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Maya Luening

Newsletter Editor: Barb Dorn

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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.

Looking Ahead – 2023

Happy New Year!

The theme for 2023 is going to be change, and although change can be scary, it can also result in amazing opportunities and outcomes.



Carolyn Jahnke

At the beginning of January, we said good-bye to board member, **Carolyn Jahnke**, as she stepped down after serving seven years on the board. We also said good-bye to long-term board member and treasurer, **Jackie Mallow**.

After 26 years of serving the board in multiple roles, Jackie made the difficult decision to leave the Association so she can concentrate full time on serving individuals with PWS and spend more time with her family. In Jackie's absence, long-standing board member, **Jamie Milaeger**, was elected as treasurer and has assumed that role. Although we will miss both Carolyn and Jackie, we know we will still see them at upcoming events throughout the year.



Jackie Mallow

As mentioned in our Fall newsletter, we also welcomed four new board members at the beginning of the year and they have already started making their mark on the Association. **Eva and Josaphine Glass** have stepped up to oversee the Junior Advisory Board and will be working diligently to recruit new members to that board. **Gavin Johnson** has started gathering valuable

information that will be useful for planning upcoming training and outreach events.

Pam Toepfer has graciously agreed to assume the volunteer accountant position as Melanie Laur remains on the board, but steps away from that role. We are thrilled that what Eva, Jo, Gavin and Pam bring to the board.

At the end of 2022, we also wished our Event Coordinator, **Angela Witzczak**, good luck as she left the Association to pursue her dream job of helping the homeless population in her community. Although we will miss Angela we are excited to share that we also began a new partnership with **Andrea Kane** at the beginning of 2023. Andrea is a local resident of the Lake Country community and will be working with us to plan and execute awareness and fundraising events throughout the year. We are very excited about the ideas and energy Andrea brings to the Association.

In closing I would like to say, change can be difficult and scary, but change is also necessary. Change brings growth and new opportunities. We are excited about the changes within our organization and we hope you will be too. So if you find yourself faced with the prospect of change, don't forget we are all here to support each and every one of you!

I look forward to seeing you all in the future.

Crystal L. Boser

Crystal L. Boser
President

Junior Advisory Board

by Eva Glass and Josaphine Glass



Eva Glass



Josaphine Glass

At a young age we were introduced to Prader-Willi Syndrome from our Aunt who worked in a group home that served individuals with PWS. We would participate in activities with the residents and our Girl Scouting group. Over the years we would volunteer at events and would look to help where we could.

At the ages of 10 and 11 we joined the Junior Advisory Board as our Aunt transitioned from working in the homes to being a member of the PWSA-WI, Inc. board. Through the Jr. Advisory Board we were taught many things that would help us in the future. We were taught maturity, patience, kindness, and to be a part of community that deserved those things.

We fell in love with the individuals we came into contact with through the events we volunteered at and created relationships with individuals that we will carry for the rest of our lives. Now as full-fledged board members we want to pass the torch to other young individuals wanting to be a part of something that will not only change their life but the lives of the people we advocate for.

We want to keep growing the Association for generations to come. We want to talk to individuals from ages 13 years and older to discuss opportunities to volunteer and grow as a young adult and give back to the communities around us. Getting High School students to earn volunteer time and growth in their personal lives is a chance to help pave their ways in the future. If you are interested in this unique opportunity please visit pwsaofwi.org/JuniorAdvisory

Membership Info

Whether you would like to support PWSA of WI by volunteering or becoming a member, we would love to have you join us! Volunteer with us on a committee, event, or project and choose when and how you would like to contribute. Or become a member, and enjoy the perks of discounts on trainings and events and many other perks.

Interested in getting involved? Fill out a volunteer interest form at pwsaofwi.org/Volunteer

Interested in becoming a member? Join us at pwsaofwi.org/Membership

Members will receive an annual email to renew their membership.

Are you unsure if you are a member? Just drop us an email at progdir@pwsaofwi.org and we can check if your membership is current...it's that easy!

How to apply for the Junior Advisory Board

Who Is Eligible?

The Junior Advisory Board of PWSA of WI, Inc. is open to all youth ages 13-17 that have an interest in supporting those living with Prader-Willi syndrome.

How Do I Apply or Nominate someone?

Interested youth should submit an application or nominees submit a nomination form for consideration. Each submitted application will be considered by the PWSA of WI, Inc. Board of Directors and voted on.

Application and nomination forms, and description of the roles and duties can be downloaded from the links at the bottom of the web page:
pwsaofwi.org/JuniorAdvisory

Space on the Junior Advisory Board is limited to 6 members, but PWSA of WI, Inc. welcomes all interested applicants to volunteer at the events held by PWSA of WI, Inc. For more information on volunteering, please go to pwsaofwi.org/Volunteer.

Completed applications can be emailed to:

ProgDir@pwsaofwi.org
or mailed to:
PWSA of WI, Inc.
38 S Main Street #226
Oconomowoc, WI 53066

Get Involved.

**VOLUNTEER.
MEMBERSHIP.
GIVE.**

Learn how to get involved.

<https://pwsaofwi.org/Volunteer>
<https://pwsaofwi.org/Membership>

Junior Advisory Board Program Goal

The Junior Advisory Board's goal is to empower the next generation by engaging our youth in event planning, volunteerism and program development within the Prader-Willi Syndrome community, and assist with fundraising to support the programming of PWSA of WI, Inc.

PWSA I USA Behavior Summit

Summary by Barb Dorn



On Tuesday January 24th, 2023, PWSA I USA held a Behavior Summit. Recordings of these webinars will be available on the PWSA I USA website (<https://www.pwsausa.org/behaviorsummit/>) or on the PWSA I USA YouTube channel. I was only able to attend 3 out of 4 of the presentations. All were very informative. I have shared some of the key points and "practical" strategies that may help you in dealing some of the more common behavior challenges. This is only a snapshot. I encourage everyone who cares for a person with PWS of all ages to watch.

Topics / Speakers:

"The ABC's of Behavior" / Stacy Ward MS, Director of Family Support, PWSA I USA

"Behavior Challenges – Prevention is Key" / Patrice Carrol, LICSW, Director of PWS Services at Latham

"Understanding Tantrum Behavior in PWS – Why it Happens and What to Do About It" / Kasey Bedard, Ph.D., BCBA-D, IBA, Behavior Specialist at Delta Behavior Services

Key Points:

- Antecedents (things that happen prior to the behavior) are often the most revealing in identifying why a person with PWS has an escalation in emotion and/or behavior. Changes (in routine, people or anything), transitions, being told "no" are some of the more common reasons for an escalation.
- Some strategies for preventing negative antecedents include:
 - Creative scheduling (schedule least favorite activity right BEFORE favorite activity).
 - Provide choices – gives the individual some control. This can enhance cooperation.
 - Foreshadow changes but don't do this too far in advance. Put change in writing.
- Add positive reinforcement (consequences) such as praise, encouragement, High 5's goes a very long way.
- Help them to identify and validate what they are feeling. Many are unable to say what they are feeling so they "act" what they are feeling instead. "I see you are frustrated".
- If a person suddenly starts having more tantrums, rule out pain. An infection is often the reason for increase behavior issues.
- Once the tantrum is over, don't rehash or review it. It often makes it worse. If you are going to do this, put in "general terms". Do not be specific to the incident. You may provide some alternative strategies to try. Get the individual to buy into it. Ask for input from them.
- They have a skill deficit in how to manage their emotions and reactions. They have inconsistent impulse control. Teach self-calming technique skills, early and often.
- Do this when the person is calm, not during any aspect of a tantrum. Rehearse and practice.
- Create a "Calming Break" area. Do NOT call it a time out. It should be a quiet, isolated area.
- Celebrate and provide a ton of praise when they end the calming process.
- Limit talking at any point in a tantrum process. Keep instructions concise and simple. They are slow to process information. Often only hear the last words you say. If you say "I need you to do X and Y, we can't go until this is done." They only hear, "we can't go until this is done." Don't make threats.
- Teach and tell them what behavior you want to see. "I need you to go the calming area". "I need a quiet voice." Avoid using the word "don't". It takes a lot to convert a don't statement to a do action.
- Avoid modeling inappropriate behavior – yelling, arguing or negative non-verbal communication.
- Let it go! Do not take tantrums personally.

Skin Picking

- The exact reason for picking is unknown. It may be a result of a lower release of endorphins. Often becomes a compulsive behavior. Sensory stimulation therapy releases endorphins. Vibration, massages and skin brushing are some successful techniques – even a vibration stool while on the toilet.
- The use of barriers, keeping hands busy and supervision are the most successful strategies for skin picking including rectal picking.
 - Nail dips (at a salon) have made it difficult for some to pick and have been very helpful.
 - Mitts and triathlon body suits have been used (at night) for those with severe rectal picking.
 - Keep your responses neutral when picking occurs. This can be difficult.

Questions and Answers on Extended School Year for the Student with PWS in the State of Wisconsin

Compiled by Barb Dorn, RN, BSN

Many students with PWS benefit from services under terms of Extended School Year (ESY). As the mid to end of the academic year approaches, many parents and advocates are involved in IEP's where this topic should be discussed. The information shared below is taken from the State of Wisconsin Department of Public Instruction Informational Bulletin Number 10.02 which specifically addresses ESY. (Information Update Bulletin 10.02 | Wisconsin Department of Public Instruction) The following are some questions and answers on ESY, along with some advocacy tips on this important topic.

What are ESY Services?

ESY services are "special education and related services provided pursuant to an IEP beyond the limits of the school term." According to the Individuals with Disabilities Education Act (IDEA), all students with a disability must be provided a free appropriate public education (FAPE). The student is entitled to special education services and related services (ex. speech, occupational, physical therapies, transportation) as outlined in their IEP. Federal guidelines provide each state discretion in determining ESY services, as long as it includes FAPE.

Is ESY the Same as Summer School?

NO. Summer school is typically an optional program provided beyond the regular school year. Schools can opt in or out of operating summer school. In many cases, summer school programs teach new content or enrichment and/or offering recreational or academic opportunities not present during the regular school year. Special education students can attend summer school and they can utilize programs to maintain learned skills or prevent loss of critical skills. For ESY, the IEP team determines the need and extent of services needed to meet the unique needs of the child. If services are not provided, a child's skills can be temporarily or permanently lost, jeopardizing progress. The decision to receive ESY is dependent on the needs identified in an individual's IEP; not on what services are available.

What Criteria Determines if a Student Qualifies for ESY?

According to the Wisconsin DPI Bulletin 10-02, "In most cases, courts consider regression during an interruption in services and recoupment of skills after services resume in determining eligibility for ESY services. The Seventh Circuit Court of Appeals, which includes Wisconsin, has held that states should engage in a multi-factored determination of eligibility for ESY services, including "the likelihood of regression, slow recoupment, and predictive data based upon the opinion of professionals." *Todd v. Duneland Sch. Corp.*, 229 F.3d 899, 907 (7th Cir. 2002). Several other Courts of Appeals have articulated a similar standard for determining whether a child requires ESY services. Specifically, in *Alamo Heights Independent School District v. Texas Board of Education*, the Fifth Circuit Court of Appeals explained:

[I]f a child will experience severe or substantial regression during the summer months in the absence of summer programming, the handicapped child may be entitled to year-round services. The issue is whether the benefits accrued to the child during the regular school year will be significantly jeopardized if he is not provided an educational program during the summer months. 790 F.2d 1153, 1158 (5th Cir. 1986).[1]"

"Consistent with the Seventh Circuit, the Tenth Circuit explained in *Johnson v. Independent School District Number 4*, 921 F.2d 1022 (10th Cir. 1990), that multiple factors are relevant in considering a child's need for ESY services. The court listed possible factors to consider, including but not limited to:

... the degree of impairment, the degree of regression suffered by the child, the recovery time from this regression, the ability of the child's parents to provide the educational structure at home, the child's rate of progress, the child's behavioral and physical problems, the availability of alternative resources, the ability of the child to interact with nonhandicapped children, the areas of the child's curriculum which needs continuous attention, the child's vocational needs, and whether the requested service is extraordinary for the child's condition, as opposed to an integral part of a program for those with the child's condition. This list is not intended to be exhaustive, nor is it intended that each element would impact planning for each child's IEP."

Accordingly, the Wisconsin Department of Public Instruction, it is recommended that school districts consider all appropriate factors in determining whether the benefits accrued to a child during the regular school year will be significantly jeopardized if the child is not provided ESY services.

(Continued on page 5)

Questions and Answers on Extended School Year for the Student with PWS in the State of Wisconsin (Cont.)

Compiled by Barb Dorn, RN, BSN

What Does Regression and Recoupment Mean?

Regression is the return to a lower level of learning or loss of what was learned.

Recoupment is to regain what is lost. It can be normal to lose some skills when they are not used.

Do all students with PWS Qualify for ESY?

NO. Students with PWS have varying abilities, needs and challenges. Some students do not require special education or related services year-round in order to prevent regression or problems with recoupment. Students with significant learning challenges; those with extreme behavior issues, and those with speech or fine/gross motor delays often do qualify.

Can a Student Just Receive Related Services for ESY?

YES. A student may have a need for some or all related services to prevent regression or recoupment of certain skills but not require special education services.

How Long Are ESY Services Guaranteed?

ESY services are only guaranteed for 1 year and are not automatically renewed. The IEP team must evaluate the student's needs and determine services every year.

What Are Some Examples Where Students with PWS Have Qualified for ESY?

Many students with PWS have qualified for ESY to prevent regression of academic skills that they have acquired during the school year. This can be supported by documentation of regression or the need for "relearning" after breaks or vacations in the school year. When a student with significant learning challenges has a 3 month break in their learning environment, it can reasonably be assumed that there will be a loss of skills learned. For many, the time to recoup these skills can be lengthy.

Students with PWS who have significant behavioral challenges, may demonstrate a regression in managing their behavior management skills during extended breaks from school and qualify for ESY.

Frequently, continued progress in speech, fine and/or gross motor skills can be maintained through ESY.

Young adults who are employed and supported in jobs through their vocational program with goals outlined in their IEP, could risk losing their job and employment skills if not enrolled in ESY.

A Few Advocacy Tips for ESY?

The following are some tips in advocating for the student with PWS for ESY:

- Watch for regression and recoupment during breaks in school – weekends, vacations. Document and share your findings.
- Ask therapists what the likelihood of regression will take place if no therapies are provided for 3 months. (If the student has significant challenges in these areas, no intervention for 3 months would most likely cause significant regression)
- For those with more behavioral issues, emphasis on the importance of ongoing, uninterrupted strategies are needed to have the student successfully gain these skills.
- Make sure ESY is on your list of topics to be discussed at the IEP meeting. If needed, there may be time for documentation and justification to be obtained.

Health Education and Advocacy

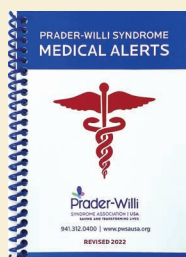
by Barb Dorn, Parent, Advocate, Educator and Nurse

Wouldn't it be nice if all health care professionals were very aware and educated about the unique health issues that most persons with PWS may face?

There was a time when you said your loved one had PWS, a health care professional would say, "Prader what"? There were no resources or PWS professionals to help. We still have a long way to go, but we are making progress. The ongoing challenge is getting health care professionals educated. This is not an easy task to accomplish. We must all take on this challenge. We can and do make a difference.

Just like many of us, health care professionals are very busy people who are being pushed to see more patients and do more with less time. They have fewer opportunities in their schedules to attend conferences and trainings. Most of their education is online and focus on health conditions that they see the most in their practice – diabetes, heart disease, and cancer, just to name a few. Even though we may not like it, parents and caregivers are the primary advocates and educators on health issues in PWS. We have a louder voice than agency administrators or other well-meaning individuals. We have the opportunity to share information one-on-one. We have the ability to educate and advocate to these professionals in a personal, meaningful way.

It's important to GET educated and STAY educated about health issues that impact persons with PWS. This can be done by taking advantage of learning opportunities that help you understand various health topics. Become members or sign up for emails from PWSA I USA (www.pwsausa.org), PW News (<https://praderwillineews.com/>), Foundation for Prader-Willi Research (www.fpw.org), and PWSA of WI (www.pwsaofwi.org). If you are not educated, reach out to those who are.



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/>

Here are a few tips:

- Don't be afraid to share and educate. Be respectful and persistent (if needed) – especially if you feel they aren't hearing you. The person with PWS can be a "diagnostic challenge" for the health care professional. When you can't rely on pain and fever to diagnose a problem – it can be extremely challenging.
- Come prepared with written materials. It's easier to share a handout than it is to share your phone.
 - **The Medical Alert Booklet** (available to purchase or download from PWSA I USA – www.pwsausa.org) Highlight the areas you want to emphasize.
 - **The GI Chart** – it's included in the Medical Alert booklet, or it can be downloaded separately.
 - **Do your research. Come prepared.** Get articles on specific topics you may need to educate the health care professional – growth hormone, scoliosis, sleep apnea (just to name a few).
- Contact PWSA I USA Family Support Staff. They are available by phone 24/7. They can be reached at 941-312-0400.
 - They can assist with providing education and advocacy. They can help you to know what to say and provide you guidance. They are there to help you.
 - If requested, they can facilitate connecting the treating health care professional with a medical professional with the expertise in PWS. These are devoted professionals who volunteer their time and expertise in PWS to help educate and help in the diagnosis and treatment of health issues for persons with PWS.
- Encourage the professional to check out the "Up to Date" website. It is a website that is frequently used by health care professionals when they come across a medical condition that they may not be familiar with. It provides information that educates health care professionals about numerous health issues specific to PWS.

Your education and advocacy efforts will not only benefit your loved one, they will also assist any other person with PWS who this clinician may treat. We must not get discouraged by the need to continue this educational journey. **We are making a difference – sometimes one clinician at a time.**

Thank You Donors! We appreciate YOU!

For over 20 years, PWSA of WI has worked hard to support, educate and advocate for persons with Prader-Willi syndrome, their families and professionals in meeting the challenges of this disability. We strive to help parents, families and professionals gain a better understanding of the unique needs of children and adults with Prader-Willi syndrome.

PWSA of WI has received so many generous gifts over the years through donations, sponsorships, employee matching, memorial gifts, Amazon Smile, purchasing items off our wish list, and the most valuable of all, through your time and volunteerism. Some contributions come to us anonymously or without notification on who to thank (examples include Amazon Smile and Employee Matching), and we want to mention we appreciate your support! **THANK YOU!**

With your contribution, we are able to provide annual social events for people living with PWS, educational training and support, scholarships and general assistance programs, the PWS card club, and much more.

Here at PWSA of WI, we cannot thank you enough. Our supporters are the reason we are able to make any difference at all. It is because of you that we can make the lives of people living with Prader-Willi syndrome a little bit brighter.

If you have specific questions about how your gift is being used, or you want further information on how to continue your support, please don't hesitate to contact us at ProgDir@pwsaofwi.org or visit pwsaofwi.org/WaysToGive

Scholarships and General Assistance Programs

Did you know PWSA of WI offers different types of assistance in order for families of a person with Prader-Willi syndrome to help meet the unique needs of these individuals and their families?

It is easy to apply for these programs at pwsaofwi.org/Scholarships These programs are outlined below:

Membership Scholarships

We offer our services to all. We request a membership registration so that we send information only to those who wish to receive our mailings. We ask that you update your contact information with our office once a year so we can ensure our information gets to you.

Holiday/Birthday Special Assistance Program

PWSA of WI, Inc has created a program to reach out to adults with PWS who are 18 years or older who no longer have family to help them celebrate holiday or birthday events. The "Holiday-Birthday Special Assistance Program" is a program that attempts to make all adults with PWS feel special and be able to continue to have special memories and gifts - no matter what their age.

Workshop or Conference Scholarships

Please see registration form for workshop or conference you would like to attend for more information on how to apply for a scholarship. Every year, PWSA of WI, Inc. sponsors a social and/or workshop for persons with Prader-Willi syndrome as well as families and others who support them. Scholarships are always available for those in need.

Camp Scholarships

Every year, the Board of PWSA of WI, Inc. sets aside funds to assist children and adults with Prader-Willi syndrome so that they can attend summer camp. These camping experiences provide a time of fun and adventure for the camper as well as a time of respite for parents and caregivers.

General Assistance

The Board of Directors allocates funds to assist persons with Prader-Willi syndrome as well as those who support them in areas that help them manage some of the extra costs they may incur because of their disability. In addition, the Board provides funds for families to attend conferences or other workshops, for respite, home modifications or other requests. Unfortunately, because our funding is limited, we are not able to approve all requests our organization receives.



HAPPY BIRTHDAY TO YOU! DECEMBER

Ben V. Ethan H.
Rachel K. Cody J.
Kelsey O. Katherine B.

JANUARY

Olivia L. Paige S.
Alexis O. Karen S.
Katie S. Greysen G.
Carley V. Laura G.
Aiden D. Siena S.
Greg B. Jessica K.
Kevin S.

FEBRUARY

Joel A. Tom A.
David B. Kyle P.
Nick R. Beth L.
Michael A. Tiffany N.
Andy C. Jake A.
Megan A. David G.
Jennifer K. Phongseeyu L.
Kevin T.



If you're interested in having birthday and seasonal cards sent to your loved one with PWS or have a change of address, please contact Bobbi Pogrانت at Pogrانت1@msn.com with the name, address, and birth date of the individual with PWS.

Results of Recent Poll

TAKE THE POLL



Thank you to all of you who completed the survey and helped us to guide our decision in what topic you want us to feature in an upcoming training event. There were 2 topics that were basically tied included: Health / Medical Advocacy and Behavior Management. The board of directors will be discussing future planning along with possible speakers to speak on one or both of these topics.

Save the Dates:

We are in the planning stages!

Please watch the PWSA of WI Facebook page and website for more events to come!

**03/09/23
PWSA-USA School Success Summit**

VIRTUAL EVENT

Details and registration coming soon on the PWSA-USA website!

SAVE THE DATE
Thursday, March 9, 2023 | Virtual Event

SCHOOL SUCCESS SUMMIT

Prader-Willi Syndrome Association | USA

**05/13/23
PWSA of WI A Walk in the Park**

Roosevelt Park • Oconomowoc, WI

Come help us spread awareness and raise money for Prader-Willi Syndrome, spend some time with family and friends, enjoy a nice lunch and dancing!

SAVE THE DATE
Saturday, May 13, 2024

ROOSEVELT PARK • OCONOMOWOC
PRADER-WILLI SYNDROME
MAY AWARENESS WALK-A-THON

**06/23/23 - 06/24/23
PWSA-USA 2023 National Convention
Orlando, Florida**

PWSA | USA's Convention will provide exciting opportunities to learn, connect (and reconnect), and hear about the latest PWS research.

REGISTER TODAY!

<https://www.pwsausa.org/convention2023/>

SCHOLARSHIPS AVAILABLE!

<https://pwsaofwi.org/AssistApplication>

United in Hope
FOR PWS

PWSA | USA 2023
NATIONAL CONVENTION

REGISTRATION NOW OPEN!

Exercise Tips and Community Activities

by Brandon Schmidt

Hello everyone! My name is **Brandon Schmidt** and I am the Athletic Director at Abilities Midwest, Inc and a board member of PWSA-WI. My job is to support the Athletic Program at Abilities Midwest. As the winter months are still among us, there are plenty of activities for an individual with PWS to do to keep themselves active. Also, individuals with PWS benefit from having an incentive option along with exercising. What do I mean by that? As I stated in my previous article, try to use a star-incentive program. For every time the individual completes a workout, provide them with a star sticker on their chart (having a visual is huge!). After 5-10 stickers are earned, head out on a fun outing with the individual to celebrate them working hard to stay healthy. While working with individuals with PWS, they seem to be more motivated to exercise with having that incentive when they are done exercising.

Community Activities For Exercise:

Local YMCA's

The YMCA is a GREAT place to go with an individual with PWS. YMCA's have treadmills for cardio, machines for upper and lower body exercises, and some YMCA's have pools for your individual to swim in. The YMCA also has different activities, such as basketball, pickleball, volleyball and even some fitness classes individuals can participate in. The YMCA is a great place to exercise, and a great place to be out in the community.

Walks outside

If the weather is appropriate, and your individual is dressed appropriately, then a walk outside around a local lake or pond could be a good option! With it being winter, it is good to get outside and get some fresh air as well as exercising in the community.

Local Schools/Colleges

I know I touched a little bit in my last article about schools, but a lot of people don't know what high schools and colleges have to offer. Many schools have their own tracks or swimming pool the community can use. Some colleges even have activities such as rock climbing, Zumba, ice skating, and open gym. All of these activities are great options for having fun, but most importantly, getting the exercise they want!. I would highly recommend contacting your local high school, college or recreation department to see if they have any of these options to offer to the community.

I believe exercising in the community allows individuals with PWS to thrive within their community, and allows them to do different activities to stay active and healthy.

Thanks for reading!
Brandon Schmidt

PWS - Research Updates

Do you want to learn more about current research findings?

Subscribe to Prader-Willi Syndrome News. You can sign up at <https://praderwillinews.com/> Every week, you will receive an email about recent reports, articles and/or findings on specific research in numerous areas that impact persons with PWS. Here is a list of a few topics that may be of interest to you:

- Liraglutide Helps Control Excessive Hunger, No Impact on Weight: Phase 3 Trial
- Respiratory Distress Treated in Toddler With PWS, Moebius Syndromes
- BDNF Gene Delivery Into Hypothalamus May Improve Metabolism: Study
- Pitolisant Eases Daytime Sleepiness In Children, Adults With PWS: Top-Line Data
- Physical Activity, Nutrition Recommended for Bone Health in Prader-Willi
- Loss of Non-coding RNA May Underlie Brain Alterations in PWS



Are you interested in learning more about clinical trials that are currently recruiting and find data being shared about ongoing or completed studies specific to PWS?

Visit the clinical trials website at www.clinicaltrials.gov. You will be able to find various trials that are being conducted for all ages, both nationally and internationally. who complete SCOUT-015 will have the option to enroll in a long-term extension safety study.

