

# 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.**

## IEP Myths

**Students with IEPs can't be placed in the regular education classroom.**

\*Students must be placed in the "least restrictive environment." This may be the regular ed classroom, special ed classroom, or a combination of both depending on the needs of the individual.\*

**IEPs will always be followed 100%**

\*Often times IEPs are very large documents with a ton of accommodations. Your child will be seen by many different adults in the school setting and it is possible that there will be things that are missed. If you find this happening, calmly let the school know so they can make it right.\*

**IEPs will be completed in one meeting.**

\*Sometimes yearly reviews or followups can be accomplished in one short meeting but often the IEP will not be completed as the coordinator will need to update things afterwards or there will be things that are not agreed upon that need further discussion.\*

**You need to sign the IEP right when the teacher gives it to you.**

\*You have every right to take it home with you, review it, and ask for changes if there are still things you are uncomfortable with. The IEP CAN be implemented without being signed as the school has a duty to come up with an appropriate plan to support the student until a consensus is received.\*

**If a school doesn't have a specific therapist needed to perform therapy outlined in the IEP that allows them to access the curriculum I have to pay for private therapy.**

\*If the school does not have a specific therapist available at school, they are obligated by law to provide a private one.\*

**Private schools must follow IEPs.**

\*Private schools are not publicly funded so they are not covered under IDEA. They are not required to provide special education services. This does not mean they won't, just that they aren't required to.\*

Compiled and written by Joshua Escher, Program Director, PWSA of WI

Do you have a child or family member that lives in a residential setting that isn't Prader-Willi Homes of Oconomowoc? We want to know about it! We would like to be able to provide them with up to date information as well as let others know what options are out there.

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## DELIVERING YOUR ULTIMATE P.R.O.M.I.S.E

Hello friends, have you ever wondered what Special Needs Planning is? It sounds simple, but if I asked 100 families with a family member with special needs, I'd be willing to bet that I would receive 100 different answers. After 16 years in the Financial Planning world and being an older brother to a sister with special needs, I still haven't quite figured out what Special Needs Planning really is. But, we do know what it isn't. Special Needs Planning isn't simple, it certainly isn't easy, and it doesn't get accomplished in a day. In fact, this may be the most challenging planning that you'll ever encounter. Having the tools and resources available to help make smart, collaborative decisions can make all the difference in the world.

My name is Patrick R. MacGrath and I am the President and CEO of Private Wealth Management Group located in Appleton, Wisconsin. We are a comprehensive wealth planning firm that also specializes in Special Needs Planning. As I mentioned above, I have a sister with special needs. My sister Heather has soft Cerebral Palsy and Epilepsy. I know, first hand, how difficult it can be to not only plan for the future, but just get through the day. Early in my financial planning career, the disconnect between the traditional wealth planning model and the special needs planning world became evident. Our primary goal is to integrate the appropriate planning needed for financial security and Special Needs care assurance.

While every single special needs family is different, there is one enduring challenge that is common to all: How do I ensure that my child will be taken care of when I'm no longer here? And sadly, there are no simple answers. What we have found through personal experience and planning with other families are common themes and guidelines that highlight many of the major areas of concern. Thus, the creation of the P.R.O.M.I.S.E outline was born.

The creation of the P.R.O.M.I.S.E outline gives families the knowledge to begin the life-long process of securing the future for their loved one. The reality is that you are planning for two generations. This process isn't easy and it takes time. However, if YOU don't address these special circumstances, nobody will. That being said, we are here to help.

Today's article is going to give you an overview of P.R.O.M.I.S.E and present you with some food for thought as it relates to planning for your loved one. Future article installments will have a deeper description of each facet on the outline thus potentially addressing many of the concerns that you have.

The P is simply Preparing a Clear Vision. In my own experience, I can tell you that my family didn't have a clear vision for what Heather's future was going to look like and how were we going to ensure that what she wants to happen, will. I'd be willing to go out on a limb and say most families idea of a vision is cloudy at best. Simon Sinek said it best, "Understand Your Why" Why do we want to plan appropriately? Simply put, nobody else is going to do it for you. We have a special needs population that is growing, but resources that are shrinking. We have increasing costs associated with all facets of care, but limited options for where to receive that care. Once we understand our WHY we can begin the planning process. It was my own realization that my family needed guidance that the traditional wealth planning world wouldn't provide that led me to create P.R.O.M.I.S.E so that other families, and there are 60 million individuals in this country who have a disability, don't have to re-create the wheel on these very complex areas.

The R is Researching Your Options. The options are as vast as the ocean, and as deeply complex as well. Questions surrounding SSI and SSDI, Medicaid and Medicare, when do these benefits begin and how do I apply for my loved one? How do I ensure that my child has a free and public education? What if the school isn't providing the appropriate learning curriculum or environment? Do I actually have to sue the school district to get funding for private schooling? Sadly, the answer is yes to that last question. But that will come later in the estate planning section. From the time of birth through early onset, all the way to potentially living a normal life expectancy, we are faced with challenges that cause consternation because what was true last year, may not be the same this year. And you can bet that with the government being involved, things are guaranteed to change. The key is having an understanding of what needs to be done when, and where to go at those important stages to get the right guidance.

The O is Open the Door. There isn't one area of planning that is more important than the others, but this might be the one that gets my vote if I had to choose. There is no proof to this point, just my gut instinct. It all comes down to the question, or statement I posed earlier about families biggest concern, "How do I ensure that my child will be taken care of after I'm gone? Open the Door is simply a phrase to let the individual, trustee, or institution know what it would be like if and when they may be responsible for your loved one. These are often called Letters of Memorandum, or Letters of Intent. This document, or sets of knowledge are the only thing these providers may have to go by should something happen to you. Imagine if I was tasked with caring for your child. What would you want me to know to make sure that his or her next day was as easy as possible? The important points of life are limitless here, and that's the point. Please begin to write some of these things down. Would you want to know that Heather loves to wear her Captain's hat? Or that she loves Lipton hot tea, but not decaf! Just try to give her the green packet instead of the yellow one! And three sugars, not two! And she has a name for her stomach, its Joe! Joe, meet the world! We each have hundreds of these little idiosyncrasies that make our loved one so special. I'm honestly smiling as I write these points because they are so poignant to Heather and if you were tasked with her future care, wouldn't you want to know them? A page a week of important information or observations, and over the course of a year you ensure that your loved one will have that easier day.

The M is Managing a Legacy. How much is it going to cost for all the services needed for my loved one? The answer, it's a really big number. One thing we haven't addressed yet, you still would like to retire someday right? What planning is being done to ensure that that happens in a manner that you would like? You see, this is the hard part. How do we financially plan to ensure that our child, and other children are protected, but also have the resources needed to live the life that they would enjoy? Oh, and on top of that, how do you and your spouse plan for a retirement of your own? There isn't enough money to go around. This concept circles back to preparing a clear vision. What is it that you would like to accomplish in your lifetime, that requires planning to achieve? Here's the rub, we often spend all of our time taking care of our loved one(s) that we forget to take care of ourselves. Personal experience speaking, I am looking at trying to plan accordingly for my parents retirement, planning to make sure that Heather is taken care of, and also trying to figure out what future plans with my wife and three kids is supposed to look like. It's overwhelming for all of us. Goal based planning can help make some of these decisions easier. Leveraging the best financial strategies and concepts can help ease the burden of determining that really big number, but if you have a plan, you can achieve it. We all realize that you need a plan of care for the doctor to write a prescription, or that in order to build a house, you need to have blueprints drawn up and approved, but to build a sound financial plan that ensures financial security, there is no blueprint required for that. Take the time to find a team that you trust to help build that blueprint and you'll be rewarded.

The I is for Interpreting your Legal Options. One member of your team that is an absolute must is an attorney that specializes in Special Needs Trusts. Just as there aren't many financial planning firms that specialize in special needs planning, the same goes for attorney's. Find somebody experienced that can help in all your legal options. First party trusts, third party trusts? What do I need? How do I maintain my loved ones benefits? What happens if my loved one is receiving benefits and inherits some money? This area of planning is so complex that there are books written just on the legal topics within special needs planning. Guardianship? How does that differ from Conservatorship? The list goes on and on and the Social Security Administration is always changing the rules and regulations on how special needs trust can be administered. Experience pays here, so do your due diligence and take your time.

The S is for Seek Support. From time to time we all need a shoulder to lean on. Days and circumstances will come up that challenge every fiber of our being. Life isn't easy period, and life with a loved one with special needs is even more challenging. There are many fine organizations in every community that help with support, whether for the parents, the siblings as well as the individual with special needs as well. In my community, a few examples are WisconSIBS, an organization for the siblings to have a safe place for talking and sharing with other kids who have family members that have a disability. The Miracle League is a baseball organization designed specifically for kids ages 4-19 who have a disability. I have had the privilege of being a coach to these All-Stars for the past 7 years and my time with them is priceless. An example of an organization that really helped my sister Heather was Reins of Hope, equine therapy. Heather just has a way with animals, and the horses she rode and interacted with loved every minute as well. These are just a few of the many outstanding organizations that can positively impact the lives of our loved ones.

And finally, E is for Evaluate and Execute. Evaluate your options for your planning team, take action on the pieces of the plan that are easy to accomplish, and make a concerted effort to plan a strategy for the more complicated elements of your special needs plan. And remember, your initial plan won't be perfect, and it doesn't have to be from day one. Things will change. Elements to the entire plan will change. Government regulation and legal precedents will surely change. The key is to remember that this is a life-long process and changes will be necessary. It honestly took my parents a very long time to come around on parts of the plan for my sister, not because they didn't want to do, it was just something they would get to later. This happens in all homes, those with a disability and those homes without.

To wrap up this first installment, a very good friend of mine has a little girl with Prader Willi. He introduced me to the Prader Willi community and I have since been embraced with open arms at the National Conference, and also with speaking engagements in New York and California later this year. Our mission is to help families like our own create and implement the appropriate special needs plan to ensure that our families are secure.

*Private Wealth Management Group and its partners understand the challenges you face. We are empathetic to your immeasurable responsibility for the lives of your loved ones. We have the experience to help guide you through life's transitions and the passion to pursue your success. Special Needs Planning has evolved over the years, you deserve to work professionals who have also walked the path.*

Stay tuned for the first installment of P.R.O.M.I.S.E, Preparing Your Vision.

Sincerely,

Patrick MacGrath CHFC,CHSNC

President, Investment Executive



**Retired Sergeant Tammie Penta visited WI to give a presentation about prevention and education with law enforcement officials.**

**14 parents, grandparents, and providers as well as 2 officers who work in communities supporting Prader-Willi Homes of Oconomowoc attended the presentation. We provided free childcare so parents could focus on learning the information Tammie brought to us.**

**A Study of Diazoxide Choline Controlled-Release (DCCR) in Prader-Willi Syndrome Patients**

Soleno Therapeutics, Inc. (Soleno) is conducting a Phase 3 double-blind, placebo-controlled clinical study to evaluate the effects of DCCR tablets compared to placebo in PWS patients.

Patients with genetically-confirmed PWS, 8 years or older may be eligible for this study.

For more information visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and use identifier NCT03440814.

Site Locations:

Children’s Minnesota

St. Paul, MN 55120

Contact: Brittany Machus, Study Coordinator

Phone: (651) 220-5730

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Principal Investigator: Jennifer Abuzzahab, MD





GLOBAL  
**PRADER-WILLI SYNDROME**  
REGISTRY

WWW.PWSREGISTRY.ORG

ORTHOPEDICS OF PWS

14%



OF REGISTRY PARTICIPANTS HAVE BEEN DIAGNOSED WITH

**HIP DYSPLASIA**

SCOLIOSIS

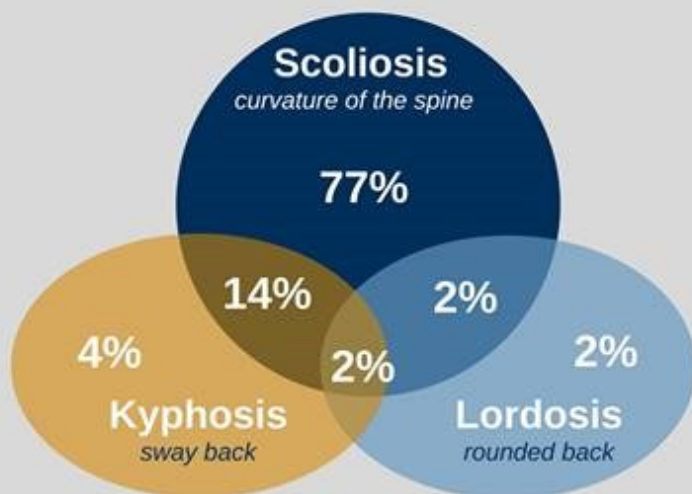


46%

OF REGISTRY PARTICIPANTS OVER THE AGE OF 2 REPORT HAVING A

**SPINAL DEFORMITY**

CURVATURE TYPES



Data as of March, 2018

With the Pittsburgh Children’s Institute being unable to keep up with the demand for PWS specific care in the areas of behavior and weight issues, a new hospital has stepped up to shoulder some of that need.

**NEXUS**

CHILDREN’S HOSPITAL

**Changes Health & Wellness Program for Patients with Prader-Willi Syndrome or Established Weight Control Problems**

Nexus Children’s Hospital in Houston, TX offers a safe, structured environment for children with established weight control problems, including Prader-Willi Syndrome (PWS). Addressing comorbid medical issues and behavioral complications characteristic of individuals with Prader-Willi Syndrome, our Changes Health and Wellness inpatient program helps our young patients who have found traditional outpatient programs unsuccessful. Because of our thorough understanding of Prader-Willi Syndrome causes, as well as Prader-Willi Syndrome symptoms, our medical team addresses patients’ medical and behavioral complications due to their PWS diagnosis. Our program incorporates low-calorie diets, set daily schedules, individualized physical training regimens, and behavioral health support for both the patient and family members. Our expert staff is dedicated to seeing each patient reach his or her health goal and maintain that goal after discharge from Prader-Willi Syndrome treatment. Visit our website to watch a patient video and learn more about our program.

<https://www.nhsltd.com/services/programs/pediatric-changes-health-wellness-program/>



**Save The Date**

PWSA (USA) National Convention

**Date:** October 23<sup>rd</sup> – 26<sup>th</sup>, 2019

**Hotel:** Caribe Royale

**Location:** Orlando, Florida



Due to flooding on the golf course we were forced to postpone our golf benefit. The new date we have set is October 14th, 2018.

The event will still take place at Windwood of Watertown in Watertown, WI.

If you wanted to golf with us but the original date didn't work for you but this one does, you can still register!

Head to this web address to register online or get a downloadable form: <https://bit.ly/2wm3pjE>



Do you know someone with Prader-Willi who no longer has family to provide them with gifts on their birthday or Christmas?

PWSA of WI has a gift giving program for these folks! Please contact us for more information so we can make their day.





## Ideas for Non-Food Treats

Available at dollar stores, party supply stores, or online shops, these low-cost items can be purchased and handed out to all trick-or-treaters, or made available in a separate bowl from candy if you choose to hand out both options. Nearly all of these items can be found in a Halloween theme or festive colors.

- \*Glow sticks, bracelets, or necklaces
- \*Pencils, pens, crayons or markers
- \*Bubbles
- \*Halloween erasers or pencil toppers
- \*Mini Slinkies
- \*Whistles, kazoos, or noisemakers
- \*Bouncy balls
- \*Finger puppets or novelty toys
- \*Coins
- \*Spider rings
- \*Vampire fangs
- \*Mini notepads
- \*Playing cards
- \*Bookmarks
- \*Stickers
- \*Stencils

Find this information and more at the website: <http://www.foodallergy.org/teal-pumpkin-project>

Hoodies, t-shirts, and coozies can be purchased from our webstore by visiting [\*\*http://tiny.cc/PWSAWIstore\*\*](http://tiny.cc/PWSAWIstore)



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**Permit #75**



<b>PWSA of WI, Inc.'s Event Calendar</b>		
AMF Bowlero Lanes, Wauwatosa, WI	Strike Out PWS Bowling Event	September 23rd, 2018
Windwood of Watertown, Watertown, WI	PWSA of WI Golf Benefit (reschedule date)	October 14th, 2018
	PWSA of WI, Inc. Snowflake Ball	January, 2019