WISCONSIN
Prader-Willi
SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

SUMMER 2022

THE WISCONSIN Connection

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

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PWSA of WI, Inc.
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NEW ADDRESS

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

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.

Letter From the President

Welcome to our newly designed Wisconsin Connection newsletter!

A lot has transpired since the last edition of the newsletter; therefore, I would like to take this opportunity to highlight the various changes that have occurred and share some exciting news about what to expect in the coming months.

In March, our Program Director, Joshua left the Association after 8 years in order to pursue a new career path. Joshua was an integral part of PWSA-WI, Inc.and his departure greatly impacted the Association. After much discussion amongst the Board of Directors, it was decided that we would restructure the Association and move the mailing address to Oconomowoc which is close to many of our board members. Our email address and phone number remain the same, but our new mailing address is
PO Box 226, Oconomowoc, WI 53066.

As part of the Association's restructure, we hired an Event Co-ordinator who will be responsible for planning upcoming social events, fund-raisers and training opportunities. If you haven't already met **Angela Witczak** at our May **Walk in the Park** event, you will definitely have the opportunity to meet her at some of our upcoming events. Angela is the mother of 8 kids, an author, a fundraiser, and she's very passionate about making the world a better place. In addition to the Event Coordinator position, we have also created a volunteer Newsletter Editor position that **Barb Dorn** has graciously agreed to fill. Barb, along with **Bobbi Pogrant** who created the new layout of the newsletter, and myself, are the new team of editors for **The Wisconsin Connection** newsletter. Barb is a retired nurse and one of the founding parents of PWSA-WI, Inc. Barb has served in a variety of roles within the Association over the years such as president, board member and program director. We are not only excited about Angela and Barb officially joining the PWSA-WI, Inc. team, but are also excited to be returning to in-person events.

Due to the COVID pandemic, PWSA-WI, Inc. decided to host a variety of virutal events throughout the past few years. In May, the Association returned to in-person events, hosting a **Walk in the Park** at Roosevelt Park in Oconomowoc. The event was a huge succces and, as a result, PWSA-WI, Inc. decided to host three additional events before the end of the calendar year. The **Family Fun Day**, held in August, provided families the opportunity to enjoy a low calorie lunch while playing various games and socializing with others. Our upcoming **Sparkle & Shine Gala**, slated toward the end of September, will provide attendees

Continued on page 7

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A WALK
IN THE PARK

A Walk In The Park

Saturday, May 7th was a beautiful day to reunite families and friends of PWSA-WI, Inc. for our recently renamed, Walk in the Park.

After taking a break from in-person events due to the COVID-19 pandemic, 228 registered participants arrived in Oconomowoc ready to show off their throwback t-shirts from walks of the past. Of these participants, 93 champions with PWS strutted their stuff down the paved path filled with signs that highlighted basic PWS facts and words of encouragement from our wonderful footprint sponsors.

Once completing the two mile walk, participants enjoyed a low calorie lunch consisting of wraps, chips, bananas, pickles and flavored water. Attendees then danced the afternoon away to tunes provided by disc jockey, **Rebecca Cox**. At the conclusion of the event, everyone left with a tie dyed bandanna and a handheld pop it set. A huge thank you to **Tom Davenport** from **RD Image** for capturing the events of the day!

We'd also like to thank our corporate sponsors who helped us walk our way toward our fundraising goal. A huge thank you to **Athena Legal Solutions LLC, Satko Oral Surgery Implant Center and Rowdy, Prader Willi Homes, TW Metals, Frito Lay, Kwik Trip, Municipal Well & Pump, and Festival Foods**! Thanks to the efforts of everyone, we raised almost $20,000!!

Family Fun Day

On Saturday, August 6th, PWSA-WI, Inc. hosted a Family Fun Day at Northlawn Park in Cottage Grove, Wisconsin.

Although the weather was in the 90's, over a dozen families joined us for an afternoon of fun and fellowship. Some attendees played Connect 4, Jenga, and Cornhole while others blew bubbles, made cool designs with sidewalk chalk and played on the nearby playground.

During a lunch that consisted of a turkey hotdog on a whole wheat bun, mini carrots, snack sized popcorn and jello, participants were able to catch up with old friends and get to know new ones. We are already looking forward to next year's event!

SAVE THE DATES:

SEPT

09/24/22
PWSA of WI Sparkle & Shine Gala
A fundraising event for friends and families of persons with PWS.
Red Circle Inn & Bistro • Nashotah, WI

09/27/22
PWSA-USA Virtual Sleep Summit
Four webinar presentations from physicians for both parents and healthcare providers about sleep issues in PWS.

SEPT-OCT

09/30/22-10/01/22
FPWR Conference • Chicago, IL

OCT

10/29/22
The PWSA of WI Masquerade Ball
A social event for persons with PWS, families and those who support them.
The Ingleside Hotel • Pewaukee, IL

JUN

06/23/23 - 06/24/23
PWSA-USA 2023 Conference
Orlando, Florida

Back to School Resources

Compiled by Barb Dorn

It's that time of year again, getting your child ready to return to school. There are a few things you can do to assist in making it is a positive, low anxiety experience. Here a few tips.

1. Review your child's IEP. If there are any questions, concerns or problems, notify the school and arrange for a meeting before school begins. Teachers and therapists can be very busy the days prior to school starting, so it's best to make the request as soon as you can. Sometimes, all it takes is a meeting to get questions answered; things clarified and issues resolved. If needed, you can ask to reconvene the IEP team. If you need assistance, contact PWSA of WI, Inc. for help.

2. If your child is attending a new school, (s)he may experience anxiety over all of the new changes they may face. It's often helpful to visit the school a few days before classes begin, when the building is quiet. Find their classroom; meet the teacher and locate other popular locations (bathroom, therapy room, gym – just to name a few). Some families have found it helpful to visit more than once before school begins.

3. Share resources and handouts about your child and PWS. Some parents create a 1-page handout about their child, incorporating key items about PWS. Include some special things to know about them – their favorite color, topics and strategies that often work to keep them engaged and happy.
   You may also want to include a few things that can be "triggers" for high anxiety and include any successful strategies to address them. Include information about PWS. Share this with all teachers - especially art, physical education and any other educators who may have contact with the student. Many times, these teachers and support staff never get to see the IEP and really appreciate it.

4. Visit the PWSA of WI, Inc website and check out several articles and education resources. The link to these resources is: **https://pwsaofwi.org/PWSInfo**

5. Visit the PWSA I USA website for resources on "School Success". There are videos, resources and information that may help you address in school concerns. The link to these resources is: **https://www.pwsausa.org/school success/**

Topics include:

- PWS Challenges and Solutions
- Individual Education Program
- Home Schooling
- Behavior Challenges
- Effective Advocacy
- Special Education Law

COME JOIN OUR BOARD OF DIRECTORS!

Are you interested in being involved in PWSA of WI's mission? Consider running for a board member position! PWSA of WI will have 4 open board positions to begin in January of 2023 and we would love to see some new additions! Board positions are 2 year positions and elections are held each October and 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 are interested in running for a board position please visit our website to download an application at pwsaofwi.org/Volunteer. If you would like more info, please contact Crystal at progdir@pwsaofwi.org. Board Applications must be submitted by Sept.15th.

Spotlight on Success

Nolan K.

PWSA-WI, Inc. would like to congratulate **Nolan K.** on his recent graduation. On June 17th, Nolan was presented with a Certificate of Completion in recognition of his successful completion of academic programming at Genesee Lake School. Nolan celebrated this monumental milestone by enjoying a special dinner attended by family, residential program staff and his longtime case manager.

Molly P.

On June 3rd, **Molly P.** received her Certificate of Completion in recognition of her completing the Course of Study prescribed by the Board of Education of the Peru High School Corporation. Not only did Molly graduate, but she did so with perfect attendance. She and her family celebrated this awesome achievement before Molly moved into her new residential home in River Falls. Congratulations on your graduation, Molly!

Jett L.

Jett L. recently received special recognition at the National FFA Organization banquet. Jett accepted the Greenhand FFA degree and Career Development Events certificate in Wildlife Ecology while dressed in his Wisconsin Holmen Agricultural FFA jacket and surrounded by family and friends. Congratulations Jett!

Do you want to share a success story of an individual with PWS to be featured in future Wisconsin Connection newsletters? Please email your story and photo to Barb Dorn at bdorn84@gmail.com.

SUBMIT
YOUR SUCCESSES!

HAPPY BIRTHDAY TO YOU!

JUNE

Victoria L.
AJ L.
Michael G.
Oliver M.
Nolan K.
Jason F.
Brielle S.

Jim J.
Jack B.
Daniel S.
Joel W.
Jillian C.
Tony S.

JULY

Julien J.
Claudia H.
Haylee Jo B.
Dan S.
Elizabeth G.
Robin W.
Hana B.

Ania B.
Jennifer M.
Renee R.
Addy P.
Marcus O.
Anna L.

AUGUST

Laura S.
Elaine Y.
Jeff K.
Martha L.
Adam B.

Jackson G.
Sydney V.
Aaron C.
Lorissa D.
Meredith W.

PWS CARD CLUB REMINDER

Are you interested in having birthday and seasonal cards sent to your loved one with PWS?
Are you in the card club and recently have a change of address?

If you answered yes to either of the above questions, please contact Bobbi Pogrant at Pogrant1@msn.com with the name, address, and birth date of the individual with PWS.

Residential Support, Education, and Advocacy Efforts

Over the past two years, we have all been impacted by the many changes the pandemic has caused. Many residential agencies have faced greater challenges to secure and retain staff to care for the disabled and the elderly. Some have cut services; closed homes; put a moratorium on admissions; and even closed their doors.

Prader-Willi Homes in Oconomowoc once served over 100 adults and children with PWS. This agency was greatly impacted by this staffing shortage. Over 20 individuals were discharged, leaving many families in desperate need of an alternative placement. Two homes were closed, including the children's home. After much time, energy and investigation, most individuals were able to find alternative placements. Unfortunately, some returned home with parents and are still looking for a solution. Volunteers from PWSA of WI served as advocates, listeners, and educators. They also became "resource investigators", researching possible solutions.

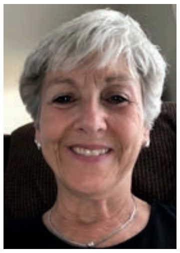
Abilities Midwest, based in River Falls, WI expanded its services to Watertown where they opened 2 adult family homes. They had been successfully operating one home in River Falls that specifically serves people with PWS. Katelyn and Brandon Schmidt, current board members of PWSA of WI, serve as co-owners of this agency. Families and persons with PWS were so grateful for their willingness to expand services.

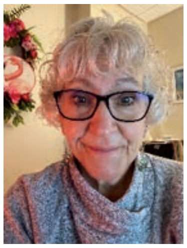
Two new homes opened in Madison, each serving 2 adults with PWS. They were new to caring for persons with PWS which provided PWSA of WI the opportunity to help educate and support this new venture.
We want everyone who supports persons with PWS to be successful.

Thanks to the efforts of Barb Dorn, Jackie Mallow and Peggy Burnes RD, several training opportunities were provided both in person and by Zoom. Barb is a retired nurse who has served in many roles over the years in the world of PWS. She was one of the founding parents and served as president, board member and later as program director for PWSA of WI. She currently serves on the Editing and Communications Work group at PWSA l USA and has written many articles and been a speaker on a variety of topics in the care of persons with PWS. Jackie Mallow, Director of Specialized Services and Community Outreach for Abilities Midwest, has also worn many hats in the world of PWS. She was the Director of Roots Connection, a consultative service agency on PWS, PWSA l USA Conference Coordinator, Director of Admissions at PWH and has served many years on the board of PWSA of WI as well as PWSA l USA. Peggy Burns, RD has been a dietician for over 30 years and was the dietician for PWH for over 13 years.

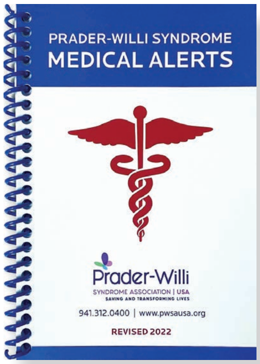
In early June, Barb and Jackie traveled to Madison to conduct in-person trainings on an "Overview of PWS", "Health Concerns" and "Behavior Management". In addition, Barb conducted a Zoom training on "Activity Planning and Exercise" and Peggy did a Zoom training on "Nutrition, Diet and Menu Planning". Staff from the two new homes in Madison, along with parents attended these training opportunities. These Zoom presentations were recorded and are available. (**Activity Planning and Exercise:** https://vimeo.com/721591488 and **Nutrition, Diet and Menu Planning Video:** https://vimeo.com/721600937)


Jackie Mallow


Barb Dorn


Peggy Burns, RD

NEW updated PWS Medical Alert Available



One of the most valuable resources a parent or caregiver can have, is a copy of the PWS Medical Alert booklet or online downloadable document. **A new updated version now is available.** It is the best health information resource out there. Keep a copy handy to help with educating and advocating health care professionals.

To download:
https://www.pwsausa.org/wp-content/uploads/2022/03/Medical-Alerts-Booklet_3.8.22Final.pdf

To order (cost is $6): https://www.pwsausa.org/shop/


United in Hope
FOR PWS

Save the Date

PWSA | USA 2023
NATIONAL CONVENTION

June 21-24, 2023 | Orlando, FL

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES


SAVE the DATE
September 27, 2022

SLEEPSUMMIT
Prader-Willi Syndrome Association | USA
Supported in part by a grant from
HB HARMONY BIOSCIENCES

To learn more about sleep issues in individuals living with PWS, PWSA | USA is hosting a six-month program entitled Sleep Issues in Prader-Willi Syndrome: A Deep Dive for Parents & Practitioners, which includes monthly focus group discussions led by a trained facilitator.

The program will conclude with a full day PWSA | USA Virtual Sleep Summit, which will be held on September 27, 2022. The Sleep Summit will include four webinar presentations from physicians for both parents and healthcare providers.

Research Updates and Recruitment

PWS clinical trials are taking place around the world to help us understand PWS and investigate new treatments. Here's a few ways you can get started:

Learn more about the basics of clinical trials and answers to common questions at **https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics**

Go to **https://www.fpwr.org/pws-clinical-trials#trials** and view all the clinical trials starting. If you're interested in a trial, please discuss it with your physicaln about potential risks and ask questions to help you decide if enrolling in a clinical trial is right for you or the individual with PWS.

PWS Clinical Trials that are currently recruiting or coming soon:

RAD-101 - A Potential Treatment for Hyperphagia- Now Enrolling Ages 8 - 65
SCOUT-015 is a Phase 2/3, double-blind, placebo-controlled study to evaluate the safety and effectiveness of RAD011 synthetic cannabidiol oral solution in people with Prader-Willi Syndrome. RAD011 is synthetically derived CBD and does not contain THC. This study is currently enrolling individuals between the ages of 12 and 65 years. Eligible individuals who complete SCOUT-015 will have the option to enroll in a long-term extension safety study.

ARD-101 (ages 17 - 65)
This Phase 2, open-label study will investigate the effects of ARD-101 in people with Prader-Willi Syndrome. This study is looking to enroll 12 individuals between the ages of 17 and 65 years at Stanford and Children's Hospital Colorado. Participants will take ARD-101 orally, twice daily for 28 days.

Guanfacine Extended Release (ages 6 - 35)
Guanfacine Extended Release (GXR), is an FDA-approved drug used to treat children and adolescents with hypertension and attention deficit hyperactivity disorder (ADHD). This will be the first study to evaluate the drug in patients with PWS to see whether or not the study drug works to reduce the aggressive and self-injurious behaviors seen in PWS.

Cannabidavarin (CBD-V) (ages 5 - 30)
This phase 2, randomized, double-blind 12-week treatment trial of Cannabidivarin (CBDV) will assess the effect of CBDV on behavior in people with PWS. The study is now enrolling patients ages 5-30 years old. Travel to the Montefiore Medical Center, Bronx, NY is required.

Oxytocin (ages 5 - 17)
This phase 2, randomized, double-blind 8-week treatment trial of oxytocin will assess the effect of oxytocin on eating behaviors, weight and body composition, and quality of life in people with PWS. The study is now enrolling patients ages 5-17 years old. Two visits to the Montefiore Medical Center, Bronx, NY is required.

The Global PWS Registry is a powerful tool for the PWS community to advance understanding of PWS, areas of unmet need, standards of care, and new therapies.

Data from the registry is shared back to the PWS community and is also used by researchers and scientists. By participating, families of those with PWS become part of the research team, helping uncover trends in causes and diagnosis as well as new directions in therapies and treatment.

The Global PWS Registry is only as powerful as the people who participate. And learning more about the experiences, medications, symptoms, milestones, and other aspects of PWS is key to advancing our understanding and discovering new therapies and treatments.

Visit the Global PWS Registry at **https://pwsregistry.org/** for more information for researchers and patients. From there, register and be part of the global community working toward brighter tomorrows for our loved ones with PWS.

Letter From the President

(continued)

the opportunity to learn more about Prader-Willi Syndrome while raising funds through activities such as a cork pull and silent auction. At the end of October, our reimagined **Masquerade Ball** will be held at the Ingleside Hotel. Similar to past years, this event will allow individuals with PWS the opporunity to participate in a prom-like experience that includes a sitdown dinner, professional photos and dancing. To stay up to date on all of our upcoming activities and events, please visit our website at www.pwsaofwi.org or follow us on our PWSA-WI, Inc. Facebook page.

These past few months have been filled with an assortment of changes and challenge, but also lots of excitement. As a board, we are thrilled about the future of the Association!

If you have any questions regarding anything related to PWSA-WI, Inc., please feel free to reach out to me via email at crystal.boser@aol.com, phone or text at 414-403-1935 or Facebook messenger.

Sincerely,

Crystal L. Boser

Crystal L Boser
President

"I wish I knew more about…."?

Send an email to **Barb Dorn** at **bdorn84@gmail.com** and let us know what you want us to help you learn about.

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