

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.

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P.R.O.M.I.S.E.

By Patrick MacGrath CHFC, CHSNC

President of Private Wealth Management Group



Hello friends in the Prader-Willi universe! Welcome to this month's installment of the P.R.O.M.I.S.E. series, focusing a bit on the ever-changing world of benefits and what they mean going forward to ensure that your child's future benefits remain protected.

My name is Patrick R MacGrath and I am the President & CEO of Private Wealth Management Group, an investment planning firm that also specializes in special needs planning. As you probably know by now, my sister Heather has special needs and is the individual responsible for me and my team wanting to bring the appropriate long term financial planning concepts to families with loved ones who have a special need.

There is a good chance that by now, most of you have heard about SSI, or Supplemental Security Income. The Social Security Administration oversees this program designed to provide assistance to families (individuals) who are unable to work. One big benefit about receiving SSI, Medicaid eligibility is automatic.

Knowing when to begin planning for benefits is an important juncture. For most families with a loved one with PWS, this stage of planning often begins about the age of 15, and in many states, transition planning is set to begin at 16 years of age. SSI is a needs based program, and up until the age of 18, the resources of mom and dad are counted in the calculation. Simply put, if mom and dad make a decent income, your child up until age 18 will not be eligible for benefits until the age of 18. When your child turns 18 though, the game changes, and the income and assets of the parents are not a countable item in the determination of benefits. Planning at this point transitions, and not the transition planning often associated with individuals with a disability, what I mean is that the planning begins to encompass the need to keep the assets and income of the child separate from the parents.

The government has certain eligibility requirements in order to receive SSI. Your child can not own any assets in their name that exceeds \$2000. Yes, that's a small amount, and here is when the new ABLE accounts fit nicely, but that is for a future discussion. Upon verification that your adult child now needs assistance, they will soon begin receiving SSI payments per month. The maximum SSI payment in 2019 for an individual is \$771 per month, a bit higher at \$1157 for a married couple. Other asset types that your young adult can own are a pre-paid burial plot, pre-paid funeral expenses and some life insurance that has minimal amount of cash value. Additionally, strangely enough too, your adult son or daughter may own a home (personal residence) and a car. These asset(s) are considered exempt for SSI purposes and not counted against your kiddo. Now, should your child own these assets is a very different discussion and one often saved for having with a qualified special needs planning attorney.

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On a personal side, my sister Heather at age 18 (which was 1995) transitioned to SSI and Medicaid. Both of my parents at the time were gainfully employed and their personal assets no longer were counted as a resource for Heather. Up until my father turned 62 (early Social Security) Heather relied on a SSI benefit and Medicaid for her care, albeit with some cross over coverage with personal insurance with my mother's health insurance plan. When my Dad retired, Heather proclaimed that she was retired as well! No more job-coaching, no more going to work and folding napkins and nobody telling her what to do anymore! At this point, Heather now transitioned to receiving a Social Security Disability Income (SSDI) benefit, called "Disable Adult Child" because my father was now receiving his Social Security. Heather was entitled and to this day is still entitled to receive this (DAC) benefit, which is also considerably higher than what she was receiving on SSI. Confusing isn't it? What if my mother's social security record benefits are higher than my dad's? Can Heather transition to receiving a benefit off my mom's social security record? The short answer is yes. At moments like this the traditional wealth planning world says don't take Social Security until the last moment you can, or wait until Full Retirement Age! In the special needs planning world, that may not make the most sense because your child can receive a larger benefit (income) off of your Social Security record. Take note and plan accordingly.


An important point to note for families approaching the timeline to apply for SSI for their son or daughter, they may not qualify! How can that be? For those who have been through the process, you will often find that they were denied at least once. The process and questioning is lengthy to say the least. Just because your son or daughter has a disability, doesn't mean they are an automatic qualifier for benefits. Often times, hiring a Social Security Disability Attorney can help for the final appeal stages.

Earlier I mentioned that my sister Heather worked while also receiving SSI, yes this is possible too. The SSI program has built in work programs, and they encourage working all the while maintaining benefits. The key take away here is that should your son or daughter choose to work, their SSI benefit will be proportionately reduced to offset the income earned from their job.

Finally, from time to time a parent with considerable means will not want government resources or benefits paid to their child because they don't want them on the system. Rightfully so, if you have enough disposable income and assets to provide a lifetime of care and benefits to your child, it would make sense. But here comes the big challenge for these families: By NOT applying for SSI and subsequently getting Medicaid, you don't receive the Ticket to Work program. Big deal you may say, I have enough that my child doesn't need to work! Without the Ticket to Work program you do not get access to workshops, job coaching, post secondary programs etc! These programs do not accept private dollars, they are only funded by Medicaid Waiver Programs! So perhaps today you don't envision your child wanting or needing these services, but what about tomorrow? When that day comes that they choose to want those programs, they will be denied access. At that point, you must apply for SSI and Medicaid. It's like Monopoly, only in this instance you do not get to pass GO and you don't get to collect \$200!

Just as with any aspect of special needs planning, there is no absolute right answer or method to ensure safety and security for our loved one. Benefit planning in itself is a very daunting process that takes time and patience, and a willingness to look forward and take an educated guess at what services and programs your child may need in the years to come. Taken collectively with the other elements of P.R.O.M.I.S.E, you can rest assured that the appropriate planning can be accomplished.

Stay tuned for the next installment of P.R.O.M.I.S.E where we take look behind the scenes at what does it really take regarding money to plan for two generations!



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.



Welcome to the Family!



We would like to welcome new board member Sherita Greer and let her tell you all a little about her.

“I am a parent of an 11-year-old boy who has PWS. I became an advocate for my son and a strong supporter of children with disabilities the day he was born. Throughout, the years I have learned that the road is not always evenly paved and can be very challenging at times. However, I am determined to do my best to assist those with disabilities. I am passionate about health and fitness, caring for others, and ensuring that we work together to grow and thrive as a community.

Currently, I serve on the Board of Directors, as the Vice President, at Highland Community School (HCS) in Milwaukee. I have served on the HCS board for the past 5 years. I also aide the local community as a Milwaukee Public Schools Special Education Liaison Family(SELF) representative. As a SELF representative, I am responsible for providing support and guidance for families who need direction regarding their child's special education needs.

Additionally, over the past 4 years I have participated, as board member, with US Bank's Employee Development Network (DN). As part of the DN, we work to increase employee engagement and volunteerism, through personal and professional development activities.

I frequently attend the PWS of WI educational events, as I truly believe that knowledge is power. I work determinedly to consistently equip myself with new information, so that I can better support for the community.

I am hopeful that my experience and desire for success will make me a great fit for the PWSA of WI board.”

Thank You!



We would like to thank Thomas Hughes for his many years of service on the PWSA of WI board of directors. Tom had been on the board since 1997 and had been our treasurer since 2004. He tried to leave us once before but this time we are letting him go for real. We wish him all the best as he heads off into retirement. Thank you Tom!

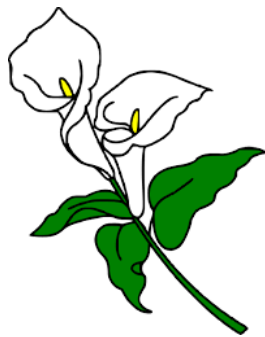


We would also like to thank Nancy Burlingame for her many years of service. Nancy has moved to Indiana and will eventually be retiring to Florida. Nancy however has chosen to remain involved with us here in Wisconsin as a Board Member Emeritus.

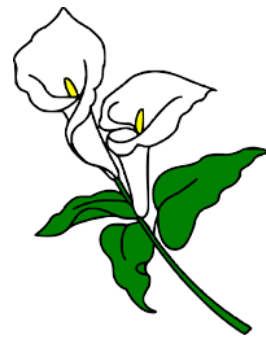
Changes!

We have also had some internal changes within our board of directors. After many years of serving as our Vice-President, Jackie Mallow will now serve as Treasurer. Kim Tula has assumed the role of Vice-President.

If you have an interest in becoming involved with PWSA of WI as a board member, please contact Josh at the office for more information or to receive an application. Elections are in October.



Donations were made over the last quarter in loving memory of loved ones and friends who were lost. PWSA of WI would like to send our deepest condolences to the family and friends of Becky Ketchum.



Dear Chapter Members:

I'd like to bring to you an opportunity participate in a new study investigating serious medical events that occur in our loved ones with PWS, the 'PATH for PWS' [Paving the way for Advances in Treatments & Health for PWS] study (www.pathforpws.com).

This 4-year study, supported by PWSA (USA) and FPWR, in collaboration with the biotech company, Zafgen, is designed to advance our knowledge of serious medical events in PWS, and help us understand how PWS-related behaviors change over time. There is no treatment given as part of the study, and no clinic visits are required. Information from the study is intended to inform development and clinical trial design for potential new treatments for PWS.

An ambitious enrollment goal of 500 has been set and we need your help in reaching that goal. In particular, we are seeking adolescents and adults with PWS, age 12 or older, to participate. Some information about the study is given below, and you should feel free contact the PATH study coordinator, Lisa Matesevac, directly with any questions you have (info@pathforpws.com).

Thank you for considering participation in this important study!

PATH for PWS is a natural history study designed to advance the understanding of the medical history and serious medical events in people with PWS. At enrollment and every 6 months, caregivers of those enrolled in PATH for PWS will be asked to provide an update on any medical issues, serious medical events, and related medical procedures or prescriptions, as well as provide information about behaviors often associated with PWS such as hyperphagia.

To be eligible for the study, participants must have a confirmed diagnosis of PWS, be at least 5 years of age, live in the United States, Canada or Australia, and be enrolled or willing to enroll in the Global PWS Registry. The primary caregiver of the enrolled person with PWS must have access to the internet to enter study data and consent to being contacted by registry staff. You are welcome to participate in other clinical trials while you are in PATH for PWS.

If you are interested in participating in the PATH for PWS study, you can do so by signing into the Global PWS registry (www.pwsregistry.org), creating an account (if you don't already have one) and consenting to this study. If you choose to participate, you will need to complete the surveys within the registry marked by an asterisk * next to the name of the survey. Step by step instructions on how to enroll can be found on the PATH for PWS website (www.pathforpws.com)

We anticipate it will take you about 2 hours to complete the initial set of surveys for the study, and about an hour for each of the 6-month follow up surveys. For the time and effort related to participation in the PATH for PWS study, participants will receive a \$100 Amazon.com e-gift card for completing the initial surveys at study entry and a \$50 Amazon.com e-gift card for completing the follow-up surveys, every 6 months.

PATH participants who live in the U.S. will be asked to consider participating in a sub-study that involves providing a blood sample for analysis of D-dimer concentration. Providing a blood sample is optional and choosing not to provide a blood sample for the sub-study does not impact participation in the main PATH for PWS study. Participants who agree to participate in the sub-study will be asked to go to a nearby laboratory where the blood sample can be collected. For the time and effort related to participation in the blood test sub-study (for D-dimer concentration), participants will receive an additional \$100 e-gift card after their blood draw is complete.

If you have any questions about the study, please email Lisa Matesevac, the PATH Study Coordinator, at info@PATHforPWS.com or call (760)420-5878. It is only through your participation that we are able to continue to build on the body of knowledge to improve care and explore new treatment options for PWS. Together we can transform the future of Prader-Willi Syndrome!



Health Highlights for Caregivers of Persons with Prader-Willi Syndrome

Date and Time: Friday, May 3, 2019: 11:00 am – 12:30 pm
Online Zoom Meeting Link: <https://zoom.us/j/8864326887>
Register Here: <https://www.surveymonkey.com/r/COWtraining>

Overview: In many ways, the body of people with Prader-Willi syndrome (PWS) works differently than most. A problem in their brain, affects their ability to control their appetite; regulate their body temperature; feel pain accurately; produce many hormones; have strong bones; swallow and digest their food properly; control their emotions and learn and understand things. They rely on caregivers to help them educate and advocate for many of their health needs. Unfortunately, many care providers do not have knowledge of these unique health needs. Educating staff on these health needs must be concise and informative.

Purpose: This presentation is designed to serve as a training tool for caregivers of persons with PWS. It will:

- Provide simple information about health issues that adults with Prader-Willi syndrome (PWS) may face in a concise, easy to understand format so caregivers can confidently monitor and advocate for the health concerns of those in their care.
- Highlight some ways caregivers can prevent and manage these health concerns if/when they occur.
- Share resources that can be accessed and utilized when they have questions or concerns.

Objectives: At the completion of this presentation, participants will be able to:

1. Identify ways that a person with PWS' body works differently and how it impacts their health.
2. List health challenges that the person with PWS may face.
3. Share at least 2 things the caregiver of the person with PWS can do to help prevent and/or manage these health challenges.
4. Identify resources the caregiver can utilize to help educate and advocate for the health needs of the person with PWS.

Time Allocation: 90 minutes (75 minutes presentation; 15 minutes questions and answers)

Format: On-line Webinar utilizing a Power Point Presentation, handouts and a Study Guide. An optional posttest will be available to verify the participants understanding of the information. Join Zoom Meeting: <https://zoom.us/j/8864326887>

Presenter: Barb Dorn, RN, BSN, Nurse Educator. Consultant, author, speaker and educator on various health topics on behalf of persons with PWS.

Topics Covered:

- | | |
|---|---|
| 1. Brief Overview of PWS – A Dysfunction in the Brain | 6. Low Bone Density – “fragile bones” |
| 2. Life Threatening Obesity - Complications | 7. Emotional, Behavioral and Mental Health Concerns |
| a. Heart and Circulation problems | 8. Skin Picking |
| b. Breathing difficulties | 9. Medication Sensitivity |
| c. Diabetes | 10. Breathing Concerns |
| 3. GI Concerns | 11. Hospitalization – Special Needs |
| 4. Body Temperature Regulation Problems | 12. Resources |
| 5. Altered Pain Response | |



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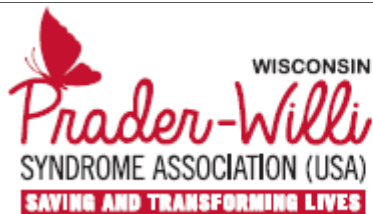
The 2019 Snowflake Ball was a huge success!

We had over 250 people at our event (a new record) and the new venue was absolutely beautiful. We already can't wait until next year!



To purchase PWSA of WI merchandise visit pwsaofwi.org/merchandise





PRADER-WILLI SYNDROME ON THE MOVE
MAY AWARENESS WALK-A-THON
RIVERSIDE PARK
WATERTOWN • WI
MAY 11 2019

PLEASE JOIN US FOR THIS NATIONAL AND LOCAL FUNDRAISING, AWARENESS EVENT
 GET MORE INFORMATION ON THIS GENETIC DISORDER THAT AFFECTS 1 IN 15,000.
 WHAT IS PRADER-WILLI SYNDROME? go to www.pwsaofwi.org

ONSITE REGISTRATION FROM 9-10AM

Due to expected construction at Roosevelt Park in Oconomowoc we have been forced to change locations for this year. We think that Riverside Park is going to be a beautiful spot for the event and will allow us to raise awareness in a completely different community!



PWSA (USA) **2019**
 NATIONAL CONVENTION



Agenda of Events

- Chapter Leaders Meeting - October 23rd & 24th
- Medical & Scientific Conference – October 23rd & 24th
- New Parent Mentors Meeting – October 24th
- Professional Providers Conference – October 24th
- Welcome Reception – October 24th (6pm – 9pm)
- PWSA (USA) General Conference – October 25th & 26th
- Youth & Infant Program
- Youth & Adult Program
- Sibling Program



PWSA (USA) National Convention

Date: October 23rd – 26th, 2019

Hotel: Caribe Royale

Location: Orlando, Florida

PWSA of WI provides scholarships to Wisconsin members. Visit our website pwsaofwi.org for more details or contact our program director progdir@pwsaofwi.org or 920-733-3077.

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PWSA of WI, Inc.'s Event Calendar		
Riverside Park, Watertown, WI	9th annual On the Move Walkathon	May 11th, 2019
TBD	P.R.O.M.I.S.E. Financial Planning Presentations	June 8th and 15th, 2019
Red Circle Inn & Bistro, Nashotah, WI	Fundraising Gala Dinner	August 17th, 2019