

# The Gathered View

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

## Multiple Drugs Trials to Treat Hyperphagia May Begin Soon

By Rob Lutz, Board of Directors, PWSA (USA)

It is an exciting time for drug development for Prader-Willi syndrome! Trials for several drugs that may treat behaviors related to hyperphagia (excessive hunger) are anticipated to begin soon. Before we get too excited, we should keep in mind drugs can fail these tests; while they are not "cures" of Prader-Willi syndrome – they could improve behavior which is extremely important to the quality of life for individuals with PWS and their families.

To determine if these drugs are successful, the companies that own them run clinical trials. Simply stated, clinical trials are carefully managed and regulated studies using volunteer participants. The results of such clinical trials are used by the Food and Drug Administration (FDA) to determine if a drug is both safe and effective to be used and prescribed by doctors. The illustration below (provided with

continued on page 2

## Fiona Raises Awareness and Research Funds to Honor Cousin

Having a Bat Mitzvah is a very special time in a young woman's life and the preparation includes



Brandon with Fiona

choosing a project that will make the world a better place.

continued on page 2

## An Uphill Battle

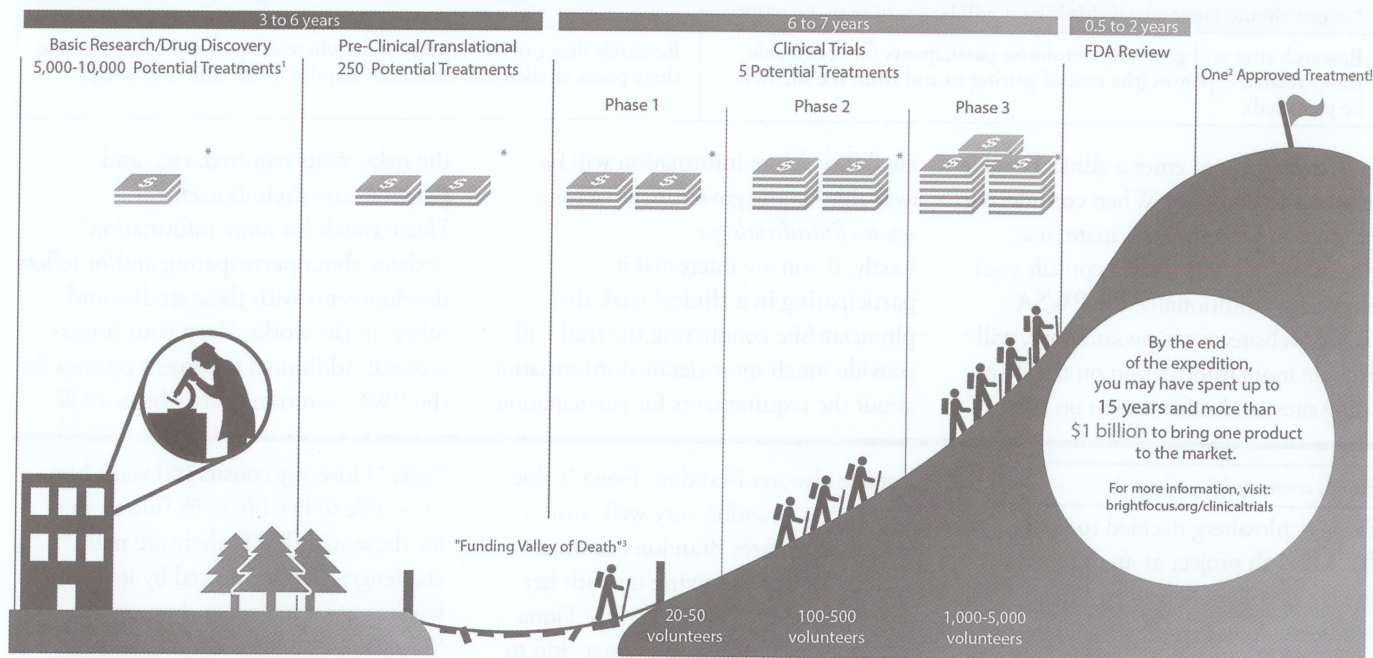
Imagine leading an expedition where every step is more difficult than the last...

The long journey begins in the lab, where scientists spend years testing thousands of ideas. Next, crossing the so-called "Funding Valley of Death" requires the resources and time needed to complete clinical trials, testing safety and effectiveness among what could end up being thousands of volunteers. At the end of this steep financial and scientific climb: Food and Drug Administration approval for a new treatment. Ultimately, it may have taken up to 15 years and more than \$1 billion to bring this treatment to the market.



**BrightFocus<sup>™</sup> Foundation**

Cure in Mind. Cure in Sight.



<sup>1</sup> Although we are using the word "treatment," clinical trials also involve medical research studies in which people participate as volunteers to test new methods of prevention, screening, and diagnosis of disease.

<sup>2</sup> After approval, the product is manufactured for sale on the market, and the process enters Phase 4 (Post-Marketing Monitoring/Clinical Trials). At this point, the FDA monitors for public safety and adverse events, and the sponsor company may begin Phase 4 Clinical Trials to obtain information about long-term effects or to test the product in special patient populations.

<sup>3</sup> The "Funding Valley of Death" is the financial challenge many promising treatments face in having the opportunity to be scientifically tested in a clinical trial. In many cases, further financial support or partnerships are necessary to proceed.

\* The cost of bringing a drug to market depends on a number of variables, but could be more than \$1 billion, including approximately \$50-\$40 million for Basic Research/Drug Development and Pre-Clinical/Translational research, and approximately \$50-\$70 million to complete all three Phases of the Clinical Trials.

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## PWSA (USA) Medical and Research View – Making a Difference!

### Drug Trials, continued from page 1

permission by the BrightFocus Foundation) depicts the journey of how drugs are developed, including the costs and number of patients required at every stage.

What's most exciting? There could be five drugs starting either a Phase 2 or Phase 3 clinical trial testing in 2018!

For the PWS community, the challenge is that each of these trials will require a number of individuals with PWS to enroll. Each Phase 2 or Phase 3 trial could require between 30 to over 100 participants. It is estimated that 500 individuals with PWS will be needed to complete these trials. Therefore, the more PWS participants that are willing

and able to enroll, the faster we'll know if any of these drugs are safe and effective, allowing them to be made available for the entire community.

Clinical trials have potential risks and require effort; participation is not a fit for everyone. The table shown below summarizes both potential benefits and potential risks of entering a clinical trial.

Potential Benefits	Potential Risks
Immediate access to a new, potentially effective treatment during the trial phase.	The new drug may not work. Normally some participants in a trial may receive a placebo treatment (sugar pill or saline injection) that will not have any effect (this is done so the trial can provide evidence of the true effect of the active drug).
You help others. By helping pharmaceutical companies, they can obtain the trial data needed to evaluate the drug in question (which could lead to FDA approval for the drug).	Potential for participants to experience unwanted adverse reactions or side effects (including death).
Even if the drug fails to do what it was hypothesized to do, it provides important information that can guide researchers toward other potentially more rewarding approaches.	Clinical trials can require significant effort. They usually involve repeated visits to the doctor (sometimes in a short time frame) and those visits may be more lengthy than usual. This inconvenience can interfere with common daily commitments and routines for the participant and their caregivers.
Typically the drug cost, medical professional fees, and costs of all medical tests are provided free of charge. No insurance is necessary.  Sometimes research sites will provide participants with a modest stipend (i.e., money) for participating in their trials, solely designed to cover costs.  No one should enter a trial thinking it will be a way to make money.	There are sometimes limits to the amount of reimbursement provided by a pharmaceutical company (by law). Participants can experience out of pocket expenses that are not reimbursed.  No one should enter a trial thinking it will be a way to make money.
Research sites will generally reimburse participants for reasonable travel-related expenses (the cost of getting to and from the site may be provided).	Research sites can be far away from where the person lives or getting there poses challenges. Travel can require much time and energy.

The decision to enter a clinical trial is serious and complex. When considering whether to (or not) participate in a clinical trial, remember to consult your physician. Additionally, the PWSA (USA) website, [www.pwsausa.org](http://www.pwsausa.org), will provide more information on the drugs, study sites, and information on trial

eligibility. More information will be available via the government website [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

Lastly, if you are interested in participating in a clinical trial, the physician/site conducting the trial will provide much more detailed information about the requirements for participation,

the risks, visits required, etc., and potential costs/reimbursement. Please watch for more information/updates about participating and/or follow developments with these studies and others in the works. Keep your fingers crossed! Additional treatment options for the PWS community may be near! ■

### Fiona, continued from page 1

Fiona Schlossberg decided to use her Bat Mitzvah project as an opportunity to help families affected by Prader-Willi syndrome.

Fiona was inspired to help those with PWS because of her younger cousin. Brandon, age 11, has PWS. She has a very special and close relationship with him and has always made extra efforts to care for him. She sees his struggles

but she also sees Brandon. Fiona is able to relate to Brandon very well, almost intuitively, shares Brandon's mother, Helene Dahan. Growing up with her sister Rachel, and their cousins, Fiona naturally and easily relates on a "kid to kid" level with Brandon, understanding the anxieties and struggles of growing up, and empathizes very well with his challenges.

As Fiona relates from her FirstGiving

Page: "I love my cousin and want him to be able to live life to its fullest. But for those with PWS, there are many challenges. Those affected by it always feel hungry, even when they are not. Since they also have low muscle tone, they are prone to obesity and related health risks. Also, if they binge eat, their thin abdominal walls could break, making the situation life threatening.

*continued on page 3*



**AWARENESS**



**FAMILY SUPPORT**



**RESEARCH**



**EDUCATION**



**ADVOCACY**

In this column, my first *CEO View* for our newsletter, let me say what an honor it is to have been named by the Board of Directors as the professional staff leader for this great association. Let me also share some thoughts about our “heart” and philosophy, which provide the foundation for how we work together for shared goals:

**We are Driven by Key Values:**

Including providing hope and support for people living with PWS, their families, and the professionals who serve them. We strive to assist families every step of the way, offering information and resources for new diagnosis, school assistance, behavior management, and more. We believe that PWSA (USA) is an important lifeline for individuals and families across the country.

**We are Inclusive and Holistic in Our Approach:**

PWSA (USA) is a community that welcomes all, one that is committed to ensuring the well-being of the whole person; PWS doesn't just affect one aspect of life, so PWSA (USA) doesn't narrow its focus to just one issue. PWSA (USA) is a collaboration of families, individuals, researchers, healthcare practitioners, and professionals, working together as a team.

**We are Saving and Transforming Lives, Together:**

We work hand-in-hand with individuals, families, medical and research professionals, education specialists, organizations, and associations to facilitate research, to spread awareness, to advocate, and to educate. Sharing the concerns and challenges of the PWS community with the “outside world,” and forming strategic alliances with other PWS and rare genetic disease-focused individuals and organizations removes barriers and unleashes the transformative power of collaboration.

**We are People with Passion and Purpose – Donors & Volunteers:**

With support from our volunteers and donors, we have created and expanded

programs for parents of newly diagnosed children, deployed life-changing family support programs, funded cutting-edge research, and provided training and information to school professionals, residential providers, and healthcare providers from across the country.

PWSA (USA) channels its supporters' passion and dedication into substantive, meaningful measures that really do **save and transform lives**. Day-to-day efforts and progress fall into the critical areas that follow:

**The Importance of Each of the Five Pillars of Support**

**Awareness** - Awareness is the precursor to action. It is imperative to gain attention for PWS in order to facilitate conversation about our community and our needs. Spreading the message of who we are and what we do, and educating others about PWS and its challenges, are two of our most fundamental tasks.

**Family Support** - PWSA (USA)'s targeted programs dealing with behavior modification, nutrition education, crisis intervention, education advocacy, guardianship, and medical intervention are an important lifeline to our families. Last year, our staff team handled over 2,370 family crisis and medical activities, and provided staff and material support to hundreds of families.

**Research** - PWSA (USA) has been supporting research since 1983. Many of the world's most renowned PWS researchers and clinicians are on our scientific and clinical advisory boards; together they dedicate thousands of hours yearly. The synergy between our advisory boards and research committee is magnified by our collaboration with other PWS and rare disease researchers and research organizations.

**Education** - This broad arena of activity encompasses informing the public; familiarizing medical providers

and school professionals with the needs of the PWS community; and providing parents and caregivers with information to enable them to meet the needs of their loved one with PWS.

**Advocacy** - In order to enhance the quality of life of those affected by Prader-Willi syndrome, we must inform the PWS community of critical public policy issues and leverage the power of grass roots supporters and state chapters. Because many do not know about PWS and its impacts, extra strategic effort is needed to pass legislation, budgets, and regulations that help our cause, and to, of course, defeat proposed laws, budgets, and rules detrimental to our community.

Your support is vital, so we sincerely thank you.

Your continued support for PWSA (USA) is so important. Every donation and every minute spent volunteering or advocating on our behalf has a meaningful impact on the lives of individuals with PWS and their families. Without you, PWSA (USA) would be unable to provide the comprehensive and crucial programs the PWS community needs.

Thank you for all the different ways you support our cause, because, together, we are **Saving and Transforming Lives**.

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**Fiona, continued from page 2**

PWSA (USA) supports research and awareness for PWS, which are two important things that we need to do.”

*Note:* Fiona's Bat Mitzvah was in November. Her project raised more than \$8,000 and continues to raise money to honor her cousin Brandon. Visit Fiona's FirstGiving page: <http://bit.ly/2nPrYAtFionaPWSAUSA> and watch her video.

Mazel Tov Fiona, on your Bat Mitzvah, and continued successes to you, and cousin Brandon. ■

Journal Article:

## Research Describes Swallowing Problems in Infants with PWS

**Silent aspiration in infants with Prader-Willi syndrome identified by videofluoroscopic swallow study**

*Parisa Salehi, MD, Holly J. Stafford, DNP, ARNP, Robin P. Glass, MS, OTR/L, IBCLC, Anne Leavitt, MD, Anita E. Beck, MD, PhD, Amber McAfee, ARNP, Lusine Ambartsumyan, MD, Maida Chen, MD*  
*Medicine (2017) 96:50(e9256)*

Everyone has experienced the sensation of something “going down the wrong pipe.” When this happens, we cough it out automatically. **Aspiration** is the medical term for this type of choking – food or liquid enters the windpipe (trachea) instead of going down the throat (esophagus) to the stomach. If the body cannot detect this wrong way path, the cough reflex will not help clear the airways and infection and damage can occur in the lungs.

Dr. Salehi presented new information about this problem at the PWSA (USA) Medical & Scientific Conference in November 2017 just before it was published in the journal *Medicine*. It is the first study of swallowing in infants with PWS. In 2016, Dr. Gross and her team published their study in individuals from age four years to 55 years which revealed high rates of aspiration. This was published in *The Gathered View*, Volume 42, Number 1, January-February 2017.

Dr. Salehi’s team at Seattle Children’s Hospital reviewed the records of children with PWS to identify babies who had been tested with a swallowing study called videofluoroscopy. Most of these studies were done after 2012. Ten infants with PWS had been evaluated with this special test; some babies were tested several times, which resulted in a total of 23 studies. These children were 3 weeks to 29 months of age. This test was performed on these children due to a variety of feeding, choking, or respiratory problems.

The children had a typical range of feeding abilities for children with PWS, with two children fully fed by mouth, 12 feeding by tube only, and nine children feeding by both mouth and tube. Half of the children were on growth hormone at the time of the testing. In this small study, there was no difference in the results in the children who were on GH. There were also no differences in the

genetic subtype of PWS.

During videofluoroscopy, there were no outward signs that the babies were having trouble swallowing, such as coughing or choking. However, 87% of the tests showed aspiration – liquid misdirected down the windpipe instead of going down the throat. Due to the lack of outward signs this is called “silent aspiration” but is just as damaging to the lungs. Thin liquids were the most likely to be aspirated, and purees the least. In addition, swallowing was incomplete, with some of the feeding remaining in the back of the mouth (pharynx) in 71% of the tests.

It is not known if all infants have abnormal swallowing. The researchers looked only at babies who had been tested, and all of them were suspected of having a problem. The next step would be to test many babies who do not have feeding or breathing problems, to see if they also have hidden aspiration or do not swallow normally. Dr. Salehi’s team took the first step needed to bring awareness. In 2017, many infants are routinely tested, and we look forward to additional research about all babies with PWS, and how to keep them safe and healthy. ■

*Written by Kathy Clark, RN, MSN, BC-CS, Coordinator of Medical Affairs for PWSA (USA), reviewed and approved by Parisa Salehi, M.D.*

## Advocacy News

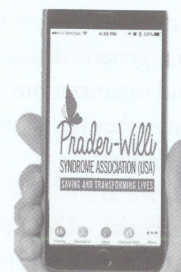
On January 22, 2018, the U.S. Congress voted to extend funding for the Children’s Health Insurance Program (CHIP) for six years. CHIP is a critical program that provides nine million children and pregnant women from across the United States with comprehensive and affordable healthcare coverage. With approximately 50% of individuals with rare diseases being children, CHIP is especially important to the rare disease community. A huge thank you to all the advocates that used their voices to #SAVECHIP! ■

~ Provided by NORD

## Access PWSA (USA) via App

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

Thanks to the Settles family, enjoy freedom to browse any and all information on our website via the ease of a free app available (link above) on all mobile devices via iTunes or Google Play. ■



# The PWSA (USA) 2017 Medical and Scientific Conference, Part II

The first half of this listing was provided in the last issue of *The Gathered View*.

Chaired by Merlin G. Butler, MD, PhD and coordinated by Ann Manzardo, PhD, both from the University of Kansas Medical Center.

**Von Economo Neurons (VENs) in the Prader-Willi Syndrome (PWS) Brain-** Janice Forster, Pittsburgh Partnership – By studying donated brains, this research found differences in the number, shape and distribution of these neurons (VENS) in the brains of persons with PWS, which may contribute to the nutritional stages and behavioral phenotype.

**Adverse effects of N-Acetyl Cysteine (NAC) Treatment of Excoriation (Skin Picking) Disorder in Prader-Willi Syndrome (PWS)** - Nicolette Weisensel, Prader-Willi Homes of Oconomowoc - Six persons, already on psychiatric medications for other diagnoses, experienced increased anxiety, worsening behaviors and moods when given NAC to treat picking which required 5-6 months to return to baseline behaviors.

**Potential Benefit of GLWL-01 Plasma AG Lowering in Patients with Prader-Willi Syndrome** - Amparo del la Pena, Eli Lilly and Company - A discussion and background information on ghrelin which plays a role in hunger. A clinical study is being designed to target ghrelin in PWS.

**Silent Aspiration in Infants with Prader-Willi Syndrome Identified by Videofluoroscopic Swallow Study** - Parisa Salehi, Seattle Children's Hospital - Swallowing study of infants demonstrated abnormalities that may lead to aspiration into the lungs but without symptoms. This underscores the need for swallowing studies in our youngest population, particularly when sleep abnormalities are present.

**Pharmacogenetic Testing in Psychiatry - CYP450** - Timothy Dellenbaugh, University of Missouri - Kansas City School of Medicine - The one hour presentation described how this testing may be used in clinical practice with limitations based on current knowledge. A more in-depth article will be provided in the future on this important topic often referred to as personalized medicine.

**Analysis of Maternal and Fetal Outcomes in PWS: Multicenter Study** - R. Mahmoud, University of California, Irvine - Description of high rates for caesarean section, preterm delivery and low birth weight in a review of 355 individuals with PWS from the NIH rare disease consortium.

**Hyperinsulinemia Promotes Early Weight Gain in Prader-Willi Syndrome** - Frederick Kweh, University of Florida College of Medicine - Evidence of increased insulin production in toddlers with PWS without a change in diet, which may help explain nutritional phases.

**Catatonia and Neuroleptic Malignant Syndrome (NMS) in Prader-Willi Syndrome** - Janice Forster, Pittsburgh Partnership - Four case examples of these rare psychiatric problems were discussed in PWS.

**Exploring the Gut Microbiome as a Therapeutic Target in Children with PWS** - Andrea Haqq, University of Alberta - Description and rationale for an ongoing series of studies in PWS using stool collections and probiotic supplements. The microbiome of the gut is known to affect weight and metabolism, but more needs to be done to understand whether it plays a role in PWS.

## Effect of Diet

**Composition on Lean Body Mass and Metabolic Status in Children with Prader-Willi Syndrome: A Randomized Controlled Trial** - Krista Viau, University of Utah - A 16-week study was described comparing two different diets in 13 individuals, the RedYellowGreen diet and a high protein, modified carbohydrate diet.

**Results of a Phase 2 Study of the Melanocortin (MC)-4 Receptor (R) Agonist Setmelanotide (SET) in Prader-Willi Syndrome** - Fred Fiedorek, Rhythm Pharmaceuticals - Despite early promise, this compound did not result in positive outcomes for individuals with PWS for either weight control or hyperphagia. The number of subjects studied was relatively small regarding a clinical trial.

**The Global Prader-Willi Syndrome Registry: Overview, Early Data, and Development** - Jessica Bohonowych, Global PWS Registry - This PWS Registry continues to provide data for clinicians and researchers for analysis. There are currently 1100 individuals enrolled.

**Survival Trends in Prader-Willi Syndrome in Relationship to Cause of Death and Historical Time Frame** - Ann Manzardo, University of Kansas - Discussion of data from 425 deaths between 1973-2015 and how the cause of death has changed over time. Early diagnosis, weight control, and improved health care have increased lifespan, but lower body weight and increased mobility may enhance the ability for young men to seek food in dangerous ways leading to accidents.

Once published in medical journals, we will present findings for parents and others interested in PWS in a future issue of *The Gathered View*. ■

~ By Kathy Clark, RN, MSN CS-BC, Coordinator of Medical Affairs, PWSA (USA); Reviewed by Merlin Butler, MD, and Ann Manzardo, PhD

## Evaluating Injuries Resulting from a Fall

By Barb Dorn, RN, BSN, Kate Beaver, MSW, CSW, Crisis and Family Support Counselor PWSA (USA) and Sharon Christman

We all fall – young and old. Because of an altered pain response and low bone density, persons with Prader-Willi syndrome (PWS) of all ages may sustain a more serious injury when a fall occurs. Many people with PWS are at greater risk of falling due to poor muscle tone, poor motor planning and decreased physical activity. Those who wear bifocals may also experience difficulty in judging depth perception. Some medications can alter balance. And, individuals who hoard often have environments where there are unsafe walking spaces.

Diagnosing the severity of the injury can be challenging. **When a person with PWS falls, he/she should be closely evaluated at the time of injury and every four hours for the first 24 hours.** If the person is complaining of severe or moderate pain or if any deformity of the area can be seen, he/she should be evaluated immediately by a health care professional. A fracture may not be visible to the naked eye. No one can accurately rule out a fracture without an x-ray. The challenge takes place when the person's complaint of pain is not severe and there is no obvious abnormality seen. Most persons with PWS are not able to accurately share the severity of their pain. Persistent complaints of any discomfort makes the need for a medical evaluation and imaging critical. It is important to take the complaints of discomfort seriously. Parents and caregivers must inform and educate the health care professional on the unique health issues seen in persons with PWS. They can utilize medical information disseminated by PWSA (USA) including their Medical Alert booklet, the PWSA (USA) app (see info on page 4), website: [www.pwsausa.org](http://www.pwsausa.org), as well as a popular website - "Up to Date" used by many health care professionals. At times, advocates must also politely yet firmly "request" that an x-ray be taken.

Because of their unique health issues, persons with PWS offer everyone a challenge in evaluating pain/discomfort and potentially serious injuries sustained in a fall. Prompt evaluation and a thorough workup, including x-ray imaging of these issues, will help to quickly identify problems and expedite proper treatment.

Here are some stories of persons with PWS who sustained serious injuries from a fall. ■

*It is important  
to take the  
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seriously.*



**CASE 1:** Tony is a 32-year-old young man who tripped and fell on an evening walk. He fell forward and landed on both hands and knees. He was able to get up immediately. A scrape was noted on his right knee and he complained of some discomfort in his knee, right elbow and his left foot. His pain was

not severe. Staff contacted his parents and they agreed to continue to monitor his injuries. If pain persisted, he would be evaluated by a health care professional in the morning. Tony's complaints continued. He was taken to the local Emergency Department. X-rays were taken of his right elbow and knee along with his left foot. Tony was diagnosed with a fractured elbow and placed in a splint. He was to follow up with an orthopedic specialist within the next 48 hours. Tony's parents took him home and made arrangements for him to be seen. Soon after his arrival home, his mother noticed that Tony was unable to rotate and turn over his left hand. She contacted the doctor and asked to have his left elbow x-rayed as well. The doctor agreed and Tony was diagnosed with a second fracture – both elbows were broken – both were cracked and not displaced. After several weeks of tender loving care (and lots of help in many personal care areas), Tony completely recovered from his injuries. ■



**CASE 2:** Amanda is a 40-year-old woman who fell down stairs in her home while in an agitated state. She immediately complained of left ankle pain and it quickly swelled. She was taken to an Urgent Care clinic and evaluated by a health care professional. An x-ray of her ankle diagnosed a fracture. She was advised to be seen by an orthopedic specialist within 24 hours. She was placed in an air boot for three weeks. Her pain and discomfort was managed well with acetaminophen and ice. Amanda completely recovered from her injury. ■

## Development / Fundraising / Events

Whether it's an **On the Move** walk or run, a Create Your Own FUNdraiser, or an online fundraising page (Donate your birthday or other big day to PWSA (USA)!), raising awareness and support for the PWS community is FUN for everyone!

**Check out these great FUNdraisers from across the PWS community:**

**The 4<sup>th</sup> Annual Clint Hurdle Hot Stove Dinner** on March 23, 2018 in Bradenton, Florida. This fun, family-friendly event features food, music, a silent auction, and of course, a chance to meet Clint Hurdle, manager of the Pittsburgh Pirates. For information about sponsorship, donating, or purchasing tickets, please contact Rikka Bos at [rbos@pwsausa.org](mailto:rbos@pwsausa.org).

**PWSA (USA) Alabama** will host its first **Spring Fling** on April 14, 2018 in Birmingham. In addition to a healthy dinner, there will be music, fun and games for the kids. The event is free. If you need assistance with a hotel room for the evening, or would like more information about the event, please contact Brittnee Peterson at [brittneepeterson8009@gmail.com](mailto:brittneepeterson8009@gmail.com).

**The 9<sup>th</sup> Annual Hunter Lens Golf Outing** will be held June 2, 2018 in Lakeville, Massachusetts. Last year the event raised over \$30,000 to help promote and fund research, education, and support for those affected by PWS. The event features 18 holes of golf, dinner, a raffle and a silent auction. For more information about supporting the event or participating, please contact John Lens at [jlens@comcast.net](mailto:jlens@comcast.net).

### On the Move Walks Across the Country

**Wisconsin** will host its 8<sup>th</sup> annual **On the Move** Walk on May 12, 2018 in Oconomowoc, Wisconsin. For more information or to register, please visit [www.pwsaofwi.org/](http://www.pwsaofwi.org/) events.

**Prader-Willi Florida Association** will host its annual **On the Move** Walk and **Family Fun Day** on May 19, 2018 at Bill Frederick Park at Turkey Lake, 3401 Hiawassee Road, Orlando, Florida. Meet at Pavilion 5 by 9:30am. Walk begins at 10:00am. Secure your Walk sponsors with your own Fundraising page. <http://bit.ly/2C8WWx1OnTheMoveFlorida>

Note: \$4.00 admission fee per carload to enter the park.

Accommodations info: 36 RV sites available at park; hotel: Comfort Suites Universal Orlando, 407-363-1967 code: Prader-Willi Florida Association. For more information, please contact Deb Peaton at [debpeaton@gmail.com](mailto:debpeaton@gmail.com).

**Michigan** will host its annual **On the Move** walk on June 9, 2018 in Jackson, Michigan. For more information, please contact Dewey Graves at [dewey.graves@gmail.com](mailto:dewey.graves@gmail.com). ■

Falls, continued from page 6

**CASE 3:** Hana is a 31-year-old female who fell on her left hip while participating in a running exercise. She was not able to stand for five minutes, but was encouraged to walk to a chair and rest. Hana continued to have pain in her hip and knee after returning to her group home where she was given Tylenol and ice. The next morning she was evaluated by the Nurse Practitioner and deemed to have a bruised muscle. Hana showed no bruising, but had a knot on her knee and continued to complain of pain. Parents picked her up that afternoon and took her to their private physician where her hip and knee were x-rayed. Hana was diagnosed with a fractured hip. Within 24 hours Hana underwent surgery for three pins in her hip. After six weeks of no weight bearing, Hana returned to her group home with light activity for an additional three months. ■



### Call for Submissions

We love hearing from our *Gathered View* readers!

A number of us have noticed that several children with PWS have great relationships with their pets. Some have a passion for music like playing an instrument, singing, or performing! We have great articles in the works and appreciate your feedback on topics our readers enjoy.

Whose child has a particular hobby, talent or gift - whether it is drawing, painting, going fishing, swimming, riding a bike, solving puzzles, playing board games, taking photos, or other activity? Or writing poetry?

Has someone recently achieved a milestone or received a recognition?

Do you have a funny little "life moment" that you believe other parents could relate? We bet you DO!

We would love to hear from you and publish your submission. Don't wait! Deadlines for submissions are the first of each month.

Please contact us at: [editor@pwsausa.org](mailto:editor@pwsausa.org). We will be sure to follow up with you.

Thank you!  
The Editor



## Balance: the Importance of Receiving a Diploma on Time with Continuing Special Education Services

One of the major questions we receive from parents is about their children graduating from high school at 18 with either a certificate or a diploma. This is a question that each family needs to consider carefully.

Generally, the right to special education ends when the student “ages out” or when a student graduates. Usually a student “ages out” of special education entitlement when the student turns 22, though in some states they terminate all education services at an earlier age where the student might age out at an age younger than 22. But, some states have also gone so far as to pass laws that allow those educational supports until the child reaches their 25<sup>th</sup> birthday. Be sure and ask your school district the age your state has set.

Federal law under IDEA allows students to stay in the educational system until their 21<sup>st</sup> birthday. State and local law can allow greater educational opportunities, but they cannot provide less than Federal law allows.

**Special education services may stop the moment your student receives a signed high school diploma,** even if your student has not made adequate progress on his or her post-secondary goals in the (IEP) Individualized Educational Plan. Since the right to a FAPE (Free Appropriate Public Education) ends at graduation, transition services can end at that time too. Parents and students (under the age of 22) may want to continue to work towards the IEP goals after the student's class has graduated.

With so many of our children falling within a wide spectrum of abilities, this question becomes even more important. For children who fall on the higher

spectrum of learning, some parents are considering having their child graduate with their class at 18 with a regular education diploma. But remember, once your child graduates they may no longer be entitled to special education support from the school or vocational support. Receiving a diploma can be looked at as to whether or not your child has reached their educational goals that are outlined in their IEP.

If you decide that your child needs more services and they stay in the school system, even though your child has not received a diploma, the IEP will not necessarily force him or her to stay in a high school setting. He or she has options outside of high school as he or she approaches age 22. For example, as long as an IEP is active, it can include community-based activities. The IEP can also include classes with supports, coaches, and services if necessary (based on the student's needs) at a local post-secondary school (usually a community college).

Some states are now putting into place IEPs that have more realistic goals in order to satisfy the requirement for a certificate, but once the child receives the certificate, again they may not be eligible for educational supports.

### Delaying and Opposing Graduation

The expected graduated date in the IEP is the day that your student will graduate unless you change that date. Schools may choose a date based on your student's class year instead of based on the IEP goals. You must pay close attention to that date on the IEP. Signing off on an IEP when you disagree with the expected graduation date can cause problems. In fact, you may not be able to extend services

beyond the listed graduation date. Do not wait until the last minute. If the IEP Team does not agree, reject the section of the IEP that lists the date. By rejecting only the graduation date, you show that you agree with the services, but do not believe your student will be ready to graduate by that date.

*Persuading the school that your student may not be ready to graduate is difficult. The school has a mandate to provide every student with access to the general education curriculum (meaning, they must follow the state's educational curriculum), so it's not enough to say that you don't care if he learns geometry or not and that you'd rather he be in a woodworking program. Signed letters and forms tell the best story. Put together a binder of important papers that show the skills your child still needs to learn. It is likely the need for social skills, self-management, decision-making, and concrete vocational skills are a great need for your child. Bring the binder to Team meetings. You may need the help of an advocate.*

### Participating in Graduation Ceremonies Without Receiving a Diploma

If your student is not ready to graduate after completing the 12<sup>th</sup> grade, he or she should be able to participate fully in graduation ceremonies and related school activities. This option is called “social graduation.” Your student may be able to celebrate and walk with the rest of his or her class, even if he or she does not receive a diploma at that time.

Your student will continue to receive special education services until he or she receives a diploma or turns 22 years old or the age your state has adopted. Your student is not required

*continued on page 9*

### Life with Nikki

*Sara Dwyer, Editor, PWSA (USA) as shared by Lauren Burns-Evans*

My older sister Nikki, age 43, has PWS. PWS has ravaged our family for a lifetime, but I wouldn't ever change her.

Life changed about 10 years ago when I left a career in New York to come home to Delaware. When Nikki's long-time caregiver was unable to continue, I happily moved into the home our parents purchased for her and took over as caregiver. With life adjustments: living arrangements, jobs, a wedding, moves to the beach over the next five years, we now have a good routine that works. Several weeks a month Nikki lives with me, my husband Tommy, and our five-year-old daughter Katy. Then a week (or two) a month, she lives with our retired parents Larry and Suzanne Burns.

Nikki's kind spirit, gentle existence and desire to make everyone she meets a friend, is what makes Nikki a joy and treasure to our lives. I don't think a single child has ever passed my sister's path without receiving a compliment on their beauty, kindness or smile!

Despite years of *valiant* efforts, Nikki was "officially diagnosed" at age 25. Nikki was tested three times for PWS with the FISH test. Decades later, further genetic testing with both parents in the DNA methylation test and the UPD test occurred. An occupational therapist recently graduated from college raised a curious question; thus my parents insisted further tests occur. Back then many state resources were limited. The love, tenacity, skill, patience and determination levels of our parents were exhausting, but diligence paid off even during the unknowing years. Nikki was never labeled "disabled" and was lovingly pushed to succeed from birth to be and do the best she possibly could every day with much help from parents, specialists, doctors, therapists, tutors, teachers and a huge family of support.

#### About Nikki

In 2011, we (my parents, Nikki and I) arrived at the PWSA (USA) convention. While checking in, Nikki saw a baby and immediately went over and *knew*; somehow she knew (even before the convention opened) this child had PWS.



*Left to right: parents Larry and Suzanne, Katy, Nikki and Lauren*

Nikki said: "I cannot take my eyes off that baby." *She knew and she HAD to meet and hold her!* The convention was wonderful and left me with a HUGE sense of humility – that I would NEVER complain about PWS again. I was grateful for who Nikki was AND for all the incredible milestones we endured. She was a miracle all on her own and I recognized it for the very first time.

#### What does Nikki give me?

**Energy.** She is a superstar in everything she attempts.

**Empathy.** Her compassion and perception of the world is limitless.

*continued on page 10*

#### Balance, continued from page 8

to participate in the graduation ceremonies if he or she does not want to. The IEP Team should consider whether participating in the ceremonies and activities is a good choice.

The right to participate in a "social graduation" is protected by some state laws. Check to see what the law is in your state. Students must have excellent attendance, be in good standing at school, and be unable to pass the standard State Comprehensive Assessment Test. If a school attempts to prevent your student from participating in graduation ceremonies, you should write a letter to the school.

In the letter, you should state that your student wants to participate in the graduation proceedings and has a right to do so with his or her classmates. If the school refuses, ask for the refusal in writing and the reasons why they are refusing. "Planning for Life After Special Education" from the Disability Law Center, Inc.

Transition plans should be started by age 16 in order to build a plan of what the possibilities are after "graduation" and what they will look like. ■

*~ Submitted by Kate Beaver, MSW, CSW, Alterman Crisis Intervention and Family Support Counselor, PWSA (USA)*

#### Questions to Ask your School

Can my child walk with his class but not receive his diploma until later?

What is the transition plan for my child after his class graduates?

What will my child do after graduation?

Until what age can my child receive educational/vocational services from the school?

If my child does not receive his diploma with his class but continues on with vocational training can he still receive a diploma later? Or a certificate?

What is the difference for my child receiving a diploma or a certificate?

## Sibling View

Nikki, continued from page 9

**Love.** Nikki is very spiritual and in tune with her heart and soul. She gives freely and has no boundaries of how she gives or shares with everyone. Nikki is high-functioning, smart and creative. Our parents ensured she was mainstreamed into our schools. She excelled, graduating high school at the top of her class and also getting a driver's license.

### Does Nikki have challenges? Yes!

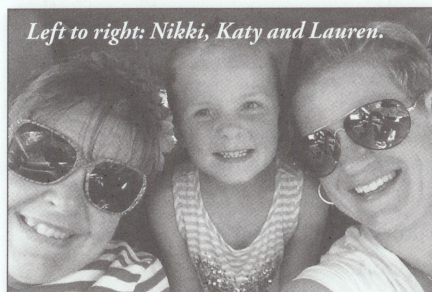
**Nikki can get bored.** Boredom usually leads to food seeking.

**Controlling her emotions** can be challenging at times. When Nikki has her feelings hurt, is overwhelmed by changes to her routine, or loose ends to a plan cause anxiety, she reverts to picking and has limited control over her actions. We've learned coping mechanisms to talk out what she's feeling and "let go" of the hurt or anxiety – both hers and ours – that weigh on her heart. Nothing is perfect, but we talk to make sure we are all doing the best we can and when we can't, we hold each other accountable and there is less damage control.

### Nikki's Companion

She has given PWS a persona: His name is Willi. On days when "I have no control over Willi" she knows she

can't "change" Willi, she'll ask us for more help. This persona also taught us there is more to Nikki than her PWS diagnosis. It allows all of us to see the parts of her that are Nikki and those parts or behaviors that are more related to PWS. "Willi" is spoken about freely in our homes and by every family member. Nikki isn't sneaking food from the fridge, Willi is. The understanding that follows is much greater when Nikki doesn't feel shamed for living in the body she was born in; there are no faults, just



Left to right: Nikki, Katy and Lauren.

acceptances. I am grateful for "Willi" so that I may adore my big sister.

Fellow caretakers and "parents" like me: love your PWS kids. Make friends with the nasty behaviors. Love them harder when things get messy. I didn't give birth to my "other child" but I love her as if I did. **Honor the disabled parts of them and the abled parts of them will radiate!** My sister proves it and at the end of the day, we are a proud,

*She has given  
PWS a persona:  
His name is Willi.*

connected family, full of love, hope, forgiveness and respect.

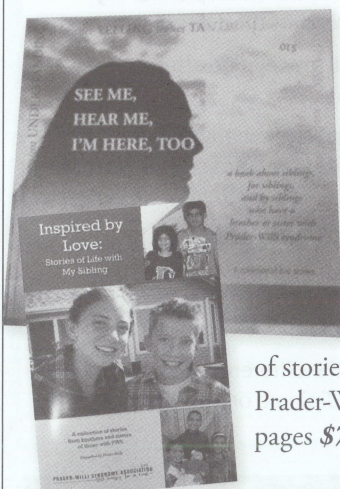
My sister is my life's greatest lesson to understanding love and **perfection is impossible, but perfect imperfection is completely lovable.** I am honored to love this soul. Blessed to have her love me and thrilled to be spending this life side by side!

### Sibling Alert

Hang in there. When you *accept the things you can not change* and you love with all your might, your sibling **WILL** be there for you! The bond **WILL** happen and the friendship you carry for a lifetime **WILL** be well worth the patience you had to have to build it!! You may always be the "bigger one" regardless of age or hierarchy, you may always be the lesson learner (gratefully) and you may always be the protector. That's ok because **it's worth it!!**

What God "takes away" from us or challenges us with, he fills other parts of us with gifts abound! ♥ ■

## Two Sibling Publications



### See Me, Hear Me, I'm Here, Too

(2006) Edited by Lota Mitchell and Nina Roberto - a book about siblings, for siblings, and by siblings who have a brother or sister with PWS. 76 pages. **\$15.00** ■ <http://bit.ly/2sYvuOQPWSsibling>

### Inspired by Love: Stories of Life with My Sibling

(2016) – A collection of stories from brothers and sisters of those with Prader-Willi syndrome compiled by Diane Seely. 20 pages **\$7.50** ■ <http://bit.ly/2GL9wRISiblingPWS>



We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more good work(s) like this. Please visit our website, [www.pwsausa.org](http://www.pwsausa.org)



# PWS Awareness

As editor of *The Gathered View*, I'm constantly looking for ideas, news items, and stories to place in the newsletter. Maintaining a balance of research along with human interest features keeps us all aware of the good this association does.

Until 2008 I had never heard of Prader-Willi syndrome (PWS). A dear friend in the Tampa area has a cousin in New York with PWS. Through the power of referrals and connections, I became the graphic designer for *The Gathered View*, working closely with then editor Lota Mitchell, and former medical director Janalee Heinemann. If you know either of the women, you know they walk on water (that's my opinion anyway). They and others have taught me so much – not only about the syndrome but also about the people and families that are impacted by PWS. And you NEVER know where the next story will appear.

Last August I visited a nail salon; anyone gutting two bathrooms in their home deserves a medal AND a manicure. A young girl, a bit flustered and prepping to have her senior picture taken, sat down next to me. We struck up a "normal" conversation – what school she attended (Ashley Hall), her busy schedule besides classes (dance and sports), plus making college plans for next year. Madison Whelpley was completely charming; I give credit to her parents, family and friends for raising such a wonderful person. I asked if I could offer a bit of advice after she commented she wasn't entirely sure of her major or chosen field/career. She nodded. I shared, "Whatever you do, you got to love it; it will show in your passion and purpose, you will be happy, and it will never feel like work." TRUTH.

Smiling, she asked me what I did. I shared that I own my own businesses (design studio and skincare company) and get to work with an incredible nonprofit organization that supports

children with a genetic birth defect. Madison asked which one. I replied: "It's rare, and it's called Prader-Willi syndrome."

Madison replied, "Oh, I've heard of that!" I replied, "REALLY?" She responded, "Yes, ma'am, I wrote a report and did a presentation on it when I was in ninth grade." (Their students have impeccable manners and social skills.)

Well, it was a good thing I was sitting down! Even the nail technicians were intrigued! The conversation continued on how this came to be.

Ashley Hall is a wonderful private school for young women in Charleston, South Carolina. Former First Lady Barbara Bush attended Ashley Hall. The seven Hallmarks of Ashley Hall are- Compassionate, Worldly, Creative, Intelligent, Collaborative, Discerning and Purposeful.

The math teacher at Ashley Hall, Nichole Carey, has a relative with the syndrome. During freshman year students present a report on a genetic disorder in Biology class on a topic they choose



*L to R: teacher Nichole Carey, student Madison Whelpley, Sara Dwyer (editor)*

or select from a list provided. Ninth grade students learn genetics from Allison Bowden and do the project in her class. Eleventh and twelfth grade students can take AP Biology from Meghan Ward, where they learn about PWS in more detail. There have been at LEAST 9-10 reports (estimated) on PWS



*Leah Bender (at age four months) loves her aunt, teacher Nichole Carey!*

by ninth graders.

I was invited onto their charming campus to interview Mrs. Carey and Madison. Nichole shared stories about her dear sister Jen Bender and daughter

Leah Bender, now age 6, with PWS. Madison spoke about her amazing school, teachers and courses.

Ashley Hall develops their students in many ways. One I recall fondly is their purposeful compassion of helping others. Example: they have a non-uniform "Jeans Day", when students are allowed to wear jeans in

exchange for a donation to a cause. Mrs. Carey names PWS as her chosen cause. She keeps a picture of her darling niece on her desk, shares "Leah stories" with faculty, staff and students, and collects donations for PWS.

I told them about PWSA (USA) research, family support and counseling. We even found the YouTube video of Mayim Bialik, one of my favorite PWS spokespersons (Mayim did her Ph.D. dissertation on PWS). I was ecstatic to be invited when the next student does a presentation on PWS in spring semester.

I have no doubt this school and its students have purpose; mine is to share this story, and remind YOU to **never stop sharing** and making others aware of PWS and this wonderful organization.

A week later, I met a colleague for coffee and catch-up. The conversation

*continued on page 12*

## PWSA-WI, Inc. Seventh Annual Snowflake Ball

*By Crystal Boser, President, PWSA-WI, Inc. & Mom to Kyle, age 22, with PWS*

On Saturday, January 27<sup>th</sup>, PWSA-WI, Inc. had the pleasure of hosting their Seventh Annual Snowflake Ball at the Watertown County Club in Watertown, Wisconsin. The venue was decorated with beautiful Christmas decorations highlighted with purple accents and snowflakes created personally by individuals with Prader-Willi syndrome. More than 235 guests dressed up and wore corsages or boutonnieres, all of which were captured during their personal photo opp with our professional photographer. Over 20 amazing volunteers helped serve a delicious sit-down dinner and a special toast was given by the organization's vice president, Jackie Mallow. Once everyone was finished with their meal, the real fun began... DANCING to fun music, provided by our new DJ Alex!! It truly was a magical evening and we are once again looking forward to the Snowflake Ball next year! ■

*Nancy Burlingame,  
grandson Kyle Page,  
Steve Burlingame*



*Siena Smith and Greysen Gaulke*



*Justice Rickenbach and Jett Lewis*

## Register now! PWS Sibling Camp April 13-15 in Texas

The first PWS Sibling Camp, Camp Blaze, is being held April 13-15th 2018 in Burton, Texas for siblings ages 10+ to come together for a very special weekend.

Camp Blaze Co-Directors (and PWS moms), Cheri Wood & Jennifer Arcaya, had a vision to further the mission of the Texas Prader-Willi Association (TXPWA), and created a community of support to organize a camp specifically for siblings of people with PWS, from

preteen to adults. Camp Blaze provides a safe place to share personal experiences in a group setting... all while having FUN!

Bring siblings together for an adventurous weekend full of new friendships, fun and laughter.

Camper Qualifications: ages 10+ and must have a sibling with Prader-Willi syndrome.

Registration is NOW Open! Visit [www.campblazetx.com](http://www.campblazetx.com) or contact us at

903-520-5178 for more information or email [campblazetx@gmail.com](mailto:campblazetx@gmail.com).

Camp Blaze is held at the same facility where we hold our "People With Smiles Camp" in the fall, with amazing facility and staff.

The mission of the TXPWA (founded in 2009), is to enhance the quality of life for all those affected by Prader-Willi syndrome through education, support and advocacy. ■

### PWS Awareness, continued from page 11

looped to children with disorders, and I explained to "Mary" (with a mid-20s age child with a disorder) about PWS and the association. A complete stranger at the next table leaned over and said, "Excuse me; I couldn't help overhearing you mention Prader-Willi." Mary and I looked at each other and I got a goose-

bump rush. I replied, "Why yes, why?" The stranger said: "My friend's two-year-old has PWS." I was grateful to continue building more awareness.

*How does one run across two occurrences of this rare condition, PWS, in one week? I don't know other than I am glad these moments happened, and I will continue to*

*spread awareness about PWS to anyone who will listen. ■*

*-Sara Dwyer, Editor, The Gathered View, PWSA (USA)*

Watch the Mayim Bialik video: <https://youtu.be/0rISRqLNZYc>

*Editors' Note: I attended two new student presentations on PWS at Ashley Hall February 22 and 23. Stay tuned.*

## Organization View

# Adults with PWS - 2018 Annual Board Meeting

*Submitted by Stacy Ward, MS, Crisis Intervention and Family Support Counselor*

The Adults with PWS Advisory Board held their annual board meeting in Florida to discuss their previous year, accomplishments, and future goals for 2018. The discussion was led by outgoing co-chairs, Conor Heybach and Brooke Fuller. The board spent some time discussing the importance of understanding benefits such as Medicaid, Social Security Insurance (SSI) and Social Security Disability Insurance. They were honored to have Michelene Bajikan, Attorney, join them to discuss these benefits further and answer their questions. Additional time was spent working on a brochure for employers that describes the challenges a person with PWS faces in an employment setting and the most effective ways to support them in the employment setting. Watch for their new brochure in the months to come.

Conor and Brooke 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 2018: Shawn Cooper and Andy Maurer. Andy and Shawn have been members of this Advisory Board for many years and are looking forward to leading the board in 2018. Thank you, Brooke and Conor, for your service. Congratulations to Andy and Shawn! ■



Left to right: Mary K Ziccardi, Brooke Fuller, Andy Maurer, Jai Ojha, Abbott Philson, Shawn Cooper, Stacy Ward, Conor Heybach.

*~Submitted by Shawn Cooper*

On January 13-14, 2018, the PWS Adult Advisory Board Members had their meeting. Five of us attended: Former Co-Chairs Conor Heybach and Brooke Fuller, plus other members Andy Maurer, Abbott Philson and Shawn Cooper.

We went to our activities; mini putt-putt golf and fed baby alligators. We had a guest come to our meeting - Conor's sister Michelene, and she talked to us about SSI and fundings and she did a presentation and it was a great meeting. And we all did thank you cards for Ken Smith and Evan Farrar for what they did for us and to appreciate and honor them both.

Andy Maurer and I wanted to say thank you to former Co-Chairs Conor Heybach and Brooke Fuller and for helping us to be the best Co-Chairs. ■

## International View



PWSA (USA) was very fortunate to have several members of IPWSO attend and participate in our national convention in Florida this past November.

Compared to many organizations who support those with PWS, IPWSO has a much broader range to cover - the whole world! PWS does not discriminate which countries have families with children or other relatives with this syndrome.

Simply stated, the IPWSO mission is similar to ours, yet on an international

scale. This begins with improving the quality of life for all people with Prader-Willi syndrome and their families, fostering the foundation and development of new national PWS Associations, and encouraging PWS Associations to exchange and share their PWS projects and experiences.

IPWSO also provides education and support on PWS around the world, free testing for diagnosis in countries where it is not available, and through international conferences, provides a forum for communication

and collaboration about medical and scientific research advances, caregiver standards, and new therapies and insights for families.

We were honored to have IPWSO President Tony Holland, plus other notable professionals present and speak in November, and look forward to sharing information on their fifth Professional Provider Caregiver Board conference in August, 2018 in Munich Germany.

To learn more about IPWSO, visit this link <https://www.ipwso.org/> ■

Visit our Site...

Go to [www.pwsausa.org](http://www.pwsausa.org) and learn, join, and be a vital part of our family network of love and support. Subscribe to our blog!

# 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 2018-2021 Board of Directors and volunteers for Committee service. We have specific needs for talented individuals in the areas of:

- Advocacy for Positive Public Policy
- Fund Development
- Research

Board and committee membership is 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](mailto:info@pwsausa.org) or by fax to 941-312-0142. *The deadline for nominations is April 10, 2018.*

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](mailto:info@pwsausa.org). There is no deadline, as volunteers are always welcome. ■

**Our Mission:** Prader-Willi Syndrome Association (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

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info@pwsausa.org 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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**Debi Applebee**, Business Manager  
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**Rikka Bos**, Development and Chapter Relations Specialist  
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## MEMBERS ONLY:

Access our Website: [www.pwsausa.org](http://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](http://www.pwsausa.org/egroups)

## The Gathered View (ISSN 10 77-9965)

Sara Dwyer, Editor

Lota Mitchell, Andrea Glass, Denise Servais, Kathryn Lucero

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# Prader-Willi

## SYNDROME ASSOCIATION (USA)

### SAVING AND TRANSFORMING LIVES

8588 Potter Park Drive, Suite 500  
Sarasota, FL 34238

Learn more about saving  
and transforming lives at  
<http://www.pwsausa.org/>

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[www.PWSA.org/Angel](http://www.PWSA.org/Angel)

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PRADER-WILLI SYNDROME ASSOCIATION (USA)

# MOVE

on the

## It's Time to Get

### 4th Annual Clint Hurdle "Hot Stove" Dinner!

## PLEASE JOIN US!

Friday, March 23rd, 2018  
Courtyard by Marriott in  
Bradenton, Florida  
Book your hotel group rate for Prader-Willi  
Syndrome Association Event by calling  
941-747-3727 or go to  
<http://bit.ly/2okRbZxHurdleHotel>

Mix and mingle with Clint Hurdle and friends while you help raise awareness and support for PWSA (USA)!

We'll kick things off with a fun and relaxing cocktail hour on the patio, then we'll take things inside for a delicious dinner and a program fit for the biggest Pirates fan!

Not able to join us, but still want to help? Sponsorship and donation opportunities are available! Wish you could bid on an auction item from afar? You can do that too! Just keep your eye on the PWSA (USA) Facebook page for more information!

For more information about ticket sales or sponsorship and donation opportunities, please contact Rikka Bos at [rbos@pwsausa.org](mailto:rbos@pwsausa.org), or at 941.487.6729.

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