



THE WISCONSIN CONNECTION

The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.

The mission of the Prader Willi Syndrome Association of Wisconsin, Inc. is to Support, Educate and Advocate for persons with Prader-Willi Syndrome, their families and professionals in meeting the challenges of this disability.

Board of Directors:

President: Crystal Boser

Vice President: Kim Tula

Treasurer: Jackie Mallow

Secretary: Amber Gaulke

Board members:

Bobbi Pogrnt

Melanie Laur

Jamie Milaeger

Sherita Greer

Andrew Gaulke

Carolyn Jahnke

Angela Catteruccia

Board member emeritus:

Nancy Burlingame

Program Director:

Joshua Escher

Junior Advisory Board Members:

Kameron Boser

Makenzie Gaulke

Maya Luening

Maddie Tula

Eva Glass

Josaphine Glass

Office Address:

PWSA of WI, Inc.

PO Box 324

Menasha, WI 54952

(920) 733-3077

Email:

progdir@pwsaofwi.org

Website:

www.pwsaofwi.org

Facebook:

www.Facebook.com/PWSAofWI

Twitter:

Www.twitter.com/PWSAofWI

Instagram:

Www.instagram.com/PWSAofWI

PWSA of WI, Inc. is a chapter of PWSA (USA)

Website: www.pwsausa.org



Letter from the Office

Joshua Escher

Program Director

Hello from PWSA of WI HQ. I hope this newsletter finds everyone happy and healthy. If the weather is a bit hot as you start to read this, check out page 2! I sit here typing this out as I am finishing up the newsletter. This one really gave me a chance to reflect on this year's PWSA (USA) National Convention. Much of the information in the pages here come directly from my notes taken during the different presentations. I definitely learned a ton again this year as I always do. I really look forward to the next one though. The National Convention has always been an amazing opportunity to meet new families and hear their stories. I didn't get the chance to do that sitting in my office looking at my computer. Hopefully the fact that it was virtual and free allowed some of you who might not otherwise have the ability to attend.

The last couple months were very busy. The end of the school year brought numerous IEPs that needed support. May brought us Prader-Willi Awareness month(2022 our On the Move Walkathon will be back!) and the daily challenges that went with it. Here we are in June/almost July and our golf benefit stuff has been sent out! I am working on a GI educational opportunity for medical providers so keep an eye out as I will need everyone's support in getting the word out on that. Summer is going to move fast so enjoy it and hopefully we will see you soon!

Are you interested in being involved in PWSA of WI's mission? Consider running for a board member position! Board members are a key part of determining the direction of our organization as we try to best serve the PWS community here in Wisconsin.

If you have interest in running for a board position or have questions about what it would entail, contact our program director Josh.

920-733-3077

progdir@pwsaofwi.org

Stay Cool!

Here are some products and strategies to beat the heat. Individuals with PWS have difficulty regulating their body temperature and are more at risk of heat stroke.



Cooley Towels



Mister Fans



Cooling Vests

Most importantly: drink water, lots and lots of water! Stay cool out there!

Spicy Food
Yes! It can make you sweat which regulates body temp.





We will be holding our 21st annual golf benefit Sunday September 26th at The Oaks in Cottage Grove, WI. Join us for a golf scramble and luncheon with raffles and prizes to raise money for PWSA of WI. All registration/sponsorship/donation information can be found here: <https://pwsaofwi.org/event-4346526>

Create a Sensory Diet

All children with Prader-Willi Syndrome have sensory processing disorders to some level.

Sypmtoms/Things you will see

- Acute awareness of background noises (can't pay attention)
- Fascination with things in their environment
- Coordination problems
- High or low activity level
- Difficulty with transitions

Vestibular (relates to the inner ear and sense of balance)

- provides information about movement, gravity, and changing of head position
- helps us stabilize our eyes when we are moving, tells us if things are moving
- balance problems often have to do with vestibular issues

Strategies: rocking, bouncing, slow spinning, walking/running, rough housing, force balance challenges

Proprioception (the feedback between sensory receptors in your body and your nervous system)

- Provides feedback/awareness of body position
- Boosts serotonin levels

Strategies: carry heavy objects, pushing/pulling items, crawling through tunnels, hanging from monkey bars, Jumping, weight training

Tactile (touch/feeling)

- Important to use a firm touch (individuals with PWS can get a creepy crawly feeling from light touch)
- Skin is always at high alert (clothing tags, socks, etc can cause irritation)
- Use of brushing can provide great relief

Oral Motor (eating is the most sensory intensive activity that we have)

Strategies: blow bubbles/whistles, cold or frozen grapes/bananas/popsicles, chewy or crunchy food, sour/tart things, sucking

Supplemental Therapies

Sensory Based Intervention

Vision therapy
Vestibular Therapy
Music Therapy
Feeding Therapy
Tactile and Proprioceptive therapy



Aquatic Therapy

*Full body physical improvements
Tie Movement with language*

Hippotherapy (horse therapy)

*Trunk core strength
Improved muscle tone
Improved motor skills*



Things you can do without the help of a specific therapist:

Swimming, open gym, art classes, ice skating, dance, rock climbing, sports/special olympics, library time, gymnastics, music, clay/pottery classes, skiing, karate/judo, biking

Do you or someone you love have Prader-Willi syndrome (PWS)?



Harmony Biosciences is seeking people ages 6-65 with PWS to enroll in a clinical trial



We will be studying the safety and impact of an investigational medication on excessive daytime sleepiness, cognition, and behavioral function in people with PWS.

What is required?

Your participation in the trial lasts approximately 4 months. During that time, there are 5 planned visits.

Patient

If you are a patient...

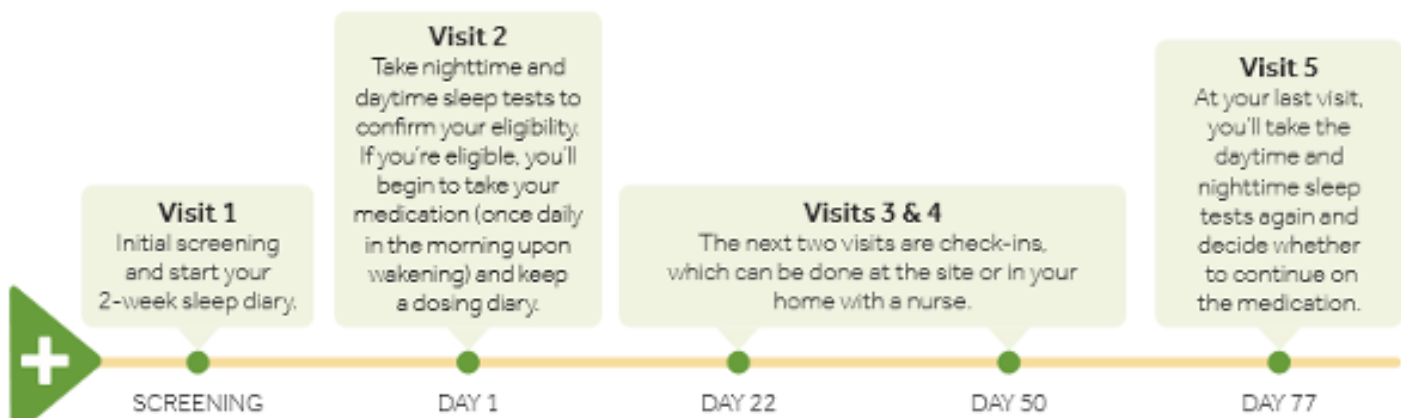
At your visits, you'll participate in sleep tests and have general check-ins on how you're feeling. You'll also need to keep a sleep diary for the first 2 weeks, and a dosing diary once you start treatment.



Caregiver

If you are a caregiver...

You'll attend all visits with the patient and help provide information to the trial researchers.



Where is the trial?



THERE ARE **10 Trial Sites** Around the US WITH MORE TO BE ADDED

Travel expenses to the site most convenient to you will be reimbursed by Harmony Biosciences

LEARN MORE!

Contact clinicaltrials@harmonybiosciences.com to learn more.



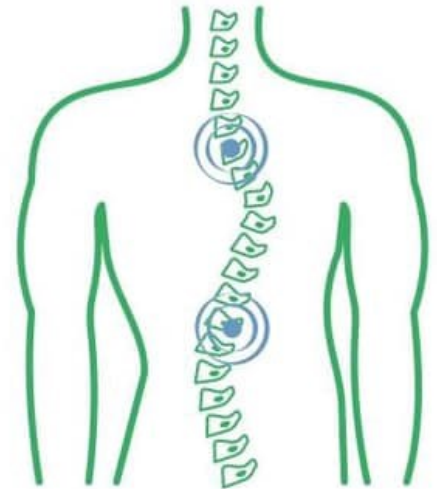
June is

SCOLIOSIS AWARENESS MONTH



2-3%

of the U.S. population has scoliosis.



46%

of Global PWS Registry participants over the age of 2 report scoliosis.

The incidence of scoliosis increases with age.

Up to 80% of people with PWS

over the age of 10 have scoliosis.



WWW.PWSREGISTRY.ORG

We want to thank everyone that participated in our May Awareness campaign. We had people from all over the country that walked with us and did our challenges throughout the month. We cannot wait until 2022 so we get to walk with all of you in person again.

Through the hard work of our fundraisers and generous donors we raised almost \$9,000 for PWSA of WI.

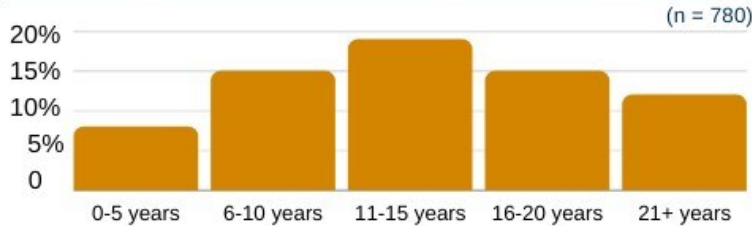
We would like to extend an extra special thank you to our two biggest fundraisers. The A-team/Christman family raised the largest amount in online donations and our buddy Alex Perez and his mom Carrie Bixby raised the largest amount in offline donations!



GI Issues in PWS

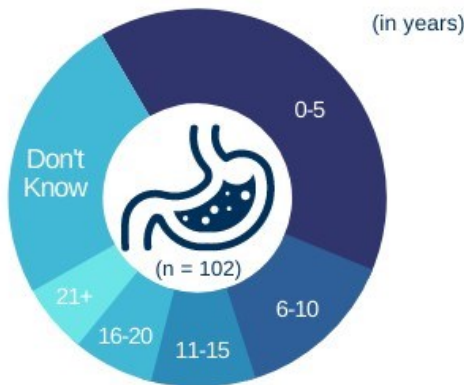
IRB Approved at the 120190361
Protocol Level #30947991.0
May 24, 2021

PWS Registry Participants Who Have Experienced Gastroparesis by Age

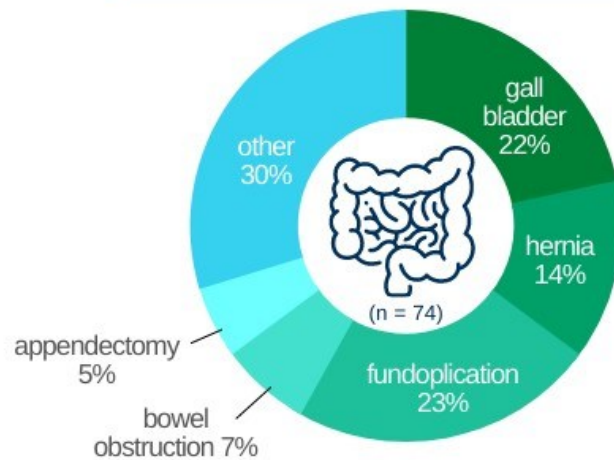


Gastroparesis, delayed gastric emptying, is common in PWS.

Age at Onset of Gastroparesis



17% of registry participants have had a GI Surgery



WWW.PWSREGISTRY.ORG

JUNE 2021



Do you have a teacher, doctor, care provider, or other professional that you think deserves to be recognized for their service to the PWS community? We want to reward them! Visit our website at <https://pwsaofwi.org/ProRecognition> and fill out an application today! Each winner will receive a certificate, a card, and a \$50 gift card.

Prader-Willi Syndrome Association of WI, Inc.
 PO Box 324
 Menasha, WI 54952
 920-733-3077
 Email: progdir@pwsaofwi.org
 Web site: www.pwsaofwi.org

Nonprofit Org
 U.S. Postage Paid
 Menasha, WI 54952
Permit #75



PWSA of WI, Inc.'s Event Calendar		
The Oaks, Cottage Grove, WI	Sunday September 26th, 2021	21st Annual Golf Benefit
TBD	January 2022	Snowflake Ball