The Gathered View

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

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

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

CEO View

We Are All Advocates

Our association's mission is *"to enhance the quality of life and empower those affected by Prader-Willi syndrome."* Given that over-arching goal, one of the best ways to fulfill our mission is to be an *advocate* for the PWS cause.

The word "advocate" is both a noun and a verb, and I believe each reader of the *Gathered View* is an advocate, with that noun's definition being *"a person who publicly supports or recommends a particular cause or policy."* The synonyms of advocate are uniformly positive words, *including champion, supporter, proponent, and protector.* No doubt that you are an advocate for your loved one with PWS each day of the week, and every week of the year.

> ***"Do what you can, where you are, with what you have."***
> ***-Teddy Roosevelt***

Switching to the fact that advocate is also a verb, it must sound familiar to recall all the ways you advocate: you recommend courses of action to teachers, uphold a regimen prescribed by medical professionals, advise caregivers, and in so many ways stand up for and support your family member or friend with PWS.

Let me suggest that there are two key categories of advocating:

- Advocating for an individual among us, and
- Advocating for all of us.

Being an advocate for a child, grandchild, or another whose well-being you value might be the more familiar type of advocacy. Let me take the opportunity to remind everyone that members of PWSA (USA)'s Family and Medical Support professional staff team can be great resources and allies in this type of advocacy. They can assist you with a school IEP, help you compose a letter to an insurance company for growth hormone or another medication, assist you in learning about residential options, and much more.

Many of you have also advocated on

continued on page 2

Call for Nominations for PWSA (USA)

Board of Directors and Volunteers for Committee Service

The source of PWSA (USA)'s strength lies in its membership - parents, extended family members, professionals, and others committed to promoting research, education, and support for families affected by Prader-Willi syndrome.

We are currently seeking candidates for the 2019-2022 Board of Directors and volunteers for committee service. We have specific needs for talented individuals in the areas of:

- Advocacy Committee (for Positive Public Policy) - Fund Development - Chapter Relations

Board and committee membership is

continued on page 3

The Light at the End of the Tunnel

By Jonah, father to Annika

Annika was diagnosed with Prader-Willi syndrome (PWS) at age 3, but her battle started at birth, as we waded through the fog of a scary, mysterious birth. Getting physical and speech therapy, dealing with insurance companies every step of the way, became our life. Qualifying Annika as a disabled person eligible for public services and a supervised group home when she becomes an adult remains an ongoing fight with the state of California. Even with no recorded instance of an individual with PWS living on their own, and other disabilities (autism, epilepsy, cerebral palsy) automatically qualifying, Annika has been rejected twice. Unless new legislation is passed or our lawyer succeeds, she will live with us. The school district battle was continuous. As public school teachers ourselves, and having great district administrators, our local schools lacked specialized facilities and expertise to keep our daughter safe.



Annika

We accumulated evidence to prove it. Starting in kindergarten we negotiated a 1:1 aide for Annika. By first grade, she was assaulting the aides and running off campus.

By third grade, things became so dangerous, we negotiated a short-term

continued on page 3

Volume 44, Number 2 ~ March-April 2019 ~ Our 44th Year of Publication

Back by Popular Demand – Global Assessment Team at the 35th National Convention





Prader-Willi Syndrome Association (USA) is excited to once again offer our families of infants ages birth to two years old a unique opportunity to ***have your little ones assessed*** by the leading experts in the field during the national convention in Orlando this October.

PWSA (USA) listens to families of little ones. How many of you wish you could have a chance to have a team of experts give you and your baby individual attention and guidance in the area of caring for their unique challenges?

Global Assessment Team Leads:

Dr. Jennifer Miller is an Assistant Professor in the division of pediatric endocrinology. She graduated with her M.D. from the University of Florida in 1998, and her M.S. in Clinical Investigation from the University of Florida in 2005. She has done all of her training in pediatrics and ***Pediatric Endocrinology*** at the University of Florida.

Dr. Jennifer Miller's research, in collaboration with Daniel Driscoll, PhD, MD, focuses on evaluating the effects of early-onset obesity (i.e. obesity occurring before age four) on the developing brain. They study three groups of individuals – those with Prader-Willi syndrome (PWS – a genetic condition known to cause early-onset obesity), those with idiopathic early-onset obesity, and normal weight control siblings from both of those groups. Because PWS can be diagnosed at birth (with currently available genetic testing) and treated with growth hormone (to increase muscle mass and decrease fat mass), parents can be given prospective counseling to help them keep the child's weight normal for height through childhood. However, without the appropriate environmental controls instituted by the parents, the natural history of PWS is for children to become obese at 18-36 months of age. *Thus, individuals with PWS are an excellent model to discover the effects of early obesity on the brain.*

Janice Agarwal is a ***Pediatric Physical Therapist*** with over 20 years of experience treating children birth to three years of age. Janice was part of the Boston City Hospital neurodevelopmental evaluation team and the St. Mary's Hospital for Children early intervention team in New York. She received certification in Pediatric (NDT) Neurodevelopmental Training at the Bobath Center in London, England. She has lectured nationally and internationally on Developmental Interventions and Sensory Integration for hypotonic children and adults with PWS, using techniques incorporating Sensory Integration (SI) to normalize development. PWSA (USA) published her book, *Therapeutic Interventions for Children with Prader-Willi Syndrome.* Janice is a former 9-year member of the PWSA (USA) Board of Directors. She is the mother of two boys, Alex, age 19 (PWS) and Sam, age 18.

There is ***no additional charge*** for this ***unique opportunity*** for your infant to be seen by the team of professionals, as long as you are a registered attendee at the PWSA (USA) National Convention.

Appointments for these Infant Global Assessments will be set up prior to the 35th National Convention General Conference. Watch for more details to be available soon on the PWSA (USA) National Convention Website. ■

CEO View, *continued from page 1*

behalf of all of us… the broader PWS community. You might have raised funds for research or the family support services just mentioned, helped to increase awareness by educating friends, neighbors, and co-workers, or even written legislators or gone to your state capital to argue for legislation making PWS a qualifying condition for funding and insurance benefits.

Case in point, the article in this *Gathered View* issue about Annika describes how a parent is both an advocate for his individual loved one; he also took the high road and is "paying it forward" by serving on a board and calling for legislative reform and PWS housing that will impact all of us affected by PWS.

"If you have a voice, use it.
If you have legs, stand up.
If you have feet, step up.
If you have each other, fight together."
~ Janna Cachola

In addition to Annika's story, there are a number of examples of positive advocacy throughout this issue of your newsletter, and we believe it is such an important way to help the PWS CommUNITY that we'll embrace it all year long.

Being an advocate is, in fact, a noble calling, particularly considering this definition of such a person: *an advocate is someone who fights for something or someone, especially someone who fights for the rights of others.* Your helping to promote the rights of all those affected by PWS, your loved one AND others, makes you a true champion – we sincerely thank you for being an advocate! ■

~ Steve Queior, CEO, PWSA (USA)

Call for Nominations, *continued from page 1*

open to family members and interested professionals.

Please contact us if you or someone you know possesses the qualities necessary to be an effective Board of Director member:

- Ability to listen, analyze, think clearly and creatively, work well with people individually and in a group
- Membership in PWSA (USA)
- Commitment to serve a 3-year term (unless nominated to fill a shorter term)
- Willingness to attend Board and committee meetings and other special events; ask questions; take responsibility for a given assignment; support the Association as generously as your financial resources allow and assume shared responsibility for generating resources to meet Association goals; open doors in the community
- Possess willingness to learn skills such as understanding financial statements; cultivating and soliciting funds; cultivating Board members and other volunteers
- Possess honesty, sensitivity to and tolerance of different views; a friendly, responsive, and patient approach; community-building skills; personal integrity; a sense of values; concern for the Association's development; a sense of humor

What will you gain in return for your service?

- A sense of pride as you work to better the lives of all persons affected by PWS
- Input into decisions and policy-making that affects persons with PWS
- Increasing your knowledge about PWS and its treatment and management strategies
- Increasing your exposure to professionals who work with individuals with PWS

To nominate yourself or someone else, please contact Leadership Development Committee Co-Chairs Lisa Graziano or Tammie Penta via the PWSA (USA) office at 800-926-4797 or 941-312-0400 or info@pwsausa.org, fax is 941-312-0142.

"When my son was diagnosed
I felt lost and afraid.
Then someone at PWSA saw
something in me I didn't
even know existed and asked me
to fill a seat on the Board.
Twenty years later I feel
educated, empowered
and hopeful –
all because I got involved."

– Lisa Graziano, M.A., LMFT
parent

The deadline for nominations is April 19, 2019. To continue to grow as a vibrant, effective organization, PWSA (USA) also needs volunteers for fundraising, advocacy, and family and research support, among other areas. If you are able to free up time to help, please email us at info@pwsausa.org. There is no deadline, as volunteers are always welcome. ■

Annika, *continued from page 1*

placement at a local private school for special needs students. By year-end, Annika was back to assaultive behavior and elopement. We documented EVERYTHING. Which led us to an overnight in an adult psych ward. Annika had run away (again) and been found by the police. Staying in the ward, against the advice of the nurses, scared our insurance company so they approved treatment at Houston's specialized ward for PWS children.

We wanted her safe, but we also had started to realize that Annika needed to be at Latham, and Houston could help advocate.

When Annika returned home from Houston, we accepted a fourth-grade placement in a public special day class. Annika destroyed the classroom on an almost daily basis. We left her there as long as possible, but we had to let her fail in order to further build our case.

Annika then assaulted her two-year-old sister. We strategically presented at an ER forty miles away, placing her in their child psych ward, and negotiated approval for her to transfer directly to The Children's Institute's specialty PWS ward in Pittsburgh. Pittsburgh recommended a direct transfer to Latham. But the district moved too slowly.

Upon discharge, we personally took our daughter to Latham and enrolled her.

Two months later, combined evidence presented Annika's failed school placements, expert analysis from Houston and Pittsburgh, and documented her vast improvements since moving to Latham. The district finally approved her placement and reimbursed us.

We've never felt more proud, relieved, or sad.

This is only half of the story. We never could have done this on our own. Behind the scenes we had immense support from PWSA (USA), PWCF, and many others, especially Annika's grandparents.

While grateful to have had the resources to get Annika to Latham, we are outraged that many families lack resources. Their disabled children may never get where they need to be.

Sending your child to live across the country doesn't sound like a success story, but it is. We recognize this fortunate journey and want to pay it forward. As a board member for the Richard De Lone Special Housing Project, I advocate for legislative reform and specialized PWS housing. Plus, joining a PWCF task force, we help educate parents and service providers on how best to navigate complex state and federal disabled services systems. These efforts express the gratitude we feel and give to others. ■

Millendo Therapeutics' Zephyr Phase 2b/3 Clinical Trial for PWS

Livoletide, an analogue of unacylated ghrelin, has the potential to be a first-in-class treatment for PWS. Ghrelin, also known as acylated ghrelin (AG), is commonly known as the "hunger hormone" and is synthesized in the gastrointestinal tract. Ghrelin functions as a neuropeptide to stimulate feeding and food seeking behavior. Livoletide has been shown to inhibit effects of ghrelin.

In a Phase 2 European study of persons with PWS, Livoletide was shown to improve food related behavior in PWS. In the trial, 42 persons with PWS were given Livoletide once daily by injection. The results were: Livoletide was well tolerated with no serious adverse events, there was a statistically significant improvement in behaviors related to hyperphagia, and there was a significant reduction in fat mass as compared with placebo.

Diamond Sponsor announced for Medical & Scientific Conference at 2019 PWSA (USA) National Convention

MILLENDO THERAPEUTICS

The next phase of the trial is the Zephyr phase which will begin recruitment in the next few months. There will be more than 25 sites in the US and Europe. Patients will be randomized into three groups (high dose, low dose and placebo) and treated for 3 months, then all patients will receive Livoletide for the following nine months. The primary endpoint will be a change in the hyperphagia questionnaire.

To be included in the study the subject:

- Must have PWS
- Be eight years of age or older
- Must have a primary caregiver throughout the study period
- May have Type 2 Diabetes but HbA1C must be <10%
- Body Mass Index of ≤65 kg/m2
- May be on growth hormone, but dose must be stable

For more information regarding the Zephyr Trial please visit https://millendo.com/our-programs/livoletide.php and send your questions through the contact us page.

Are you ready to bring an idea to life and spread awareness and momentum for PWSA (USA)? We'd love to partner with you and make a difference in the lives of those with Prader-Willi syndrome! Contact squeior@pwsausa.org

The PATH for PWS Study Needs You!

By Mary Burr, D.N.P., C.P.N.P., Medical Coordinator, PWSA (USA)

What is Path?

The **PATH for PWS** study (**P**aving the way for **A**dvances in **T**reatments & **H**ealth for PWS) is a four-year non-interventional, observational study of serious medical events in PWS, intended to inform the development and clinical trial design for potential new treatments for PWS.

Are you interested in joining this life-changing study?

Every six months, caregivers of people with PWS enrolled in the study will be asked to provide an update on any serious medical issues experienced and related medical procedures or prescriptions; updates to also include information about conditions often associated with PWS such as hyperphagia. You will be compensated for your time and participation.

Clinic visits will not be required, as the information will be provided through internet-based surveys and questionnaires. Collected data will be analyzed to evaluate the incidence of serious medical events, prescription medication use associated with medical events of interest, patterns of hyperphagia-related behaviors, plus other areas of importance to the PWS community such as changes in body weight, management strategies for hyperphagia, and characterization of traits and actions common to individuals with PWS. The analyses will also help the Prader-Willi research community identify potential areas for future study.

Eligibility Requirements

To be eligible for the study, subjects must have a confirmed diagnosis of PWS, be at least 5 years of age, live in the United States, Canada or Australia, and must be enrolled or willing to enroll in the Global Prader-Willi Syndrome Patient 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 and allowing registry staff to enter specific data on their behalf. Participation in

continued on page 6

FDA Grants Betahistine Orphan Drug Status in the treatment of Prader-Willi Syndrome

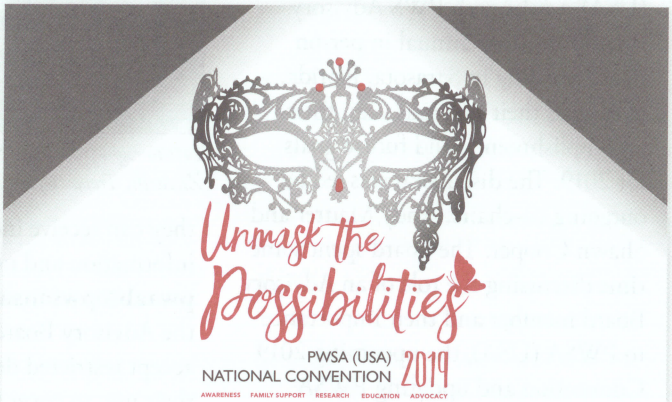
By Mary Burr, D.N.P., C.P.N.P., Medical Coordinator, PWSA (USA)

In a December 2018 press release, Auris Medical Holding AG announced its plans for strategic expansion of its intranasal formulation of Betahistine. The company acquired Orphan Drug Designation (ODD) for Betahistine from the FDA for the treatment of obesity that is associated with Prader-Willi syndrome (PWS). The company also signed a letter of intent to in-license exclusive rights to two US patents relating to the use of Betahistine in the treatment of atypical depression and attention-deficit/hyperactivity disorder (ADHD).
Orphan Drug Designation (ODD) is a special status granted to a drug or biologic product to treat a rare disease upon request of a sponsor. For a drug to qualify for ODD, both the drug and the rare disease must meet certain criteria specified by the FDA. Granting of ODD does not alter the regulatory requirements and processes for obtaining marketing approval. Safety and efficacy must have been established through well-controlled clinical trials.

Betahistine in the oral form has been approved in 115 countries for the treatment of vertigo and Meniere's disease and has an excellent safety profile. The efficacy of the oral form has been challenged by poor stability and activity. The bioavailability of the intranasal form is significantly higher overcoming these limitations in clinical practice.

Betahistine is a molecule with a similar structure and action to histamine but, unlike histamine, it can cross the blood-brain barrier and reaches the brain. It is known to enhance blood flow to the inner ear and brain as well as stimulate the release of biochemicals to increase brain arousal. Histamine plays a role in the regulation of many behavioral and psychological functions. These include appetite, drinking, sleep-wakefulness, learning, attention, and memory.

Progressive hyperphagia and obesity, delayed cognitive ability and behavioral issues, as well as sleep disturbances, characterize Prader-Willi syndrome. The introduction of Betahistine into the treatment of PWS could bring hope to individuals with the disease and their families that quality of life and independence could be improved. ■



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

Corporate Partners

Latham Centers • Levo Therapeutics • Prader-Willi Homes of Oconomowoc

Soleno Therapeutics • Millendo 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 three different levels of partnerships. ■

Adults with PWS Advisory Board Holds Annual Meeting

Appoints 2019-20 Board Co-Chairs

By Stacy Ward, M.S., Director of Family/Medical Support and Special Projects

January 19th and 20th, the PWSA (USA) Adults with PWS Advisory Board held their annual in person board meeting in Sarasota, Florida, to discuss their previous year, their accomplishments, and future goals for 2019. The discussion was led by outgoing co-chairs, Andy Maurer and Shawn Cooper. The board spent some time discussing the role of an Advisory Board member and their importance to PWSA (USA), the upcoming 2019 Convention and updating PWSA (USA)'s "Management of PWS in the Work Setting" brochure.



Left to right front row: Stacy Ward, Andy Maurer, Shawn Cooper, Brooke Fuller. Middle row: Mary K Ziccardi, Trevor Ryan, Abbott Philson, Janalee Heinemann. Back row: Kate Kane

The Advisory Board is pleased to announce an email box where they can receive inquiries, questions, information and notes. Use the email: **pwaab@pwsausa.org.** Additionally, the Advisory Board is now able to accept restricted donation funds for their use, to cover Convention costs for an Advisory Board member to attend Convention, to defray the cost of publications written by the Board or help support any number of other Board activities, as the donor desires. Please consider designating a portion of a future donation to Advisory Board use.



Trevor Ryan, Mary K. Ziccardi, Abbott Philson

The Advisory Board participated in a panel discussion at the 2017 General Convention which focused on employment strategies and challenges. The Advisory Board hopes to be able to participate in another panel discussion at the 2019 General Convention and looks forward to your engaging interactions. Watch for us all around the Convention venue and for more announcements in upcoming editions of *The Gathered View*.



Andy and Shawn have served the Adults with PWS Advisory Board well as co-chairs. Their last task as co-chairs during this board meeting was to announce the new co-chairs for 2019: Kate Kane and Abbott Philson. Kate and Abbott have been members of this Advisory Board for many years and are looking forward to leading the board in 2019. The Advisory Board expresses its appreciation for the co-chairs who have led this group in past years – Brooke Fuller, Conor Heybach, Shawn Cooper and Andy Maurer. Congratulations Kate and Abbott! ■

Andy Maurer

PATH, *continued from page 4*

clinical trials and other non-interventional studies will be permitted while enrolled in **PATH for PWS**.

***The PWS Global Registry is still going strong! Enroll now at: https://pwsregistry.org/**

Questions? To learn more click on http://bit.ly/2MR0Op2Path4PWS. Visit www.PATHforPWS.com or contact us at info@PATHforPWS.com for study details or enrollment. ■

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 visit our Web site, https://www.pwsausa.org/

Therapeutic Interventions for the Child's First Year

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

Note: This article, a synopsis from a recent webinar, is derived from the book Therapeutic Interventions for the Child with Prader-Willi Syndrome. *This comprehensive 60-page booklet, included in the PWSA (USA) Package of Hope, is designed for families of those newly diagnosed with PWS.*

It's imperative to understand the proper sequence of developmental milestones. This aids in creating individualized plans that most naturally follow normal development of an infant's muscles and tone to optimize balance, coordination, and cognitive acquisition. We must encourage an infant's natural curiosity to reach out, explore objects, and interact with their environment. As your infant learns new movements and prepares for higher activities, each new developmental milestone must build on that critical solid foundation of one of your infant's previously well-developed skills. Therapists (and parents) must recognize, understand and feel each new movement (and control it) so that an infant learns to move with purpose and confidence.

Head Control Head control is the first movement an infant achieves as they become more alert and look around. Head control requires strength and coordination of the neck muscles; this strength and coordination slowly moves down the back as they attempt to prop up their forearms while on their bellies.

While our babies are on their belly, they are strengthening their neck and shoulders. The strength achieved in their arms and shoulders will allow them to better utilize their hands later for fine motor activities. They develop righting reactions; those reactions that allow them to put their hands out and protect their head when they are falling. They also develop their ribcage and increase their respiratory function. Lastly, as strength moves down the spine, we hope to achieve symmetrical muscle development to help prevent scoliosis when they become more upright.

Creeping and Crawling ***(The most important developmental milestones)*** When an infant becomes stronger in their arms and back, they will begin to shift their weight from side to side and move forward and backward with purposeful effort to reach a toy or object. This is called creeping. Creeping is defined as moving around on one's stomach or rolling to obtain objects. The next step: crawling is raising one's stomach off the ground and moving around on arms and knees.

When infants are ready to crawl on their own, they will often become more vocal and will start pushing objects in different directions. This is an important time; they develop neural connections to learn how to coordinate leg and arm movements to move and retrieve objects. The infants continue to strengthen their shoulder girdle and spine/trunk in gravity-lessened activities, and develop symmetrical strengthening of their spine. Again, this is very important to prevent scoliosis in the future. While crawling, they are learning how to control their pelvis in a pre-locomotive fashion; this will be necessary for future walking. It's so important to push to achieve this milestone, *before* they try to go upright, to gain as much function as possible.

Sitting Once a child is crawling, they will find that with a small bit of spine rotation, they can easily transition into sitting. I strongly encourage families to *not* place a child into a sit (or tripod) position ***until the child is able to transition into that position itself*** without assistance. Why? They need to have: 1. first developed the strength in their arms to protect themselves if they fall forward. 2. symmetrically developed spine muscles, so when they use those muscles to maintain a seated posture, one side does not pull more than the other.

If one side needs to pull more, the muscles will develop asymmetrically, which could lead to scoliosis.

Good crawling is also a great way to really know that a child has the appropriate neck, shoulder, and arm strength to take the next steps toward higher developmental skills.

Pull to Stand Once infants have developed the strength, coordination and balance to move freely on the floor by crawling, they will begin to pull up to a stand. This normally will start with the child coming into a high kneel on both knees, facing a sturdy piece of furniture. This is a great time to work with your therapist to fit your child with orthotics to correct any weaknesses in the foot that can lead to future problems in standing and walking.

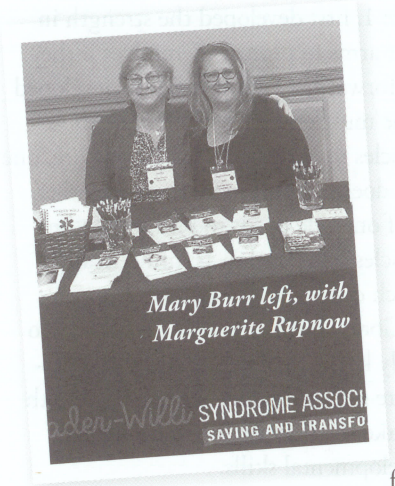
The parent of every newly-diagnosed child receives one of these books in their *Packet of Hope*. If you have not received the book or a packet, visit: **https://www.pwsausa.org/new-diagnosis/** to register online or please contact the PWSA (USA) office so we can get you connected and keep you informed. Donations to PWSA (USA) go towards our many programs: https://www.pwsausa.org/donate-today/ and are greatly appreciated.

I look forward to our next conversation: ***Sensory Integration.*** Until then, please refer to *Therapeutic Interventions for the Child with Prader-Willi Syndrome* for more details. Order online at: **http://bit.ly/2SuuZaITherapyPWS** ■

continued on page 7

PWSA Pennsylvania Chapter Mini-Conference

By Mary Burr, D.N.P., C.P.N.P., Medical Coordinator, PWSA (USA)



On November 9 - 11, 2018 just outside Pittsburgh, Pennsylvania, families arrived to attend the state chapter's annual conference. A meet and greet reception welcomed attendees as they registered Friday night, including appetizers and beverages. Games, balloon sculpting and airbrush tattoos were enjoyed by the younger set. Parents participated and enjoyed the fun and fellowship.

Saturday morning PA chapter president Deb Fabio began the conference with opening remarks. Parents had uninterrupted learning; their children were cared for and kept busy and happy with age-appropriate activities by trained caregivers.

Attorney Nora Chatha covered the parental/caregiver role of guardianship of a disabled child or adult at the first session. She clarified what having power of attorney meant, and ways to establish a special needs trust fund, assuring financial security for children with PWS throughout adulthood.

Dr. Luigfirsti Garibaldi, from Children's Hospital of The University of Pittsburgh, followed in the next session with an overview of the PWS genetic defect, hypothalamic dysfunction, plus research behind the current treatment modalities used in the treatment of PWS. He explained the reasons for treatment with GH, addressed pubertal issues, and the use of dietary and homeopathic therapies, and concluded with a description of the ongoing research studies currently recruiting subjects at the University of Pittsburgh Medical Center.

Cindy Szapacs, behavioral analysist and mother of a child with PWS, presented at the luncheon. She focused on Applied Behavioral Analysis and its application in caring for/treating behavioral issues in children with PWS.

Dr. Janice Forster presented on the dynamics of mental health and behavioral problems and PWS, in terms of the progression of behaviors across the stages of development. Janice explained the root of most troublesome behaviors (manifested in individuals with PWS) are translated from unaddressed stressful feelings and expectations. She also discussed issues of hyperphasia, skin picking, repetitive and destructive behaviors, and the relationship to processing delays. An in-depth discussion on the treatment of mood disorders in PWS with psychotropic medication began; she felt it is not well understood and there are few effective choices. Many medications have serious side effects that, in some instances, can cause behavioral problems.

Amy McTighe gave the final in-depth presentation on supporting students with PWS in the school setting. This included developing an IEP and 504 plans to facilitate optimal educational environments for children with PWS.

Saturday evening concluded with dinner, followed by music and dancing. Sunday morning a breakfast buffet was enjoyed by the 100+ attendees and exhibitors.

Parents were provided breaks and opportunities to visit with exhibitor tables in the conference room. Parents inquired about the family support services offered by PWSA (USA), and information on current research studies. The PWS Global registry and PATH study coordinator helped parents understand the data entry and survey process. The conference gave families time to network and establish new relationships, and catch up with old friends. Several families shared that it was both an educational and fun weekend for all who attended.

PWH
OCONOMOWOC

"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

PWSA-WI Snowflake Ball!



Teresa Brinda Price and Molly P.

On Saturday, February 2nd, PWSA-WI, Inc. hosted our Eighth Annual Snowflake Ball at the Red Circle Inn & Bistro in Nashotah, Wisconsin. Members of our Board and Junior Advisory Board decorated the venue in a red, silver and black theme, which included beautiful centerpieces they made for each of the tables. 250 members of the PWS community dressed up, wore corsages & boutonnieres, and enjoyed a delicious meal served to them by our amazing volunteers after the organization's treasurer gave a special toast. As people finished their meal our new DJ, Spencer Dominguez from Xcite Entertainment, kicked off the dancing by playing crowd favorites such as Uptown Funk and YMCA. Our longstanding photographer, Tom Davenport from RD Image, captured the entire evening by taking photos of the people in attendance.



Sherita Greer and her son Quemont

It was a magical evening and we are already looking forward to next year! ■

~ Submitted by Crystal Boser, PWSA-WI

May is Prader-Willi Awareness Month!

May is Prader-Willi Syndrome Awareness Month, and we need YOU to help us spread the word! Throughout the month, PWSA (USA) will be posting PWS-related information and resources in emails and on Facebook and Twitter. We're asking everyone in the PWSA (USA) family to share what we share to help others find the hope and support they need, and to help spread awareness about the challenges and needs of the PWS community. Be sure to check your email and social media for **May Awareness Month** updates!

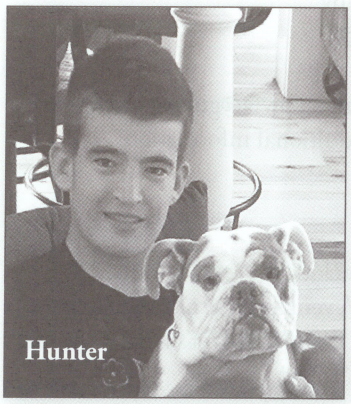


Looking for another way to help? Be sure to check out the many PWSA (USA) chapter fund and awareness raising events being held in and around May! No events scheduled in your area? Host your own! The staff at PWSA (USA) is happy to help you get started!

See upcoming fund and awareness raising events on pages 9-11. ■

Please join us!

Tenth Annual Hunter Lens Golf Tournament



Saturday, July 13, 2019
The Back 9 Golf Club
17 Heritage Way
Lakeville, MA
1:00pm shotgun start

Hunter, age 20, has Prader-Willi syndrome, and leads a happy, active life despite his daily challenges. Supporting PWSA (USA) will open more doors for Hunter and others with PWS, which ultimately means a better life. Please join us on this special day in honor of Hunter.

Registration & payment deadline: June 30, 2019
bit.ly/2DjW9bW-LENSgolfpwsa

Golfer: $125 (Includes golf, prizes, and awards celebration dinner)

Golfer under age of 16: $75 (Includes golf)

Awards Celebration Only: $55 (Includes dinner)

Checks made payable to: PWSA (USA) Mail check and completed form to: John or Lori Lens, 22 Beechtree Drive, Lakeville, MA 02347 **For more event information,** please contact: John Lens: 617-429-7664 - jlens@comcast.net or Lori Lens: 508-789-5047 - llens@comcast.net ■

UPCOMING CHAPTER EVENTS

Texas - TXPWA Spring Conference
April 13th, 2019
Spring Branch Presbyterian Church, Houston, TX
Registration: $25; Child Care: $20 For more information, please contact Susie Reisenbigler, executivedirector@txpwa.org; 713-742-3737
Speakers: Dr. John Cassidy, Dr. Ann Scheimann, Dr. Linda Gourash, Melanie Silverman, MS, RD, IBCLC, Susan Hedstrom, Executive Director, FPWR
Accommodations: Four Points by Sheraton Houston-Citycentre. Discounted hotel rooms available until 3/31/19
For reservations: Carolina Menjivar, (713) 827-3507, cmenjivar@valenciagroup.com

Florida - PWFA Conference and Walk
April 26th-28th, 2019
Registration deadline: March 15, 2019
Begins Friday, April 26, 6:00 p.m.
Saturday April 27, 8:30 a.m.
Westgate Lakes Resort
9500 Turkey Lake Road, Orlando, FL
Speakers: Dr. Jennifer Miller,
Hannah Stahmer, MS, RDN, Dietician, Pediatric Endocrinolgy
Sandy Wainmain - Hippotherapy
Hotel registration: 877-502-7058
Group Code: SO 64-947
Please contact Catt Pudney: pudneypwfa@gmail.com or 415-794-1644 for details and additional information.

2019 Fun Walk
April 27th, 2019
Begins at 4:00 p.m.
Registration: $30 per walker, includes an event t-shirt!
https://www.firstgiving.com/event/pwsausa/floridaotm
Bring your family, gather your friends, and let's have some fun supporting the PWS CommUNITY!





See page 2 – **Back by Popular Demand**
Global Assessment Team
at the 35th National Convention

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! To register and more info, please visit: https://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. For more information, please contact Kristi Rickenbach at kristi_cole@yahoo.com.

Texas - TXPWA Ninth Annual Charity Golf Tournament
Monday, 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

on the MOVE
PRADER-WILLI SYNDROME ASSOCIATION (USA)

CHUCKLE CORNER

Kimber: "Mom, can I have apple juice?"
Me: "No Kimber, apple juice has lots of carbs. Remember?"
K: "Oh ya...mom does broccoli have lots of carbs?"
Me: "No, broccoli is good..."
K: "Ok; then can I have some broccoli lemonade?"

~ Submitted by Alyssa Nielsen
Cove, Utah
mother to Kimber, age 5, with PWS



Cherie Fifi being held by Katherine

Katherine Elizabeth Connell - October 10, 1962 - January 16, 2019

Submitted by her mother Janet Connell

A much-loved daughter, sister, aunt, niece, cousin and friend, Katherine Elizabeth Connell was given her angel wings on January 16. A native of Mobile, she was a friend to everyone she met and gifted unconditional love, teaching all of us in the process. She bravely fought cancer while continuing to enthusiastically create art until her last days.

Katherine attended/worked in Mobile ARC, a sheltered workshop, for 34 years. She was very social, making friends wherever she went. Katherine was also able to live independently in a residence from 2009 - present, and blossomed on her own. She loved animals, real and stuffed ones. A talented artist, Katherine was drawing pictures for the hospital nurses towards the end.

Katherine taught me much about life. She thought she had a successful life, as she conveyed to me when asked: "What do you think of your life, Katherine?" She said, it was good. Toward the end I said, "Katherine, I am sorry for fussing and yelling at you." She said, "That's ok Mom, cause you took it all back." She was kind and loving to everyone.

A celebration of Katherine's life was held Saturday, January 26, 2019 at Mobile Memorial Gardens Funeral Home, Mobile, Alabama. Memorial donations may be made in her memory to Mobile ARC, 2424 Gordon Smith Dr., Mobile, AL 36617 or the Prader-Willi Syndrome Association (USA) online: www.pwsausa.org or 8588 Potter Park Drive, Ste. 500, Sarasota, FL 34238 ■

Fifth Annual Clint Hurdle "Hot Stove" Dinner

The Fifth Annual Clint Hurdle "Hot Stove" Dinner on March 22 in Bradenton, Florida promises to be more fun than ever!

We're excited to announce Pier 22 as our awesome new location (and 2019 Venue Sponsor), a gorgeous restaurant situated alongside the breathtaking Manatee River! This can't-miss event will also feature a casual cocktail hour, delicious dinner and decadent desserts, silent and live auctions, and live music. You'll be able to have your picture taken with everyone's favorite feathered friend, the Pirate Parrot, and meet Clint Hurdle, manager of the Pittsburgh Pirates (Clint's daughter, Maddie, has Prader-Willi syndrome). Most importantly, the event is an opportunity to raise awareness of and support for Prader-Willi syndrome and PWSA (USA)'s Family Support program.

Join us for this year's fun and family-friendly Hot Stove Dinner (Kids of all ages are welcome)! For more information, to purchase tickets, be a sponsor, make a donation, please visit **https://bit.ly/2FXEIRd** or contact Rikka Bos at rbos@pwsausa.org

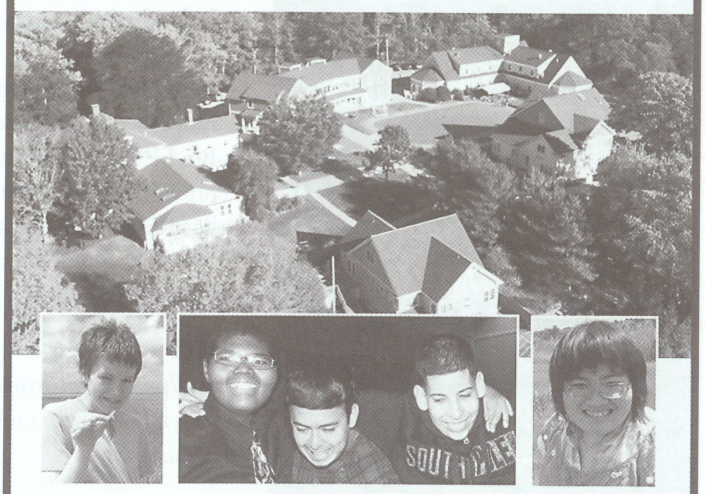
Your purchase, sponsorship, or donation will make a real and meaningful difference in the lives of individuals with PWS and their families. Your support ensures PWSA (USA) can continue to provide the comprehensive programs and services the PWS commUNITY has come to rely on.

Thank you! ***We look forward to seeing you on March 22nd!***

PIER 22
Restaurant • Patio • Catering

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

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

New Rules and Regulations for Home and Community Based-Services (HCBS) Significantly Impact Health and Safety of Persons with PWS

The Centers for Medicare and Medicaid's Services (CMS) new Home and Community-Based Services Rules and Regulations include a provision that "individuals have freedom and support to control their schedules and activities and have access to food any time." This provision is life-threatening to persons diagnosed with PWS because all persons with PWS have some degree of the PWS hyperphagia symptom. This symptom drives the brain to seek and find food and eat without ever feeling full/satisfied no matter how much food is eaten.

"New tools to help providers comply with the new rules while ensuring the health and safety of their residents have been developed."

~ Lisa Graziano

New tools to help providers comply with the new rules while ensuring the health and safety of their residents have been developed. Prader-Willi California Foundation's HCBS Task Force has been working closely with the Centers for Medicare/Medicaid, Community Care Licensing, California's Department of Developmental Services, and various PWS specialists in support of both staff and residents.

Some of these new tools include

- Request to CCL for Locking Waiver template
- Physician's Note Symptom & Treatment Checklist
- Individual Agreement Regarding Food and Locks
- Individual Agreement Regarding Elopement and Locks
- Brief PWS Overview Training Video providing guidance to other state's licensing departments
- Person-Centered Plan Cheat Sheet (Program Plan)

VISIT

http://pwcf.org/forprofessionals/ to access any of these tools and read more details.

Please contact the PWSA (USA) office or email Lisa Graziano, LisaG@pwcf.org directly with any questions. Note: info for families is in the sidebar to the right.

On behalf of PWSA (USA) and PWCF's Board of Directors and the families of the residents you support, we thank you for your care and dedication. ■

Reminders for Improving Parent/Provider Relationships

By Barbara J. Goff, Ed.D.

Do

- Say positive things to the staff; your support means more than you can imagine
- Attend your child's planning meetings
- Coordinate your child's home visits with the staff so they can plan house activities accordingly
- Ask for the program's policies and procedures in writing and discuss any questions or concerns up front
- Follow-up with staff when your child tells you about something terrible that happened to him or her at the program
- Follow the communication chain - creates good faith with the staff (and doesn't preclude you from going straight to the top when you really need to)

Don't

- Blame, threaten, or yell at direct service staff - bring your concerns to the appropriate supervisor
- Question a decision made by a staff person in front of your child or other program participants
- Do your child's household chores for him/her
- Forgo his diet plan entirely during home visits
- Believe that absolutely every behavior issue that arises is a result of PWS and isn't subject to change (after all-do we really know for sure?)
- Believe everything you hear from a staff person about an incident-check it out with a supervisor who usually has the bigger and more complete picture

Lastly

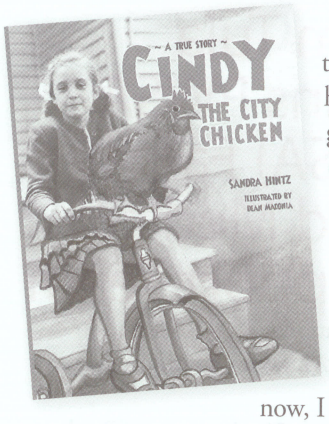
- Don't expect that any program can provide all that you provide as a loving parent, but do acknowledge what your child gains by being in a work or residential program. There are trade-offs and most are very worthwhile.

SOLENO THERAPEUTICS

DEVELOPING NOVEL THERAPEUTICS FOR THE TREATMENT OF RARE DISEASES.

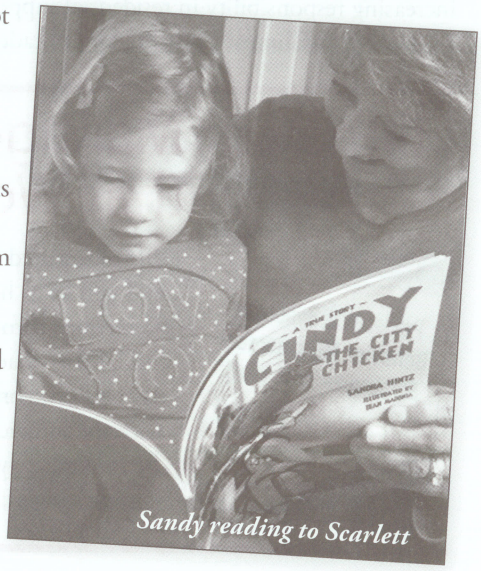
1235 Radio Road
Suite 110
Redwood City, CA 94065

Tel: (650) 213-8444
Fax: (650) 213-8383
Email: info@soleno.life
https://soleno.life



Cindy the City Chicken is a true story about a special pet I had as a young child. My parents gifted me with four baby chicks one Easter, as I was allergic to cats and dogs. Cindy was one of those four chicks, and our adventures landed us on the front page of the *Kalamazoo Gazette*.

I always wanted to write about Cindy, so years from now, I could have a written voice; leaving something more than simply a name on a family tree to future grandchildren and others is meaningful. Retired from teaching, I finally got this story finished!



Sandy reading to Scarlett

After my granddaughter Scarlett was born, I began writing; her diagnosis of PWS made me decide the profit from sales of *Cindy the City Chicken* would benefit those affected by the syndrome. At the end of 2018 I was able to donate $675.00 to PWSA (USA) and also to our local chapter.

To learn more, visit the website, *Cindy the City Chicken* https://www.cindythecitychicken.com/ Books may be purchased from any bookstore by giving the information: *Cindy the City Chicken* by Sandra Hintz, online at Amazon or AmazonSmile: https://www.pwsausa.org/other-ways-to-give/ ■

PWSA (USA) is With You 24/7

Is PWSA (USA) in 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 with a touch of your mobile screen. Forget a handout you wanted to share with a teacher or doctor? No problem. It's all on your phone! Through this app you can:

- Show your child's doctor important medical information during an appointment.
- Watch a school video with your child's IEP Team.
- Read the latest news on research and other topics of interest.
- Provide ER staff with key medical alerts during emergencies.
- Conveniently explore family support and other resources available to you.

Encourage family, friends, and professionals in your child's life to download this app to know about PWS and also support the needs of your child at your fingertips. ■

http://bit.ly/2CsjHsnPWSAmobileapp



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."

CFC® Combined Federal Campaign *Approved Charity*

PWSA (USA) CFC ID # is 10088

To learn more click or visit https://www.opm.gov/combined-federal-campaign/



Kim Tula Joins PWSA (USA) Family and Medical Support Team

Prader-Willi Syndrome Association (USA) is pleased to announce Kim Tula as its newest Alterman Family Support Counselor.

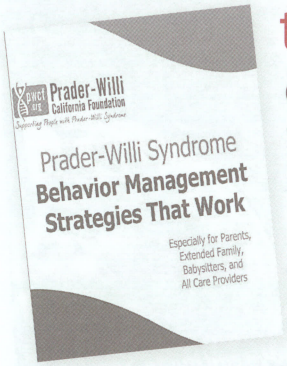
Kim comes to PWSA (USA) with 20-plus years of Prader-Willi syndrome career experience. This included roles of increasing responsibility in residential support and behavioral counseling as Clinical Coordinator at Prader-Willi Homes of Oconomowoc. She holds a bachelor's degree in psychology and sociology and a master's degree in multi-disciplinary human services. Kim has also been an active participant in PWSA of Wisconsin and has led the coordination of the Youth and Adult Program (YAP) at PWSA (USA)'s biennial national convention.

PWSA (USA) CEO, Steve Queior, remarked, "Kim's unique expertise and experience, along with her passion and commitment to the organization's mission to enhance the quality of life and empower those affected by PWS, makes her a great addition to our professional staff."

Born and raised in Wisconsin and an animal lover, Kim owns two horses, two dogs and a cat. She is a Walt Disney fanatic and frequently visits Walt Disney World with her husband and teenage daughter.

Please join us in welcoming Kim; we are thrilled to have Ms. Tula join our PWSA (USA) staff. ■

Behavior Management Strategies that Work (DVD)



(2015) Presented by Lisa Graziano, MA. Parents of the toddler or younger child will learn how to create a foundation that encourages cooperative interactions throughout the lifetime. Parents and care providers of the older child, teen, or adult will learn strategies that can improve the flow of the day and everyone's overall quality of life. No matter what your relationship with the individual with PWS, the information provided in this DVD will be immediately beneficial. $30.00 To purchase: shop on our PWSA (USA) online store at: http://bit.ly/2IfPWlRPWS_BehaviorMgt_DVD ■

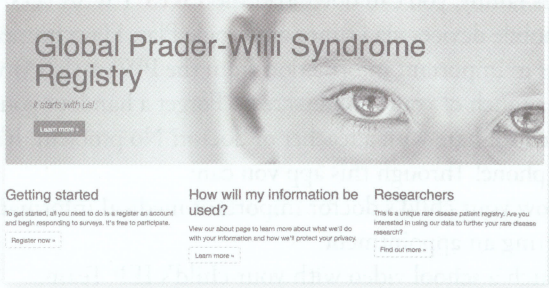
Especially for parents, extended family, babysitters, and all care providers

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



4-yr-old Soha, with mother Sabika

Visit:
https://www.pwsausa.org/membership/
http://bit.ly/2zNEb1C_PWSAusa



Every Person Matters

Global Prader-Willi Syndrome Registry

You can advance PWS research by providing researchers with comprehensive, accurate, and research-ready data. Whether your loved one with PWS is 2, 15 or 52, we need they are ALL included to provide a complete picture of the PWS community.

Please build the Global Prader-Willi Syndrome Registry by visiting www.pwsregistry.org. ■

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

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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Sarasota, Florida 34238
800-926-4797 ~ 941-312-0400 ~ Fax 941-312-0142
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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

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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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If this mark looks familiar, it's because it's one of the icons represented in our Five Pillars of Support. *By definition,* ad·vo·ca·cy /ˈadvəkəsē : *the act or process of supporting a cause or proposal : the act or process of advocating something*

Advocacy is the theme in this issue. Topics vary but these voices are the heart and passion of our organization represented in many ways. Which one sounds like your voice? Look for this mark representing voices enhancing the life of someone with Prader-Willi syndrome. Join the chorus and advocate for those with PWS. ■

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.

CAREPWS

levō

www.levotx.com/care-pws

www.clinicaltrials.gov - NCT03649477



https://www.pwsausa.org/2019-pwsa-usa-national-convention/

In this Issue

2019 Convention Global Assessments 2
PATH for PWS Study 4
Corporate Sponsors 5
Adults with PWS Advisory Board 6
Family Support 7
PWS Awareness Month 9
News You Can Use 12

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