Whether you come for the laughs, the love, or the chance to stand up for a rare cause, this is your invitation to show up — for PWS families and others on a rare disease journey.

Learn more about "Prader Silly: A Night of Rare Laughs" and how you can participate by clicking the button below.

PRADER SILLY EVENT

United We Brunch: Bagels and Jam in Missouri

When: **Saturday, June 21, 10 AM - 12 PM CT**

Bagels and Jam: Lola's Journey of Gratitude, our final United We Brunch of 2025, is happening this Saturday in Missouri! The event will take place on June 21, 2025 (10 AM – 12 PM, casual come-and-go style), at St. Paul Lutheran Church. It will be an opportunity to learn more about PWS, share in the family's gratitude over all God has done for Lola through an incredible community of support, and enjoy a brunch of bagels and homemade jam. Whether you're able to attend in person or participate from afar, your involvement helps raise vital awareness and foster hope for families impacted by Prader-Willi Syndrome. Learn more and donate to this fundraiser by clicking the button below.

LEARN MORE

PWS hope united
BUILDING BRIGHT FUTURES FOR PWS FAMILIES
Prader-Willi Syndrome Association | USA

Interested in hosting a PWS Hope United event in your city? Contact hopeunited@pwsausa.org and click the button below to get started!

Become a Hope United Champion

PWS UNITED PODCAST UPDATES

A Podcast for the PWS Community

This is the next episode in our *Pioneers in PWS* series, a podcast series from PWS United celebrating PWSA | USA's 50th Anniversary!

Before there were conferences, support groups, or even a central source of information on Prader-Willi syndrome, there were pioneers. Parents, professionals, and advocates who built the foundation of the PWS community - one connection, one breakthrough, one act of determination at a time. In honor of PWSA | USA's 50th anniversary, we're diving into their stories. Pioneers in PWS was originally a PWSA | USA blog series produced in 2021 by our dedicated volunteers. Throughout 2025, we'll look back on these articles to explore where we've been, how far we've come, and recognize the pioneers who made it possible.

In this episode, we look back at the foundation of our parent mentoring program - how it has evolved over the years and the incredible women who have passed the torch of support. We hear a brief testimonial from two current parent mentors about some of their favorite experiences of being a mentor. This episode closes out with an interview with the current director of the parent mentoring program, Kristi Rickenbach. She shares with us how she got involved, what she loves about this work, and ultimately, what her goal is as a parent mentor.

Find the latest episode of PWS United on your preferred podcast app or by clicking the button below.

LISTEN ON PODBEAN

ADVOCACY

PWSA | USA Advocacy Ambassadors Join Forces with Patients Rising on Capitol Hill

Six of our dedicated **PWSA | USA Advocacy Ambassadors** (Dorothea Lantz, Elaine Towle, Jessica Kempa, Sheri Mills, Michelle Torbert and Jennifer Garzia - also joined by her family, including her son Rocco who is 20 years old living with PWS) traveled to Washington, D.C., last week to take part in Patients Rising's 4th annual "We the Patients" Fly-In - the organization's largest and most impactful event to date. Alongside 86 patient advocates from 27 states, our team helped bring a powerful rare disease voice to 110 Congressional meetings, including nine with sitting members of Congress.

The advocates called for support for two critical health care bills and advocated for a broad, patient-centered policy platform. They participated in a robust policy briefing opened by Alex Aramanda, Principal Deputy Director for Medicare, and attended a high-profile Congressional Reception, along with meeting other important lawmakers.

Advocacy is critical for our loved ones with PWS, and we are so grateful to our advocates for showing up! Click the button below to read the full account of their trip to Capitol Hill last week.

READ MORE HERE

FAMILY SUPPORT

New Blog Post: Hippotherapy and PWS

Hippotherapy, "treatment with the help of a horse," is gaining popularity in the PWS community and beyond. Riding horses helps develop core strength, which can help mitigate scoliosis concerns, and can have positive social, emotional, and behavioral benefits. Melanie Zalman, mom to Josie (living with PWS) shared this blog post about their family's experience with hippotherapy. From first learning about it in a Facebook group, to seeing Josie ride backward, to letting go of her fears watching Josie feed carrots to the horses, hippotherapy has been an incredibly positive experience in their lives. Read Melanie's blog by clicking the button below.

READ MORE

Developing Residential Site Offers Options and Meaningful Futures for Young Adults with PWS

C-15 Foundation, a registered 501(c)(3) organization dedicated to creating opportunities for individuals living with PWS, is announcing the creation of a Live, Work, Play, and Thrive community in Chattahoochee Hills, GA, approximately 20 minutes from the Atlanta Airport.

This first-of-its-kind, dedicated PWS development will be home to “high-functioning” PWS young adults (current ages of 20-30) who have the desire and ability to reach greater heights of independence and self-development. The 108-acre C-15 campus is proposed to provide a genuine opportunity to live a more self-supportive life, while still receiving guidance and light oversight from on-campus coaches. Additionally, all residents will be required to have a part-time job on or off campus.

The campus will offer 24 private, kitchenless apartments consisting of a large private bedroom and bathroom with connected common areas, an ultra-secure dining hall, activity center that includes a pool, walking track, and more, and a working farm.

C-15 Foundation expects to begin conducting resident interviews in 2026 with a goal to open in mid-2027. Please visit the website, which can be found at the button below, for more information in the coming months and to follow the construction progress. If you believe your loved one with PWS has the desire and ability to live in a semi-independent environment, please reach out to the foundation.

LEARN MORE

Interactive Map for Washington | Oregon PWS Families

Shared on behalf of the Oregon and Washington Chapter of PWSA | USA

The Oregon and Washington Chapter of PWSA | USA is proud to launch the PWS Link Map, a new platform designed to be a life-changing resource for our community.

This map allows families to find other families who choose to “join” the Map. They will be able to securely message one another through the platform's messaging system. To protect privacy, the contact information and exact location is never revealed. Participants can choose to share that information directly through a message and meet outside the map platform if they desire to. This initial version is just the beginning, and the plan is to introduce additional search options as the platform's population grows.

A Vision for National Connection.

The primary challenge for national expansion is moderation. To be successful, each state requires a dedicated moderator to ensure the map remains a focused resource, free from spam or unrelated content. Here in the Northwest, our knowledge of local families allows us to moderate effectively. We are eager to brainstorm with other state leaders to develop a sustainable national model. Another option is for individual states to join. Contact us if you are interested in brainstorming with us. For any questions, feedback, or assistance with logging in, please contact pwsawaor@gmail.com.

A Powerful Tool for Research

Beyond its role as a connection hub, the PWS Link Map has the potential to be a valuable tool for researchers. Data could provide invaluable insights into the prevalence of service needs, the geographic distribution of PWS subtypes, age group demographics, and more. Mass messaging by businesses or researchers will not be permitted.

Visit the map by clicking the button below.

LEARN MORE

Ask Nurse Lynn

Male, 27 years old, Deletion subtype

What would a critically hazardous weight be for someone with PWS whose height is 4’11”? Also, what is considered a good range for their blood sugar levels in PWS with diabetes?

Visit our blog to read Nurse Lynn's response and find links to connected resources.

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

RESEARCH

Peer-to-Peer Challenge: Interactive Case Studies in Prader-Willi Syndrome

This educational activity is intended for an audience of pediatricians, endocrinologists, psychiatrists, geneticists, nurse practitioners, physician assistants, nurses, and other clinicians who care for patients with Prader–Willi syndrome in the United States.

The goal of this activity is for learners to have improved awareness, understanding, appreciation, and management of hyperphagia in people with PWS.

Upon completion of this activity, participants will:

- Have greater competence related to

  - Early recognition and diagnosis of hyperphagia in people with PWS
  - Management of hyperphagia as part of a comprehensive PWS treatment plan

- Greater confidence in their ability to

  - Provide team-based care for people with PWS

Learn more about this opportunity by clicking the button below.

LEARN MORE

Aardvark Therapeutics HERO Phase 3 Trial Now Enrolling!

2 New Sites Open

HERO, Phase 3 Clinical Trial for ARD-101, Now Enrolling

2 New Sites Now Open

San Diego, California: Rady Children's Hospital

Atlanta, Georgia: Emory University School of Medicine

Aardvark Therapeutics recently launched **HERO**, a global Phase 3 clinical trial investigating ARD-101, an innovative, orally administered treatment designed to help reduce hyperphagia (excessive hunger) and food-seeking behaviors in individuals with Prader-Willi syndrome (PWS).

This randomized, double-blind, placebo-controlled trial is an important step toward identifying a potential new treatment option for the PWS community, and now, trial sites across the United States are actively enrolling participants. Click on the button below to learn more about the open trial sites.

To learn more about the HERO Study, visit www.heroforpws.com.

LEARN MORE

Video Testimonial of PWS and Excessive Daytime Sleepiness

Harmony Biosciences, sponsor of the TEMPO clinical trial for Pitolisant, created a powerful video with Kristi Rickenbach - a dedicated member of the PWSA | USA team - and her daughter Justice (21, living with PWS). Kristi and Justice open up about their personal journey with Prader-Willi syndrome and the challenges of excessive daytime sleepiness. We encourage you to watch this video at the button below.

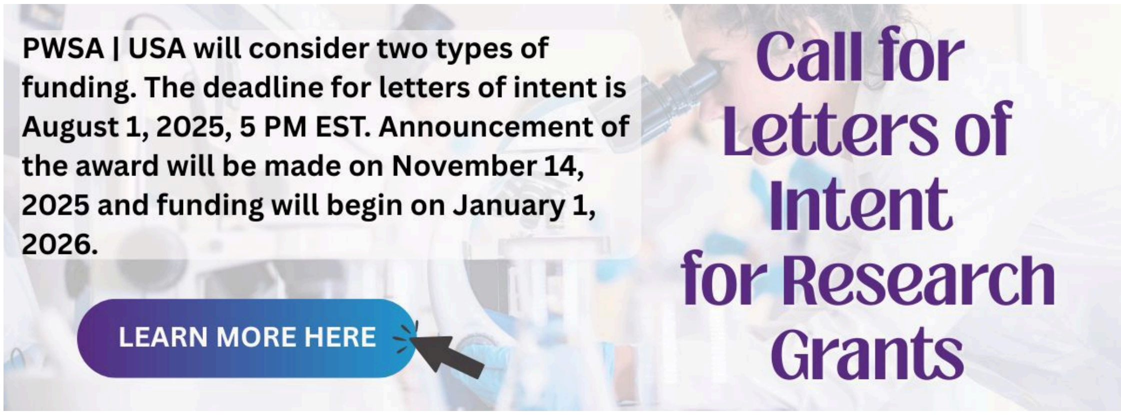
Learn more about the TEMPO study at [TEMPO PWS Clinical Study For Prader-Willi Syndrome - Enroll Today.]()

[WATCH HERE]()

Supporting PWS Research

Prader-Willi Syndrome Clinical Scholarships Available

$25,000 USD to support providers in enhancing their understanding of PWS through clinical proctorships with experts in the field. Available to providers currently in practice in the US and who presently care or plan to care for patients with PWS.



Call for Letters of Intent for Research Grants

PWSA | USA will consider two types of funding. The deadline for letters of intent is August 1, 2025, 5 PM EST. Announcement of the award will be made on November 14, 2025 and funding will begin on January 1, 2026.

PWSA | USA ANNOUNCEMENTS

PWSA | USA Resource Spotlight

With conference on our minds, we wanted to share an older blog post from a past conference attendee. This post, from Daniel and Amanda Yanik (parents to Saoirse, with PWS), shares their decision to attend the 2017 convention, and the invaluable information they received while there. According to Daniel and Amanda, what was even more important were the relationships they formed and strengthened while at the convention. As we head into conference week, remember this will be a time not only for education, tools, and knowledge, but also a time to connect with other parents and families with PWS and build the foundation of those lifelong bonds. Read this blog by clicking on the button below.

READ HERE

Your gift to PWSA | USA ensures individuals and families living with Prader-Willi syndrome have the connection, guidance, and hope

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they so desperately need. Thank you!

PWSA | USA June 2025 Special Edition Pulse Newsletter

www.pwsausa.org | 941.312.0400

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Summertime is here!

Suggestions and tips for a fun, PWS-friendly summer.

Summertime is here! In a PWS household, there may be many conflicting emotions around this. In some places, this means the weather is nicer for fresh air and exercise outside. In hotter places, caregivers now must be vigilant about the stress of heat and sun exposure. Perhaps you are looking forward to a schedule that is more free (if your loved one is of an age ruled by school hours) or you are struggling to organize the day. This Special Edition Pulse, Summertime Edition, offers tips and ideas for navigating the summer months.

In this week's blog post, we offer suggestions for "Navigating Summer Celebrations." With suggestions and tips on how to make BBQ meals more PWS-friendly, prepare your loved one for social situations, and protection against the summer sun, this blog can help families have safe and enjoyable summer celebrations. Read this blog by clicking the button below.

Keep scrolling to learn more about keeping schedules during the summer months, a wide range of activities for indoor, outdoor, and adventures away from home, and some PWS-friendly recipes suggested that our staff enjoys.

Our big **United in Hope** conference is finally here! We hope those at home stay tuned to our social media to see what's going on and to be a part of the conference with us. We will be posting some session videos and podcast recordings at a later date to help spread the information and knowledge shared. If you're inspired, please join us for a PWS United Livestream of a conference session. Learn more below.

READ BLOG HERE

Join Us for the PWS United LIVESTREAM from the United in Hope Conference

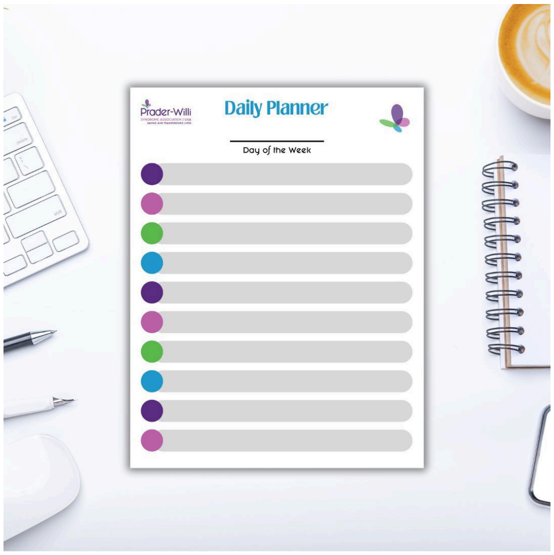
Saturday, June 28, at 2:15 PM PT | 5:15 PM ET

"Teaching Emotional Regulation in Individuals with Prader-Willi Syndrome: ABA Strategies for Lasting Success" presented by Kasey Bedard

Summer Schedule and Activities

If your loved one has the summer away from school or day programs, you may welcome the lack of schedule. Your loved one, however, may not do well with the change or lack in schedule. They may become bored or anxious which can lead to challenging behaviors and upticks in PWS characteristics like skin picking and perseveration on topics. Even if you don’t have daily plans, consider making a schedule.

If the summer months disrupt your loved one's schedule or they need more direction to their day, create a schedule for home with regimented activity times. Make a physical copy of this schedule and hang it up where they can see it. Be sure to include mealtimes. Creating a schedule can help lower your loved one's anxiety level, provide them with enriching activities, and help you find time to get any necessary chores or work done. Click the button below to download a daily planner template.



DOWNLOAD HERE

Indoor Activities

Stationary Activities:

- Puzzles
- Word searches
- Sticker-by-number books
- Reading (encourage with reward system)
- Audiobooks
- Legos or blocks
- Sensory bins with uncooked rice (if it will not trigger your loved one), sand, small pebbles in a pan or tub (include a variety of objects)

Crafts:

- Knit, crochet, yarn play (YouTube videos can help teach yarn skills)
- Draw, color, paint (pick flowers on a hike and create a still life, look up how-to-draw videos on YouTube or get special drawing books)
- Create a collage (gather old magazines and newspapers, help your loved one choose a theme, cut pictures and letters, and paste onto posterboard or other paper)

Movement:

- Yoga or workout videos on YouTube
- Dance party (let your loved one choose the music that gets them moving)

- Animal charades (take turns moving like different animals and guessing what they are)
- Obstacle course (use couch cushions, pillows, broom sticks, and other household items to create a safe obstacle course that inspires movement)

Outdoor Activities

Outdoor Activities:

- Neighborhood walks
- Sprinkler or water play (bucket of water and various containers)
- Nature hikes or nature scavenger hunts (Identify birds/animals-rewards set up for # identified, etc.), any water activity
- Make fairy houses out of plants and materials found in the yard

Scavenger Hunts:

Scavenger hunts can be a fun way to get our loved ones moving with a purpose, offering them a variety of settings, and practice paying attention to detail. Create a list of animals, insects, and plants you may find before heading out on a nature hike. If it’s too hot outside, create a fun list of things to find or observe at your local mall. Create a reward system for finding a certain number of items on a list. Scavenger hunts can even be done around your house or your yard. This can be a great way to get parents and caregivers some time while your loved one is safely searching through your living space.

“Our grandkids and their cousins planned and put on a "Family Olympics" last summer and plan to do it again this year - they each picked a sport and planned the events and had to make the medals for their events - it was great!”

– Elaine Towle, mom to James (living with PWS)

Adventures Away from Home

Adventures Away from Home:

- Splash or water parks

- Amusement Parks
- Indoor playgrounds
- Museums
- Historical sights
- Library visit/ storytelling hour
- Outdoor movies on lawns
- Zoo and aquarium visits
- Ball games
- BINGO Nights
- Karaoke
- Community block parties
- Farmers markets

Summer Recipes

Classic Hummus

- 1 can (15 oz) of chickpeas, drained and rinsed
- 3 tablespoons of tahini (sesame seed paste)
- 2 tablespoons of fresh lemon juice
- 2 tablespoons of olive oil
- 1 clove of garlic, minced
- 1/2 teaspoon of ground cumin
- Salt to taste
- 2 to 4 tablespoons of cold water
- Paprika, for garnish (optional)
- Fresh parsley, chopped, for garnish (optional)

Instructions:

1. In a food processor, combine the chickpeas, tahini, lemon juice, olive oil, garlic, cumin, and a pinch of salt.
2. Process the mixture for about 30 seconds, then scrape down the sides of the processor bowl.
3. Continue processing and slowly add cold water, one tablespoon at a time, until the hummus reaches your desired consistency. You want it to be creamy and smooth.
4. Taste and adjust the seasoning, adding more salt or lemon juice if needed.

5. Transfer the hummus to a serving bowl and drizzle a little olive oil on top. Garnish with paprika and chopped parsley if using.
6. Serve with sliced vegetables like cucumber, bell peppers, or carrot sticks for a balanced snack with fiber.

Remember, it's important to balance this carbohydrate-rich food with some protein and a vegetable to ensure a well-rounded and nutritious meal. You can pair hummus with whole-grain pita or bread, but always remember portions should be controlled.

Nicoise Salad

Vinaigrette

- 1/3 cup lemon juice or red wine vinegar
- 3/4 cup extra virgin olive oil
- 3 tablespoons finely chopped shallot
- 2 tablespoons finely chopped fresh basil
- 1 tablespoon finely chopped fresh thyme
- 2 teaspoons finely chopped fresh oregano or tarragon
- 1 teaspoon Dijon mustard
- Salt and freshly ground black pepper

Salad

- 2 to 3 (5-ounce) cans tuna, drained, or 2 (8-ounce) grilled or otherwise cooked tuna steaks (see recipe note for cooking instructions)
- 6 hard boiled eggs, peeled and quartered lengthwise
- 1 1/4 pounds small young red potatoes or fingerling potatoes
- Salt and freshly ground black pepper
- 2 medium heads Boston or butter lettuce, torn into bite-sized pieces
- 3 small ripe tomatoes, cored and cut into wedges
- 1 small red onion, thinly sliced
- 8 ounces green beans, trimmed and cut into 2-inch pieces
- 1/4 cup Niçoise olives
- 2 tablespoons capers, rinsed and/or several anchovies, optional

Making the Vinaigrette:

- In a jar, place the oil, lemon juice or vinegar, shallots, herbs, and mustard. Cover with a lid and shake until well blended. Add salt and pepper to taste.
- Marinate the onion slices in some of the vinaigrette.
- Place onion slices in a small bowl and sprinkle with 3 tablespoons of the vinaigrette. (The onions soaking in the vinaigrette will help take some of the bite out of them.)

- Cook the potatoes, cut, and dress with vinaigrette.
- Place potatoes in a large pot and cover with 2 inches of water. Add 1 tablespoon of salt. Heat on high to bring to a boil. Lower the heat to maintain a simmer. Cook for 10 to 12 minutes or so, until the potatoes are fork tender. Drain.
- While the potatoes are still warm, cut them into halves or quarters, depending on the size of the potatoes.
- Place them in a bowl and dress them with about 1/4 cup of the vinaigrette.
- Boil the green beans.
- While the potatoes are cooking, fill a medium-sized pot halfway with water, and add 2 teaspoons of salt. Bring to a boil on high heat. Add the green beans to the boiling water.
- Cook until tender but still firm to the bite, about 3 to 5 minutes (more or less, depending on the toughness of the beans).
- Drain and either rinse with cold water to stop the cooking, or shock for half a minute in ice water.
- Arrange the salad on a bed of lettuce.
- Arrange a bed of lettuce on a serving platter. If using tuna steaks, cut them into 1/2-inch thick slices. Mound tuna in the center of lettuce. Sprinkle the tomatoes and onions around the tuna.
- Arrange the potatoes and green beans in mounds at the edge of the lettuce.
- Arrange hard boiled eggs, olives, and anchovies (if using) in mounds on the lettuce bed.
- Drizzle everything with the remaining vinaigrette.
- Sprinkle with capers if using.
- Serve immediately. Should be served slightly warm or at room temperature.

**This recipe came from Simply Recipes. Visit the site below.*

NICOISE SALAD

PWS-Friendly Chocolate Smoothie

Ingredients:

- 1 cup unsweetened almond milk or unsweetened soy milk or 2 % regular milk
- 2 tablespoons unsweetened cocoa powder
- 1 tablespoon almond butter or peanut butter
- 1/2 small ripe avocado
- A handful of fresh spinach
- 1 cucumber pealed
- 2 fresh or frozen berries/ strawberries

- Shea seeds, flax seeds and other seeds (optional)
- A handful of ice cubes (if using fresh berries)

Instructions:

1. In a blender, combine the unsweetened milk, unsweetened cocoa powder, almond butter, avocado, veggies and fruits.
2. Add a handful of ice cubes to the blender for a chilled effect (do not add ice if you are using frozen berries and fruits).
3. Blend until smooth and creamy.

This smoothie may not be too sweet, but it's rich and creamy due to the avocado and nut butter. And the fruits gives a balanced sweetness. It's a great way to enjoy a chocolatey flavor without added sugars or sweet substitutes. Remember to enjoy this smoothie in moderation and as part of a controlled portion diet.

Prader-Willi
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