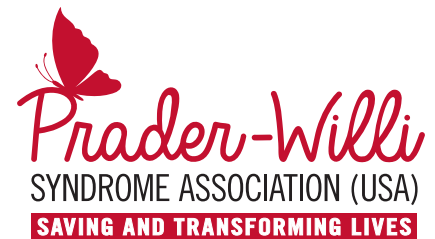


The Gathered View

National Newsletter of the Prader-Willi Syndrome Association (USA)



Our mission is to enhance the quality of life and empower those affected by Prader-Willi syndrome.

CEO View

Expanding PWS Awareness is Job #1



When PWSA (USA) developed its *Five Pillars of Support* two years ago – to capture what are the most important reasons our association exists – “Awareness” was selected as one of those key elements. Not only was Awareness selected, but we list it **first among the five priorities**, as helping people understand the nature and implications of Prader-Willi syndrome has to occur before they, in turn, can help us *Save and Transform Lives* of those affected by PWS.

How many times a week do you explain the basics of PWS to someone who has never heard of the syndrome or is not familiar with it? How often do you need to reexplain what your child’s needs are to someone who has heard of the syndrome but doesn’t know the vast complexities? We need to continually raise awareness about PWS as only approximately one

“Awareness is like the sun. When it shines on things, they are transformed.”

~Thich Nhat Hanh

continued on page 2

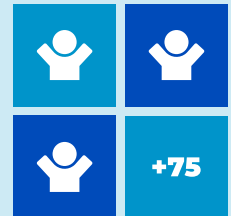
Age 12+?

WE NEED YOUR HELP

75 people with PWS ages 12 and up are **still needed** to enroll in the PATH for PWS study

Learn more at www.PATHforPWS.com and enroll today.

PATH for PWS
Finding the way for advancing
the treatment & health for PWS



ENROLL TODAY

Your PATH is Important.



Each day, caregivers navigate the world of being a special needs family with new and unexpected challenges, many of which are serious medical events.

Caregivers can make a difference by contributing to PATH for PWS, a knowledge bank of Prader-Willi syndrome.

This PATH study serves as a repository of knowledge which has the potential to inform clinical trial design and potential new treatments.

WHY Am I Being Asked to Participate?

As parents of a child with PWS, you hold a vast amount of knowledge about your personal experiences living with the

continued on page 3

Time-sensitive Convention News



Celebrating PWS Awareness Month

We’re excited to share exciting news with you. **ALL General Conference registrations made during the month of May will qualify for two drawings! The first lucky winner will receive: ONE General Conference registration and Gala ticket reimbursement (\$305 value). The second lucky winner will receive TWO General Conference Gala ticket reimbursements (\$110 value).**

Be sure to register for General Conference before June 1 to qualify for these drawings!

Questions? Contact Jackie Mallow: jmallow@pwsausa.org or call 941-487-6726.

<http://bit.ly/2LswNekPWSA2019NationalConvention>

Meet your 2019 General Conference Chair Kristi Rickenbach

Kristi Rickenbach and her husband John ran a non-profit organization for 12 years. This ministry has touched the lives of children in 48 states and 23 countries worldwide. Working with the youth in South Africa has become a yearly trip for the Rickenbachs; it changed the way they view the world. Married 30 years, Kristi and John have five amazing children and three beautiful grandbabies. Their youngest child, ninth grader Justice Faith (15), was diagnosed with PWS (UPD) at one month of age. Justice loves helping kids that are also dealing with PWS.

Three of Kristi’s passions in life are her faith, family, and helping families and children that are affected by Prader-Willi syndrome. Kristi is president of the PWSA Minnesota chapter, a parent mentor, and a board member of PWSA (USA). ■



Volume 44, Number 3 ~ May-June 2019 ~ Our 44th Year of Publication



out of every 15,000-25,000 babies are born with this condition.

After all, think of all those that need to have knowledge and understanding of PWS – diverse individuals ranging from family, friends, co-workers, and neighbors to medical providers, therapists, educators, caregivers, insurance company employees, and legislators. When you add in the fact that the range and severity of symptoms can vary widely for people with PWS, such that each person with this condition has his or her own strengths and challenges, increasing awareness is a complex challenge. As the saying goes, “if you have met one person with PWS, you have met one person.”

But increasing awareness about PWS has many benefits, as it:

- Improves the care and treatment others provide to our loved ones;
- Raises the chances of our passing PWS-friendly legislation, regulations, and funding opportunities at both the state and federal level;
- Demonstrates that we as a CommUNITY believe there is a positive future for all loved ones with PWS;
- Increases the level of comfort others have interacting with individuals with PWS and their families; and
- Accelerates progress we make in creating better educational, vocational and residential options for those we know with PWS.

For these and other reasons PWSA (USA) works in numerous ways to increase awareness, including:

- Accelerating progress we make in creating better educational, vocational and residential options for those we know with PWS;
- Producing and distributing more than 100 informational publications;
- Exhibiting and speaking at conferences of medical and pharmaceutical professionals;

- Offering you branded and logo merchandise and materials to communicate about PWS;
- Partnering with the Rare Disease Community to join voices and have a larger impact for all;
- Provide trainings and letters to parents, schools, physicians, and disability service organizations to help them better understand PWS;
- Creating and joining educational and marketing efforts such as Rare Disease Day and May PWS Awareness Month, during which we'll post 30 messages to social media about PWS; and
- Supporting your efforts at the chapter and grass-roots level.

All you do – day in and day out – to spread the word about Prader-Willi syndrome is making a positive impact and very much appreciated by the entire PWS CommUNITY!

Working together, we can steadily bring the understanding of PWS to a whole new level, and that will benefit us all.

Many Thanks,
Steve Queior, CEO

Federal Employees!

The Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide “all federal employees the opportunity to improve the quality of life for all.”

PWSA (USA) CFC ID # is 10088

To learn more click or visit

<http://bit.ly/2UHGxJv-CFC-PWSAusa>



2019 Convention News

Conference Session Spotlight Legal Planning and Guardianship Protection for Individuals with PWS

Do you wonder how to legally protect your child with Prader-Willi syndrome? Do you worry about how to care for your child and preserve their benefits now and after you pass away? Come spend a productive hour with Lisa Thornton, an attorney for 31 years who has helped hundreds of families secure guardianship and special needs legal planning. Lisa will present ideas for protecting your child's SSI and Medicaid benefits. She will also show how to put legal protections in place for you and your child with PWS, including securing guardianship and setting up a special needs trust. A free sample of a special needs trust for your child will be provided to all attendees. A PWS mom, Lisa understands the particular legal issues our families face.

*Presented by
Lisa Thornton,
J.D.*

Lisa Thornton's daughter Kate with PWS, age 16, is the delight of her family! Lisa has



four (two presenting and helping with the 2019 convention) other children, and a wonderfully supportive husband, Sid.

Lisa has served as president of the Utah Prader-Willi Syndrome Association for the last 14 years and was a board member for PWSA (USA) for six years. She helped start a very successful medical clinic in Utah, which has served adults and children with PWS for the last 10 years. Currently, she is helping with two college-like life-long programs for adults with intellectual disabilities, which serves 80+ students.

Lisa practices in estate and special needs legal planning. She has helped hundreds of families secure the legal planning needed to protect themselves and their child with special needs. ■

ENDO 2019 in The Big Easy

PWSA (USA) was well-represented at the March 23-25 ENDO Expo 2019 Convention organized by the Endocrine Society in New Orleans, Louisiana. Medical Coordinator Mary Burr, and Kim Tula, Alterman Family Support Counselor, spent their days speaking and gathering valuable demographic info from attendees for potential Prader-Willi syndrome (PWS) providers. There was a great deal of interest in PWSA from pediatric and adult endocrinologists who currently manage pediatric patients with PWS. Additionally, we spoke with pediatric and adult endocrinologists who would be willing to care for patients with PWS. We will continue cultivating these relationships, plus gathering information and demographics from doctors across the country willing to see patients with PWS. Ms. Burr engaged with the medical directors of three pharmaceutical companies developing long-acting growth hormone products:

Ascendis Pharma has recently released data on their Phase 3 trials of a long-acting growth hormone. They plan to pursue the indication for Growth Hormone (GH) deficiency in children. They anticipate entering the commercial market in 2020. Ascendis plans to continue trials in special pediatric populations, including PWS.

Pfizer Pharmaceuticals has partnered with OPKO Health Inc. to develop and commercialize treatment with a long-acting growth hormone. Following Phase 3 trials, Pfizer plans to seek FDA approval for the pediatric indication of growth hormone deficiency as well as special populations with GH deficiency to include PWS.

Novo Nordisk is also seeking FDA approval for a long-acting growth hormone for adult GH deficiency. The data is ready to publish, and they feel confident they will bring the product to market for adults in 2020. Novo will

continue the current trials for long acting growth hormone for pediatric patients and eventually special populations such as PWS. In addition to long-acting GH, Novo has acquired and is currently marketing Macrilen; an oral medication that has been approved by the FDA for growth hormone stimulation testing. The 90 minute test can be done in an office setting and has little to no side effects, making GH deficiency testing much more accessible for patients and providers. Novo plans to continue trials of Macrilen use in pediatrics, including special populations. Ascendis, Pfizer and Novo Nordisk are very interested in continuing to work with special populations including PWS. Great news indeed. Ms. Tula and Ms. Burr attended the ENDO 2019 welcome reception hosted by Millendo Therapeutics and enjoyed networking with the leadership of the company as well as other ENDO attendees. ■



Mary Burr with Kim Tula at ENDO 2019

PATHforPWS, continued from page 1

demands of this syndrome. That body of knowledge grows, and that lifetime experience has value.

We invite you to share your experiences so that we can ALL learn about PWS complexities.


With your input, we will better understand the serious medical events that may occur in our loved ones. Those that come after us will have the advantage of this knowledge and may better prepare them for the challenges.

How Long Does It Take?

The amount of time to complete the surveys will depend on the complexity of your child's medical history. You DO NOT have to do them all at one time.

On an average, it can take about an hour and a half to complete the 14 required surveys. You may break down the process into manageable parts, completing the surveys at your convenience.

Please join us! More information can be found by visiting www.PATHforPWS.com. ■



Unmask the Possibilities

PWSA (USA)
NATIONAL CONVENTION 2019
AWARENESS FAMILY SUPPORT RESEARCH EDUCATION ADVOCACY

October 23-26
Caribe Royale, Orlando, Florida

Events

Medical & Scientific Conference
October 23rd & 24th

Professional Providers Conference - October 24th

General Conference – October 25th & 26th

Youth & Infant Program
Youth & Adult Program
Sibling Program

Questions? Contact Jackie Mallow at jmallow@pwsausa.org or 941-487-6726

Orthotics, For When The Foot Hits The Ground

By Janice Agarwal, PT, CNDT (mother to son Alex, age 19, with PWS)

Time flies. Here's an update to a 2002 *The Gathered View* article on orthotics.

Children with PWS have generalized hypotonicity (low tone) and often present with ligaments that are too loose to hold bones in optimal alignment for optimal function. Added to the excessive flexibility of the joints of the foot, hypotonicity causes instability and negatively affects the mechanics

of standing, walking, running and jumping. When joints and muscles are not aligned for best mechanical activation, children cannot efficiently use what strength they have. With strength not generating maximal power, these children use more energy during each skill, fatigue more quickly, and learn to compensate using other muscles. This results in faulty alignment and impaired performance, limiting a child's ability to walk.

When the feet provide a balanced

foundation, the rest of the body can work together more effectively. For children with low tone, flexible custom-made orthotics help support and encourage normal foot function, which in turn prevents the body from developing faulty biomechanics. As walking is a vital lifetime skill, it's very important to be proactive in promoting optimal alignment and function beginning when hypotonic children learn to stand. This article discusses some of the issues related to poorly aligned and unsupported feet.

What is pronation? (see picture)

Excessive pronation of the foot occurs when the heel (calcaneus) rolls inward (up on its medial undersurface, into valgus), causing the inside arch (medial longitudinal arch) to collapse and elongate, forcing the forefoot to turn away from midline (abduct, drift laterally). This is often referred to as flat-footedness. A child with abnormally pronated feet likely has:

- poor ankle/foot positioning
- feet that are flat and collapsed/rolled medially (inward)
- a wide base of support (feet kept apart)
- genu valgus (knock-knees)
- hip adduction – thighs held together
- arms in high guard (hands held up high at shoulder level to keep balance and protect during falls)
- poor balance/coordination

How does foot pronation affect my child?

The foot functions as the base link of a biomedical chain. If foot alignment is compromised or not supported correctly, the rest of the body has to work harder to try to balance over the feet. This can significantly increase fatigue and reduce endurance. We then see:

- Genu valgum (knock-knees) when standing. Foot pronation forces



use of muscles that do not normally support and stabilize the foot and ankle. Excessive strain on the medial ligaments of the knee. When the medial sides of knee-joints weaken, the knees bang into each other.

■ Leg length discrepancies. Excessive pronation forces muscles from the foot to the pelvis to work harder and changes the amount of weight supported by each joint. To compensate, a child will favor one side, making one leg seem shorter than the other. Compensation for leg length discrepancies (or spinal irregularities) causes side-to-side pelvic tilting (pelvic obliquity).

■ Anterior pelvic tilt. With hypotonic and weak abdominal muscles, the pelvis lacks the stability needed to compensate for irregularities of the feet and ankles, or of the spine. Children with PWS typically present with hips tilted forward and with sway back (hyperextension of the lumbar spine) when standing, both

of which push the hips forward.

Movements of one joint influence the movement and position of other joints. As the lowest link of this chain of joints, every step subjects the foot to the force of the ground. In normal walking, the foot needs to be flexible to hit the ground and react appropriately. The foot has to absorb shock, support the body while it is moving, then become rigid enough to allow a push off for the next step. In simplified form, a child's normal gait cycle should look like this:

■ Heel Strike. When the foot first makes contact with the ground, it should do so on the outside aspect of the heel when the knee is fully extended and weight is being transferred from the opposite leg. As the foot comes down, body weight is a gradually distributed across the entire foot.

■ Midstance. As the leg becomes vertical and body weight shifts over the foot, the full weight of the body comes down directly onto the foot and is distributed evenly across the foot, roughly half on the heel and half on the forefoot. At this moment, the foot should be in a neutral alignment. It is when alignment is the most crucial, as the body is most influenced by the misalignment of the knee and hip joint.

continued on page 5

Orthotics, continued from page 4

■ Propulsion. As body weight shifts forward, the midfoot unlocks and the foot pushes down into the ground. At this point, the foot needs to be able to pronate slightly to allow a push off on the ball of the great toe (first metatarsal head). That foot then leaves the ground and that leg launches into the “swing phase” of the gait cycle, during which the foot bears no weight until contact with the ground occurs again.

Such balance cannot exist when the foot is pronated. The pronated foot remains loose and weak throughout

*Excessive pronation
is one of the
main reasons a
hypotonic child has
difficulty walking.*

walking. Because the forefoot does not become rigid, the foot cannot effectively transition from midstance to push off.

Excessive pronation is one of the main reasons a hypotonic child has difficulty walking. When weight shifts forward on a pronated foot, the medial aspect of the rolled in foot (instead of the flat ball of the foot) pushes into the ground and muscles that are not normally used

to support and stabilize the arch of the foot and the ankle during propulsion are forced to work harder, become strained, then weaken, limiting strength and endurance. A child with uncorrected pronation will strain and grip with toes and sides of feet to maintain balance. Until excessive pronation is corrected, simple activities like walking, running, and jumping are performed inefficiently, causing prolonged abnormal stress on all the upstream links of the chain, including the knee, hip, and spine.

Reducing foot pronation lessens the biomechanical force straining the medial ligaments of the foot, surrounding muscles, and knee, but hypotonia, underdeveloped ligaments, and poor postural control prevent spontaneous correction of pronation. Orthoses can help.

What type of foot orthotic is most effective for a hypotonic child?

First, a disclaimer: I do not receive payments from or have any kind of financial interest in medical or Orthotics companies. Dynamic supra-malleolar orthoses (SMOs) are lightweight, very thin and extremely flexible, distinguishing them from conventional orthoses. Dynamic SMOs have contoured foot plates to support and stabilize the arch of each foot and can be designed to prevent excessive pronation. This has four positive effects:

■ The foot is maintained in neutral alignment, improving stability.

■ When fit snugly around a foot, the flexibility of the lightweight plastic gives to the foot information about where it is in 3-dimensional space (proprioception). This information is sent by nerves to the spinal cord and brain to help coordinate balance reactions to help the body stay upright. The rigidity of the plastic also prevents extreme movements that cause abnormal compensations for poor alignment.

■ Because they better match the contours of each foot, pressure is distributed more evenly and skin breakdowns are reduced.

■ Lightweight, thin, and flexible plastic allows for regular shoes and socks. Most conventional orthoses require shoes two to three sizes larger than the child needs, further inhibiting the natural development of proprioceptive awareness and balance reactions.

When should my child start using orthotics?

When a hypotonic child who shows foot pronation begins to stand, orthotics should be used to maintain proper foot alignment and help symmetrically strengthen foot, leg, and postural muscles so that a child properly learns the mechanics of foot placement. Please work with your therapist to assess for foot pronation and if needed, use orthotics to help your child develop strength and balance. Over time, as your child learns good mechanics, the orthotics will no longer be needed. ■

Corporate Partners

**Latham Centers • Levo Therapeutics • Millendo Therapeutics
Prader-Willi Homes of Oconomowoc • Soleno Therapeutics**



PWSA (USA) works with Corporate Partners to coordinate the efforts of PWSA (USA) and corporate leaders, in a collaborative environment, to advance the field of Prader-Willi syndrome research, patient care, and family support. Both PWSA (USA) and Corporate Partners benefit with positive recognition, mission achievements and other benefits.

Contact Steve Queior at 941-487-6730 or email squeior@pwsausa.org to learn about different levels of partnerships. ■

Music and PWS

By Denise Servais, mother to Maya age 15, with PWS

Music can be found in all parts of the world and in every culture. It is believed that music has helped humans deal with emotions and connect with one another since the beginning of time. Music has been shown to cheer us up, help to focus, ease pain, increase energy levels, and keep us calm.

Besides listening to and engaging in music, research has also shown the positive effects of learning a musical instrument on cognition. Playing a musical instrument engages almost every area of the brain. Learning how to play an instrument can improve attention, concentration, impulse control, social functioning, self-esteem, self-expression, motivation and memory.

Susan McMahon, from New Hampshire, knows very well of the positive impact that learning an instrument has had on her daughter, Betsy. Betsy, age 35, has Prader-Willi syndrome, and has been playing the piano since 2010. After hearing her niece play the piano, Betsy expressed interest in also playing. Susan bought Betsy a full-size keyboard and signed her up in a special needs program at the Manchester Community Music School.

Susan stated that finding an instructor who had high expectations and could keep Betsy interested has been important. Susan reported that music benefits Betsy in keeping her calm, stimulates her memory and continually challenges her to master each piece she is given, to the best of her abilities. Susan reported, "The musical process also requires her to focus and improve through repetition until the muscle memory and music reading skills are firmly established. We feel like this carries over into many other areas of her life and helps maximize her intellectual skills and, of course, she gets a real sense of accomplishment." Betsy practices three times a day most days and her favorite song to play is the Jig Medley.

During recent years, there has been a steady growth of research on the impact of music with people with disabilities. Music therapy programs exist throughout the country such as in hospitals and schools. Music therapy is evidence-based use of music to establish a therapeutic program. Unlike music training, the goal is not necessarily to emerge from the

Betsy benefits from playing and practicing her lessons

therapy with a higher musical talent, but rather to meet the goals set that create positive changes in behavior and emotional well-being. According to the American Music Therapy Association, music therapy can strengthen and reinforce areas of speech, cognitive abilities, motor coordination and range of motion.

Given the vast amount of information that supports the positive impact that music has on our bodies and minds, one does not need to play an instrument or take a music class to experience the benefits of music.

Whether it's dancing to a favorite tune or listening to music to relax or fall asleep, the power of music can be felt in many ways. ■



LathamCenters

Creating brighter futures since 1970.



Internationally renowned for our expertise and success in working with individuals with PWS, Latham offers residential programs for children and adults. We invite you to visit our therapeutic Children's Program campus on Cape Cod.

Consulting services available.

Latham Centers, Inc.
1646 Main Street
Brewster, MA 02631

Latham Centers is an
equal opportunity
provider and employer.



(508) 896-5776 ext. 237 | LathamCenters.org | admissions@lathamcenters.org

We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more resources like this. Please use the enclosed envelope or visit our website,
<https://www.pwsausa.org/>

May is PWS Awareness month, and that makes it the perfect time to partner with PWSA (USA) to *Save and Transform Lives!*

Hosting an **On the Move** run or walk, or other FUNdraiser is easy! No matter how you choose to help, all dollars raised help!

These funds are used to raise awareness, promote education and advocacy, provide family support services, and help facilitate research for individuals and families with **Prader-Willi syndrome!**

Get Started Today!

Need more information, or ready to get started on your fundraiser?

Contact: Rikka Bos
e: rbos@pwsausa.org
p: 941.487.6729



Kick Off May Awareness Month with a Fundraiser for PWSA (USA)!

Host an "On the Move" Run or Walk

Hosting an **On the Move** walk or run in your area is a great way to raise awareness, connect with other families in the PWS community, and raise donations for PWSA (USA)! We will work with you to plan, promote, and host a successful event!



Donate Your Birthday!

Dedicate your birthday or other special day to honor a loved one with PWS! Facebook makes it easy to set up and share your fundraiser with friends, family, and coworkers! Not on Facebook? Head over to pwsausa.org and create your own fundraising page that you can share on social media, in emails, or even via text!



Create Your Own FUNdraiser

Do you like to bake? Run races? Whatever your hobby, turn your passion into a fundraiser for PWSA (USA)! Whether you want to host a bowl-a-thon or collect donations or sponsorships from an athletic event you're participating in, our staff is here to help every step of the way!



Create your fundraising page today at:

www.firstgiving.com/pwsausa

Development and Fundraising

Fifth Annual Clint Hurdle "Hot Stove" Dinner



Dinner, dessert, island music, baseball, old friends, and new...that was this year's Clint Hurdle "Hot Stove" dinner! Nearly 200 attendees joined countless more donors and sponsors in support of the fifth annual event, together raising over \$220,000 to benefit PWSA (USA)'s Family and Medical Support program. Monies will help provide resources and support to the PWS community in areas such as school support and training; behavior management; nutrition education; crisis intervention; legal, and legislative advocacy; medical intervention; and much more. Just as importantly, the event brought much-needed attention to the needs of individuals with PWS and their families.

Special thanks to everyone who supported the event, including: Pier 22; the Helton Foundation; Bob Kocis; Dawn Allard; the Seminole Hard Rock Casino; Pirates Charities; PNC Financial; Carmeuse Lime and Stone; and the Hurdle family. ■



Well done. Teamwork makes the dream work. Many thanks for a great event!

PWSA (USA) is With You 24/7

On your phone or tablet! Thanks to the Settles family, you can download the **FREE** PWSA (USA) app for mobile devices via iTunes or Google Play. Have immediate access to important information from the PWSA (USA) website via your mobile screen. Forget a handout? It's all on your phone! With this app you can:

- Show your doctor important medical information.
- Watch a school video with your child's IEP Team.
- Provide ER staff with key medical alerts during emergencies.
- Conveniently explore family support and other resources.

Encourage all involved in your child's life to download this app. ■

<http://bit.ly/2CsjHsnPWSAmobileapp>



Photos provided and reproduced with permission by the Pittsburgh Pirates



The Hurdle family



DCCR Efficacy and Safety Trial IN Young children and adults with Prader-Willi Syndrome

Phase III Clinical Research Study with an oral drug in PWS patients

If someone you know has Prader-Willi Syndrome (PWS), he or she may be able to participate in a clinical research study. In this Phase III clinical study, sponsored by Soleno Therapeutics, researchers are trying to figure out if Diazoxide Choline Controlled-Release Tablet (DCCR) can reduce PWS patients' appetite, amount of body fat, and aggressive and destructive behaviors, as well as improve other aspects related to PWS.

Version 3.0 26 February 2019

PARTICIPANTS MUST:

- BE 4 YEARS OLD OR OLDER
- HAVE PRADER-WILLI SYNDROME
- HAVE THE SAME CAREGIVER FOR AT LEAST 6 MONTHS PRIOR TO POTENTIAL PARTICIPATION IN THE STUDY

THE STUDY WILL LAST FOR APPROXIMATELY 15 WEEKS AND REQUIRE 7 VISITS

PARTICIPANTS WILL TAKE DCCR (ACTIVE DRUG) OR PLACEBO BY MOUTH, ONCE A DAY FOR THE DURATION OF THE STUDY

PARTICIPANTS WHO COMPLETE THE STUDY MAY BE ELIGIBLE TO ENROLL INTO A 9-MONTH EXTENSION STUDY WHERE THEY WILL RECEIVE DCCR (ACTIVE DRUG)

IF YOU ARE INTERESTED, PLEASE VISIT:

www.clinicaltrials.gov
NCT03440814



A Parent Mentor Tale

By Amanda Yank, mom to Saoirse with PWS,

Parent Mentor for PWSA (USA)

The first and only person that mentioned Prader-Willi syndrome to us while our daughter Saoirse was in the NICU was the incomparable geneticist, Chin-To Fong, M.D.. I have a vague recollection of him coming in on a Friday night after the first week of our NICU stay. He mentioned a previous patient of his who had been given the diagnosis of PWS. After a week of the most intense stress we have ever experienced, I was in no mental state to take in any more information at that point; it barely registered. A month later we met again with Dr. Fong to discuss the details and pertinent information about PWS that we would need to know. We discovered that he is also a professor with the University of Rochester, whose medical center is world-renowned.

Dr. Fong travels the globe doing research for his department. To our surprise, he asked if we would be interested in presenting in one of his first-year medical classes. We were honored, but as PWS parents know, the first year is tough with a capital T. We rescheduled a few times and eventually a year and a half went by. He reached out to us again this winter and asked if we could come to class during the spring session and, on a whim, we agreed!

So on a cold Thursday in February, we loaded up Saoirse – dressed in her cutest tutu and big hair bow, we drove to Strong Memorial Hospital to speak with a class of over 50 first-year medical students. Though my husband does not care for public speaking, I love it! I find it empowering, and exciting! It's even more so when you can use that platform as your safe space: bringing forth all those scary, dark emotions and all those days you spent fighting and advocating. We use chances like this to spread awareness.

It's powerful. Saoirse, the youngest of our three children and the reigning princess of the family, naturally ate up all the attention. She danced, clapped, laughed, talked, and waved to the students during the hour-long presentation. The students simply adored her and she basked in her spotlight.

We were able to share our story from the very beginning



Sweet Saoirse loves her swing and sunshine! Such joy!

when I was pregnant, and continue through our entire two-year journey as parents of a child with special medical needs.

Dr. Fong simply wanted us to present our lives to his class to show that, when medical professionals give a diagnosis to a family, it's not just a conversation. It's a profound, monumental moment that they will forever remember. Those parents' lives are altered in ways that they as doctors, may not realize the significance of this life-changing news.

We also used this class as an opportunity to really delve into how to give a diagnosis. We basically offered some guidelines and pointers of what to do and/or say (and what not to do). We developed and created these guidelines by polling over 30 parents of children with genetic disorders.

After the class ended, the students came up to us to genuinely thank us for the advice. They let us know that we gave them critical tools to use that they couldn't have gotten anywhere else except a special needs parent.

It was pretty amazing to know that from our sharing we may have just saved a future family from having a devastating diagnosis experience. We left the hospital that day feeling like we really made a difference in our medical community. We were so honored to have been given the opportunity: to use our crazy and chaotic new life as a way to offer insight to these students into the world of a special needs family.

This is truly just one more way our beautiful daughter Saoirse has made us better people, and the world around her a better place. ■

✻
*...I find it empowering,
and exciting! It's even more
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that platform as
your safe space: bringing
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dark emotions and
all those days you
spent fighting
and advocating.
We use chances like this
to spread awareness.
It's powerful...*
✻

UPCOMING CHAPTER EVENTS

New York - PWANY 29th Annual Conference

May 3rd and 4th, 2019

Holiday Inn – Binghamton. 2-8 Hawley Street, Binghamton, NY. Registration opens February 1st, 2019. For more information, please visit: www.prader-willi.org/conference

Colorado - PWS Derby Day

May 4th, 2019

Infinity Park, 4400 E Kentucky Ave., Glendale, CO
For more information, to purchase tickets or a sponsorship, or to make a donation, please visit: <https://pwsaco.org/derby2019/>



Wisconsin - Ninth On The Move Walk-A-Thon

May 11th, 2019

Riverside Park, 812 Labaree St, Watertown, WI
Join us for fun and help spread awareness for Prader-Willi syndrome. Spend time with friends and family, enjoy a nice lunch and some dancing! For more info, please visit: <http://www.pwsaofwi.org/>
Tickets: <http://bit.ly/2GQpvkA-2019OnTheMovePWSA>

Minnesota - 2019 Minnesota Golf Scramble

May 17th, 2019

Majestic Oaks Golf Club, 701 Bunker Lake Blvd. NE, Ham Lake, MN **Register before May 7.**
<http://bit.ly/2Gm7p9fPWS-MN-2019GolfScramble>
For more information, please contact Kristi Rickenbach at kristi_cole@yahoo.com.

Texas - TXPWA Ninth Annual Molly's Pub Charity Golf Tournament

May 21st, 2019

10 a.m. Cypresswood Golf Club, 21602 Cypresswood Dr., Spring, TX
To learn more, <http://praderwilligolf.wix.com/pwsgolf> Register online: <http://txpwa.org/register-golf-tournament-2018.html>

Prader-Willi Syndrome: A Bright Future

June 1st, 2019

Glastonbury, CT Co-hosted by Latham Centers and The MAC PACT An opportunity for PWS families, specialists and providers to meet, network, learn and share information and knowledge. To register or more info: <http://bit.ly/2KBVCI7pws-Latham> or email Katrina Fryklund, kfryklund@lathamcenters.org.

Chapter Leaders Meeting at the 35th National Convention



Leaders! Please email Crystal Boser at crystal.boser@aol.com your feedback on topics for the Chapter Leaders meeting at National Convention. She is waiting to hear from you! ■

Future Events: Watch for more details

Visit <https://www.pwsausa.org/find-a-chapter/>

Oregon/Washington Walk/Run On the Move July, 2019

Tacoma, WA - Contact the Chapter Vonnie Sheadel for more details.

Tenth Annual Hunter Lens Golf Tournament/Dinner July 13th, 2019

The Back 9 Golf Club, 17 Heritage Way, Lakeville, MA

Registration Deadline: June 30, 2019

<http://bit.ly/2DjW9bW-LENSgolfpwsa>

For more event information, please contact:

John Lens: 617-429-7664 - jlens@comcast.net or Lori Lens: 508-789-5047 - llens@comcast.net

Wisconsin - PWS Gala

August 17th, 2019 Save the Date. Watch for details!

Wisconsin - 19th Annual PWSA-WI Inc. Charity Benefit

September 29th, 2019 Save the Date! Details to follow.

Delaware - 5K Walk/Run

November 17th, 2019

Milton, DE

Please join the Delaware PWS Chapter at our very first 5k Walk/Run to raise funds for both the Delaware Chapter and PWSA (USA)! Our goal is to raise awareness in "The first state"! More information will be forthcoming.

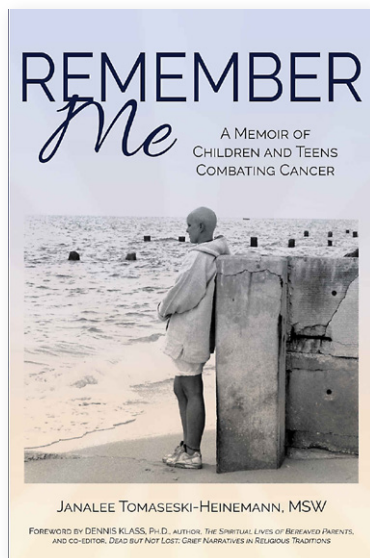


*"As our awareness grows,
so we grow."*

- Anonymous

REMEMBER ME

A Memoir of Children and Teens Combating Cancer



That is the title of a brand new book by Janalee Tomaseski-Heinemann. The PWS community tends to forget that Janalee had a life before Prader-Willi syndrome. Among other positions in PWSA (USA), she was a member of the board of directors, president, and Executive Director, in addition to becoming through marriage mother to a son, Matt, with the syndrome. However, for ten years prior, Janalee was an oncology social worker in St. Louis with children and teens combating cancer. She kept notes because their stories were “too beautiful, too profound, too sad, too inspiring, and too spiritual not to be told”. This is the fulfillment of a promise to them and to herself that they would not be forgotten.

One might think that a book about children and teens with cancer has nothing to do with Prader-Willi syndrome; they would be wrong. A parent’s world is changed forever the day their child is diagnosed, whether it is cancer or PWS. She provides profound and valuable

insights into the new world that they as parents have entered and must navigate.

One would feel such a book would be depressing; again, they would be wrong. The spirit, the resiliency, the hope even when there was no hope, and even humor shines through. Corey, a talented musician, kept on performing, with “the trumpet in one hand and a bucket in the other.” Jason, who loved doing magic, wanted a magician at his funeral to make people laugh—so they wouldn’t be sad.

After Janalee shares the stories of others, she shares her own story of her adult son Tad, who has been diagnosed with advanced life-threatening cancer of the head and neck with a poor prognosis.

Individual stories, brief vignettes, the teens-with-cancer support group insights, and her reflections are all part of her journaled memories and wisdom imparted with sensitivity and caring. Merlin Butler, M.D., Ph.D., says the book “will encourage each of us to better appreciate life and living.” Marilyn Dumont-Driscoll, M.D., Ph.D., states, “Moreover, this book provides valuable insights to health care professionals. We face ongoing challenges in our work; but we must ‘speak their name’ and above all remember they are not their disease, but first and foremost, our patient and ‘someone’s child.’”

174 pages, Published March 2019.
More proceeds will benefit PWSA (USA) when you purchase online from our website: <http://bit.ly/2W32qQ6-PWS> \$14.95 paperback ■

~ Submitted by Lota Mitchell, former PWSA (USA) board member, board chair, president, and editor of *The Gathered View*; mother to Julie age 49, with PWS.

Please email info@pwsausa.org if you would like to “Go Green” and receive *The Gathered View* (only) by email.



Kirk Zuhone

“I would like to get into a time machine and fly right out of here.”

CARbetocin Efficacy and Safety Study in PWS

Research is uncovering new approaches to treating the hallmark symptoms of Prader-Willi syndrome. Levo Therapeutics is currently enrolling patients with PWS in our Phase 3 clinical trial investigating intranasal carbetocin (LV-101) in children ages 7-18 as a treatment for hyperphagia and behavior associated with PWS.



CARE PWS

levo

www.levotx.com/care-pws

www.clinicaltrials.gov - NCT03649477

From the Counselor's Corner

Our children with PWS will soon have the summer off from school. For parents or caregivers, this can be a very difficult time. Toward the end of the school year, plans are being made about what to do for the summer, but before it ends, there are some things to consider that could make a big difference returning to school in the fall.

One of the best ways to make a difference is to start an individualized school portfolio for your child. A school portfolio follows your child through their school years from beginning to graduation. The portfolio can include school handouts as well as yearly teacher and parent questionnaires. Before your child leaves school for the summer, have your child's

current teacher fill out the questionnaire. You may be surprised by what you may find there.

It will help your child transition to different schools or teachers. This can also be used as a way to see how much progress your child has made from year to year.

When summer vacation finally arrives, you may need to find and maintain meaningful activities and structure throughout the day. Of course, you may have your child in summer camp, but most are not that lucky. What are some great strategies that are important for your child with PWS?

First you need to find some structure for your child and organize your child's day. Have a schedule of chores, tasks, or activities done at a certain times during the day. Have your child complete harder tasks first when he

has more stamina and is more alert at the beginning of the day. As you structure the schedule, think about your child's routine. When chores and tasks are a part of the routine, it becomes so much easier. Make sure your child is very comfortable with the routine. Consistency, predictability, foreshadowing are also very important. Using visuals and motivators are also extremely helpful to maintain a consistent, structured routine.

If you would like more information on making a school portfolio for your child as well as tips for the summer, contact a crisis counselor, or visit School Issues under the Family Support link: <https://www.pwsausa.org/family-support/>



Two-day Conference Programs for Attendees with PWS



Did you know we have almost 200 children and adults participate in our two-day programs? Register now to save your spot!

Youth & Infant Program (YIP)

0 – 1 year old: Our warm, nurturing nursery is staffed with individuals very

caring in addressing the specific needs of each little baby, all within a short distance from their parents.

2 – 6 years old: Little ones with PWS, or young siblings of those with PWS, have fun with arts, crafts, storytelling, puppets, music, and magic in structured play and staff-guided activities.

Youth & Adult Program (YAP) – ages 7 years and

up: This two-day program fills quickly to capacity each year. Children and adults diagnosed with PWS are involved in an innovative structured program designed to meet their medical, physical and emotional needs.

Being a part of a peer group that truly understands one another is fun. New friendships are formed and old ones renewed.

Divided into age-based groups, attendees are supported by highly-trained staff members who fully understand the unique challenges of PWS. YAP members are motivated, praised and encouraged to try new activities in a safe and therapeutic environment.

Sibling Program:

For siblings of those in YIP or YAP programs, this program was developed to enhance their individuality and reinforce their sense of importance. Home life revolves around the complexities of their sibling's environmental and care needs. This program allows them to have fun, meet and develop relationships with others who are in similar situations, explore new possibilities, and share experiences.

The PWS Global Assessment Team at General Conference returns

Families of children ages birth to 35 months have the opportunity to have their infant assessed by the PWS Global Assessment Team (pediatric physical therapist, speech therapist, endocrinologist and others). These specialists perform infant evaluations and address parent questions and concerns. There is no additional charge to registered Convention attendees. When registering for the General Conference, please indicate that you would like to be scheduled for a global assessment. Prior to the Convention you will receive your individual time slot to meet with our Global Assessment Team. It's that simple! Assessments are scheduled on a first-come, first-served basis, so please register! ■



“Providing Homes with a Heart”

Prader-Willi Homes of Oconomowoc specializes in providing residential services and support to people with PWS. For more than 30 years, PWHO has been recognized nationally and internationally by the PWS community for excellence in the therapeutic treatment and care for individuals diagnosed with PWS.

Contact us
(262) 569-4848
P.O. Box 278
Dousman, WI 53118
www.pwho.com



*“Let us not look back in
anger, nor forward in fear,
but around in awareness.”*

- James Thurber



So we've all been sick for the past few days. We told Mikey he needed one more day off school to rest. He didn't want to hear that. He called me from upstairs to tell me to call the school back and tell them he was coming - that 911 was taking him! Sure enough we got a knock on the door. Thankfully they're familiar with him and just needed to stop and make sure everything was ok. But no, they're not an Uber service and did not take Mikey to school!

*- Submitted by Nikki Henshaw
Pittsburgh, Pennsylvania
mother to Mikey, age 19, with PWS*

Thank you PWSA (USA)
for your unwavering support
of IPWSO and its mission!

This year IPWSO, the
International Prader-Willi
Syndrome Organisation,
is celebrating its 30th

anniversary. IPWSO is also holding its first ever international conference in a Spanish speaking country. This tenth conference that convenes scientists, families and care providers from around the world will be held in Cuba from November 13th to November 17th. Please check this opportunity out at www.ipwsoconference.org and consider coming to what will be a wonderful multicultural experience. English is the official language of IPWSO but there will be simultaneous translations if you or your friends are Spanish speaking.

Last year was a big year for IPWSO and this one is even bigger. Last year, there were meetings in India, Bangkok, Chile and a large gathering of the PPCB (Professional Provider Caregiver Board) in Germany to develop additional standards appropriate for international caregivers. Famcare Articles were translated to Arabic, Dutch, German, Italian, Hindi, Mandarin, Russian and Spanish. Famcare is the group that develops care and management guides to help families throughout the world. In most countries, adult children never leave home and there are few or no supports for young children who have special needs.

This March, there was a large conference of families, physicians, med students and therapists in Colombia and also a first time meeting in Bulgaria. For two days after the Colombia conference, an endocrinologist and geneticist met individually with families who had never seen a PWS physician. This fall, a group of families and professionals will participate in a first PWS conference in Vietnam. Physicians in Hanoi treat 100 children with GH but actually have no knowledge about the unique developmental and behavioral needs of children who have PWS.

Most exciting are the 41 children from all over the world who received a free diagnosis of PWS from IPWSO because their own country has no genetic testing. Testing is performed at the BIRD Institute in Italy. A life can be changed by a small drop of blood mailed to BIRD on a piece of paper!

PWSA (USA) has partnered with IPWSO from the beginning. You have generously shared materials and expertise. IPWSO's volunteer boards, similar to those of USA, serve the world for free. Dr. Daniel Driscoll, your PWSA (USA) Scientific delegate to IPWSO, chairs the IPWSO Clinical and Scientific Advisory Board. None of this could have happened without PWSA (USA) support for the past thirty years. Thank you! ■

Joan Gardner
PWSA (USA) parent delegate to IPWSO





Kristen with son Zackery

Meet Kristen Starkey

Kristen Starkey is starting her fifth year as a member of the PWSA (USA) staff team this month. A dedicated professional, Kristen and her financial and administrative work often are behind the scenes, but know that she is a fun, tireless member of the PWSA (USA) family at the national office.

Kristen grew up working with her Grampa in a family store. He sat her down (at age 12) with his giant ledger book and she recalls recording transactions with him (her first love of numbers!). Six months into her accounting studies at Suncoast Technical College, her instructor shared about an opening at a local non-profit. During her interview, Kristen heard the personal experiences from a guardian of an adult with Prader-Willi syndrome (PWS). Like most, Kristen had never heard of this rare syndrome.

Joining this organization expanded her knowledge of the syndrome and the struggle of the families. Her days involve recording all income and expenses to PWSA (USA), sending all honoree/memorial cards (per a donor's specification) and ensuring timely tax receipts to donors. During heavy donation times, this is quite a task! In supporting roles, Kristen can be heard answering phones, assisting staff with a variety of tasks, managing the National Convention store, plus tasks that have her engaging with the public and her PWSA (USA) family.

Kristen shares: "My first convention (2015) was eye-opening as I'd been with PWSA (USA) only six months! It was an introduction to both the beauty and struggle of those affected

by PWS. I met so many with the syndrome, from newborns to adults- each face full of joy. Knowing every tummy felt empty, I was amazed at their strength.

The people - the community - hands down, make this organization life-changing."

Kristen and her husband, Todd, have a wonderful son, Zackery, who just turned seven. Together they enjoy exploring nature and theme parks. At home, this avid reader keeps her Kindle nearby. Please say hello to Kristen at the desk or Convention Store in October. She'd love to meet you. ■

Want to be a part of the world's largest PWS advocacy community?

Join Our Family!



Visit:

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

http://bit.ly/2zNEb1C_PWSAusa



PWSA (USA) for Healthy Tomorrows

By Stephen D. Leightman, Development Chair, PWSA (USA) Board of Directors

This morning I received notice that a supporter of our Association has changed the beneficiary of her life insurance policy to include PWSA (USA). She is a friend of a parent with an eleven year-old daughter who has the syndrome.

Last week I was informed of a friend of a family that for estate planning and tax purposes is establishing a charitable Trust and is naming PWSA (USA) as the recipient of \$50,000 upon their death.

A third situation came to my attention when another friend of a family has decided to include PWSA (USA) in their will.

The future of our Association depends not only on present gifts, sponsorships and grants, but as we continue to grow and serve more and more families, it is important to plan

for our future. These are three examples of how to fund our future health:

- Insurance
- Trusts
- Wills

What is remarkable about these stories is that NONE of these gifts are being made by parents, grandparents, aunts or uncles – just friends. We can't begin to express our thanks for their thoughtfulness. It does, however open our eyes to the opportunities for the readers of this article to examine estate and tax planning to secure a healthy future for themselves, their families and hopefully to include PWSA (USA) as well.

We will be happy to work with anyone interested in exploring planning strategies and working with their financial professionals. ■

Our Mission:
Prader-Willi Syndrome Association (USA) exists to enhance the quality of life and empower those affected by Prader-Willi syndrome.

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info@pwsausa.org <https://www.pwsausa.org>**

Deadlines to submit items to The Gathered View:
**Dec. 1; Feb. 1;
Apr. 1; June 1;
Aug. 1; Oct. 1**

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MEMBERS ONLY:

Access our Website: www.pwsausa.org for downloadable publications, current news, research, and more.

The Members Only section requires a password: member20

E-mail Support Groups: We sponsor nine groups to share information. Go to: www.pwsausa.org/egroups

The Gathered View (ISSN 10 77-9965)

Sara Dwyer, Editor
Andrea Glass, Denise Servais
The Gathered View is published bimonthly by PWSA (USA). Publications, newsletters, the Website, and other forms of information and communication are made possible by our generous donors. Consider a donation today to help ensure the continuation of these resources.

The information provided in *The Gathered View* is intended for your general knowledge only and is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this publication.

Learn more about Saving and Transforming Lives at <http://www.pwsausa.org/>

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...when medical professionals give a diagnosis to a family, it's not just a conversation. It's a profound, monumental moment that they will forever remember...

Read Amanda's story on page 9



If this mark looks familiar, it's because it's the second of the five icons represented in our Five Pillars of Support. *By definition, a-ware-ness /ə'wɛrnəs/ : the quality or state of being aware : knowledge and understanding that something is happening or exists* **Awareness is the theme in this issue.** Topics vary but the stories, resources and information are the heart and passion of our organization represented in many ways. Which messages capture your attention and make your heart pound? Look for this mark representing a professional, a mother, a counselor or a friend who is sharing with others about Prader-Willi syndrome. Learn more and discover the joy in spreading awareness about PWS. We want to hear your story. ■



ZEPHYR, a pivotal Phase 2b/3 clinical trial of livoletide for the treatment of hyperphagia in patients with Prader-Willi syndrome, is underway in the US and Europe.

Visit www.clinicaltrials.gov (Clinical Trial: [NCT03790865](https://clinicaltrials.gov/ct2/show/study/NCT03790865)) or www.millendo.com for the latest information

PATHforPWS **Needs you!** *See page 1*

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