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

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



Be an Angel...

The 2017-2018 Angel Drive campaign will end soon, but there's still time for you to help make the PWS commUNITY stronger than ever before!

When you support the 2017-2018 Angel Drive campaign, you are joining a community of individuals, families, and professionals all working together to make a real and meaningful difference in the lives of others. PWSA (USA) receives no reimbursement or funding for the services and programs it provides. We rely solely on the generosity of angels like you to make change possible. Your gift saves and transforms lives!

With your support, we can continue to:

- Raise **AWARENESS**
- Provide holistic and comprehensive **FAMILY SUPPORT** services
- Facilitate **RESEARCH** that saves and improves lives
- Provide **EDUCATION** to those serving or working with the PWS community, such as medical professionals, education professionals, and residential providers
- **ADVOCATE** for the needs of the PWS community

These five pillars serve as the foundation of who we are.

They represent the power of community and what we can accomplish working together to save and transform the lives of those affected by Prader-Willi syndrome.

Thank You!

For over 40 years, PWSA (USA) has channeled the **love**, **compassion**, and **hope** of the PWS community into ground-breaking research, effective advocacy, comprehensive family support programs, education, and greater awareness. These initiatives have brought hope, health, and enhanced quality of life to thousands of individuals with PWS and their families, giving them strength to thrive in the face of a rare genetic condition.

PWSA (USA) and you…Together we are Saving and Transforming Lives! Thank you!

New for the 2017-2018 Angel Drive Campaign!

With your gift of $500 to $999, one PWS family in need will receive a one-year membership! With your gift of $1,000 and up, two PWS families in need will receive a one-year membership!

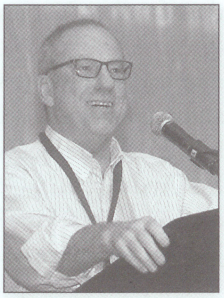
Visit https://www.pwsausa.org/angel-drive/ to make your gift today!

PWSA (USA)'S FIVE PILLARS OF SUPPORT



Executive Director View

By Steve Queior, Acting Executive Director, PWSA (USA)



As I write this, the days have moved swiftly toward being filed in Memory Album 2017. End of the year always brings two special events for PWSA (USA) – the convention and the Angel Drive.

The 2017 national convention in November hosted 840 people involved in the Prader-Willi community, including babies, individuals with PWS, siblings, parents and caregivers, grandparents, providers, professionals, volunteers, and presenters. Gathered "Together in Paradise" in Orlando, Florida, they were there to learn more about PWS and its management, to share knowledge, to meet old friends and meet new ones – and to have fun.

Here's a representative evaluation comment from someone who attended: *"A sense of balance in the crazy world I live in. The feeling of 'not being alone' in this journey. Helpful information. Connections for my daughter for a sense of belonging."*

Under the experienced leadership of Michelle Torbert, Jackie Mallow, and all the dedicated staff and volunteers who work so hard to put together our 2017 national convention, "the mission was accomplished!"

As you read this, 2018 is here, and the 2017-2018 Angel Drive campaign is in full force. Every gift strengthens the financial foundation for PWSA (USA) to be able to continue to provide

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Volume 43, Number 1 ~ January-February 2018 ~ Our 43rd Year of Publication

Pediatric PWS Clinic at Vanderbilt

By Kathy Clark, RN, MSN CS-BC, Coordinator of Medical Affairs, PWSA (USA)

There is a new pediatric PWS clinic at Vanderbilt University in Nashville, Tennessee. Dr. Jessica Duis finished her pediatric genetics fellowship at Johns Hopkins, with a goal of providing comprehensive care for children with PWS. Her research during her training focused on understanding the transcriptional signature of the transition to hyperphagia in the SNORD116 deletion mouse model of PWS.

The clinic started in April 2017 and is held once per month with a plan to increase frequency to make the team more available to individuals with PWS and their families. Her team consists of Drs. Ashley Shoemaker and Nathan Bingham (pediatric endocrinologists), Dr. Althea Shelton (neurology and sleep medicine), Dr. Mohammad Fazili (pediatric pulmonology and sleep medicine), Dr. Megan Mignemi (pediatric orthopedics), Ms. Elizabeth Roof (senior research and behavioral specialist), Ms. Andrea Huxtable (dietician), Ms. Anna Childers (genetic counselor), Ms. Lisa Robinson (clinic coordinator), Ms. Carla Jackson (social work), and Ms. Christy Mullen (case manager).

Dr. Duis has a special interest in PWS that is both personal and professional, so she has both the heart and the mind to understand the challenges and the triumphs. Her sister is an inspiration to bring new therapies to PWS and help families with the daily struggles that PWS can bring. She is also the mother of three young children – Gracie (age 4), Henry (age 4) and Ariella (age 2).



Dr. Merlin Butler and Dr. Jessica Duis at national convention.

Dr. Duis attended our convention in November, attending the scientific and family conferences, and meeting many experts, researchers, and of course many families. She brings great energy and compassion to this new endeavor – it is a significant challenge to set up specialty clinics. There could not be a better place than at Vanderbilt, where there is a premier behavioral and research program at the Vanderbilt Kennedy Center for PWS Initiatives. ■

"It is such an exciting time to be a part of the PWS community. We are talking about how early diagnosis and interventions like diet are changing the natural history of disease! There are many exciting leads for real treatments. Our next generation is clearly going to see real benefits from the work going on in the field. The conference highlighted for me how important it is for our new multidisciplinary clinic to have a support system in place to make sure our kids and adults are receiving comprehensive care. We will work to improve access and make sure every individual receives the standard of care and beyond."

Jessica Duis, MD, MS, Assistant Professor, Division of Medical Genetics and Genomic Medicine, Department of Pediatrics, Vanderbilt University School of Medicine ■

Executive Director, *continued from page 1*

its five pillars of support for our PWS community—awareness, family support, research, education and advocacy. Without those funds from many angels, PWSA (USA) could not continue to serve its many families. Please, spread your wings and be one of those angels!

A new year always brings that most important element that Emily Dickinson described as "the thing with feathers:" hope. We all hope for an important breakthrough for a medication that will improve the lives of our individuals with PWS and their families, for ground-breaking research, for a renewed sense of purpose as we work to "Saving and Transforming Lives" of those living with PWS."

HAPPY NEW YEAR TO ALL! ■

MANAGEMENT CHANGE ANNOUNCEMENT

The Board of Directors of Prader-Willi Syndrome Association (USA) announced the departure of Ken Smith as Executive Director of PWSA (USA), effective December 4, 2017. Ken served our Association as a member of the Board of Directors and Executive Director for over two decades and served the Prader-Willi community at-large through his connection with The Children's Institute in Pittsburgh. His dedication to our families and our mission over the years is greatly appreciated. Most of us owe Ken a debt of gratitude for saving and transforming our own individual PWS family. We all wish Ken the best as he embarks on the next chapter of his career.

The tasks of the executive director position will be handled by Steve Queior as Acting Executive Director. Steve joined our team in March of 2017 as the Director of Fund Development and has excelled in that position, including taking on additional responsibilities. Please direct all executive director level communications to Steve (squeior@pwsausa.org). ■

The PWSA (USA) 2017 Medical and Scientific Conference

The second half of this listing will be provided in the following 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, this conference was well-attended by over 85 clinicians and researchers from a wide variety of specialties and interests. We appreciate the hours of work and creativity needed to organize this event. It was packed with wide-ranging topics that showcased the most recent advances in understanding and treating PWS.

Many talks discussed research projects and observations, some preliminary. Once published in medical journals, we will present findings for parents and others interested in PWS in a future issue of *The Gathered View.*

Based upon the need expressed by parents, there was an emphasis on understanding psychiatric problems, including a lecture from an expert in psychiatry and pharmacogenomics. While Dr. Dellenbaugh is not a PWS provider, he provided the audience with information about known limitations and use of selected psychiatric medications and special needs of individuals with PWS. This complex topic will be more fully explained in an upcoming edition of *The Gathered View.*

The medical and scientific program included the following topics and speakers.

Overview of PWS: Infancy Through Adulthood - Jennifer Miller, MD, University of Florida – The one hour presentation reviewed the clinical findings at different ages, nutritional phases and management of individuals with PWS.

NIH Rare Disease Consortium: Prader-Willi Syndrome and Early-onset Morbid Obesity - A Review of Natural History Study - Merlin G. Butler, MD, PhD, University of Kansas Medical Center – Description and research design of the NIH funded study on the natural history, genetics and clinical findings in 355 individuals with PWS.

Experience of the First Multidisciplinary Adult PWS Clinic in the USA - June-Anne Gold, MD, University of California, Irvine – Description of a new clinic held every other month, specifically for adults with PWS.

Bipolar Disorder, a Previously Unexplored Psychiatric Comorbidity in Patients with Prader-Willi Syndrome - A Case Series - Deepan Singh, MD, NYU Winthrop Hospital - Bipolar disorder (BP) may be more common than suspected in PWS, where it presents with irritability and catatonia instead of euphoria or mania. The use of SSRI medication may worsen the symptoms. Having the correct diagnosis is key - medications should be used when the diagnosis is known. BP in PWS typically is a short-lived problem.

SNORD116 Missing in Prader-Willi Syndrome Regulates Microexon Splicing and mRNA Stability of Immediate Early Genes - Stefan Stamm, MD, University of Kentucky – Description of a non-coding RNA (SNORD116) missing in PWS that may be related to hormone protein production and regulation influencing the activity of neurons in the brain. ■

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

Psychiatric Medications

A 2017 PWSA (USA) Convention presentation by Tony Holland M.D., Professor of Psychiatry, Cambridge University

Review by Andrea Glass, mom to Ian, with PWS

Tony Holland, M.D., Professor of Psychiatry at Cambridge University, reviewed the various psychiatric medicines used in the PWS population. Individuals with Prader-Willi syndrome have a high probability of developing a comorbid psychiatric illness, particularly those with maternal uniparetnal disomy (mUPD). There are several classes of psychiatric medications used to treat various psychiatric illnesses in PWS, including antipsychotics (typical and atypical), antidepressants (SSRI's and SNRI's), CNS stimulants, antiepileptic and mood stabilizing medications. Before considering using any medication, a diagnosis must be made. There is no medication to treat the behaviors of PWS, but there are treatments for diagnoses like anxiety, bipolar disorder, and ADHD. Dr. Holland pointed out that it is particularly challenging to diagnose those with PWS. It is difficult for the person with PWS to describe their symptoms. Additionally, the development of the brain is sufficiently different in the PWS individual so that their response to drugs may be different than expected. It is only useful to use drugs where there is a diagnosed disorder, and not just symptoms.

As a parent of a 22-year-old son with PWS, I clearly identified with this approach. When is the strange behavior we see as caregivers just PWS, and when is it a psychiatric illness? Trying to determine why the person is having the behavior may be helpful in the diagnosis. Could the behavior have an environmental cause, such as a change in

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Psychiatric Medications, *continued from page 3*

routine or staff at school or work? As you look at the person over time is there a change in mood or behavior that is unexplained? Medication, if used, should be part of a comprehensive care plan that includes psychological, environmental and other interventions.

The treatment of anxiety involves determining whether it is part of a mood disorder, or a response to a specific situation. A good care plan will manage the uncertainties for the individual by providing food security, visual supports, structured routines, and a plan for outbursts. If the anxiety is still a concern, a doctor may cautiously prescribe an SSRI to reduce the anxiety. The caregiver would monitor to see if this helps and watch for undesirable side effects which can include activating the troublesome behaviors. Mood disorders are evidenced by changes in sleep pattern, concentration, and general interest. It may manifest as depression, hypomania or mania, or bipolar disorder. Prescribed treatments may be antidepressants, major tranquilizers, and mood stabilizers. A mood disorder can be temporary or permanent. To make this determination, the doctor may stop the medication after the symptoms are controlled to see if the symptoms have resolved.

Trying to determine why the person is having the behavior may be helpful in the diagnosis.

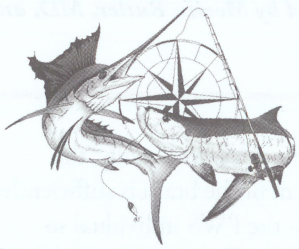
Psychotic illness presents with deterioration in behavior or a new, bizarre behavior. The onset can be sudden or gradual, and is associated with an abnormal mood state and the development of abnormal mental experiences. Research has shown that the PWS genotype predisposes the individual to a risk of mood disorders, and the mUPD is a 'second hit' for psychotic illness. A good care plan includes prescribed medication, keeping the person safe, monitoring his/her mental state, proper support and reassurance, and a low demand environment until the illness resolves.

Dr. Holland points out that psychiatric medication is frequently overused in the disabled population. There are parallels to the excess prescribing of antibiotics. Managing difficult behaviors that affect everyone in the home increase the pressure to "do something." Prescribing a medication may seem easier than environmental or behavioral approaches.

In closing, Dr. Holland speaks enthusiastically about advances in neuroscience that will involve treatments that are non-pharmacological, including oxytocin, vagus nerve stimulation and treatments for hyperphagia. ■

PWSA (USA) Wishes to Express their Generous Appreciation to our 2017 National Convention Sponsors

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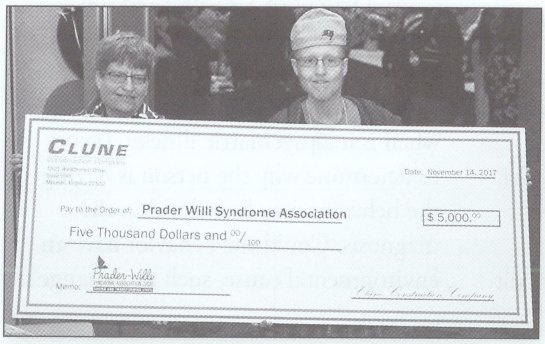
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Thank you to those who contributed to the Convention Scholarship Fund



Clune Gift is Transforming Lives

Thank you to the eastern region of the Chicago-based Clune Construction Company, L.P. Their generous donation to the Prader-Willi Syndrome Association (USA) is in recognition of an employee's child being affected by this genetic disorder. The gift was presented to Brooke Fuller (left) and Conor Heybach, of the Adults with PWS Advisory Board. This will be used in PWSA (USA)'s work across the areas of awareness, education, family support, and research to improve the lives of families with a member dealing with the syndrome. ■

2017 Tennessee On the Move Walk

The Tennessee Prader-Willi Association held its annual ***On the Move*** walk on Saturday, October 28, 2017 at the Granny White Park in Brentwood. Although it was a cold and blustery day, turnout was great with 68 people attending, including 15 individuals with Prader-Willi syndrome (from ages 10 months to 39 years). After the walk, the group celebrated the grand opening of the new Monroe Carell, Jr. Children's Hospital's new PWS Clinic, headed by Dr. Jessica Duis. Dr. Duis spoke about the clinic's offerings, as well as current research initiatives and emerging therapies. Later, the group enjoyed a PWS-friendly cookout and had time for families to connect with each other for encouragement and support. The event was a great success (they raised over $6,400 in online donations!), and they are looking forward to an even bigger turnout in 2018! Way to go Tennessee!



68 attendees at Granny White Park

Idaho 2017 On the Move Walk & Silent Auction

On Saturday September 30th, the Idaho Prader-Willi Syndrome Association hosted their 2017 ***On the Move*** walk and silent auction. Nearly 200 of their closest friends and supporters attended, including seven PWS "warriors," and the Timberline Garrison of the 501st Legion (dressed as well-loved Star Wars characters). Special guests Merida, Belle, Tinkerbell, Spiderman, and Rapunzel visited with walk attendees, and later helped pass out medals to honorary guests and the kids.

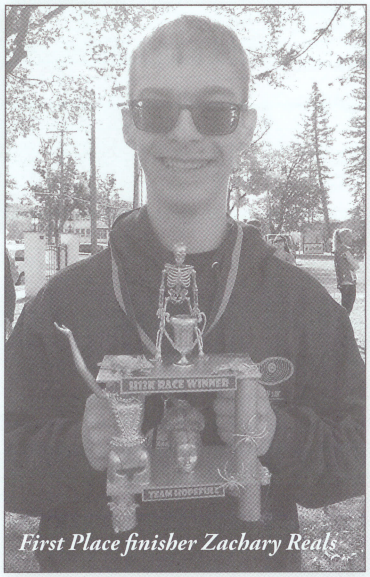
The popular silent auction featured over 60 various gift baskets suitable for both children and adults, and included donations from nearly 30 local restaurants. Competition for items was "fierce" at times, especially between a few PWS families who found their kids trying to outbid the parents. All in all, everyone who looked found something to their liking, and every item received a bid.

Music by DJ Scott Baker (of Utah PWSA) kept everyone on their feet and dancing to favorites like the "Chicken Dance" and "YMCA." Before ending the busy day with a healthy snack, On the Move walk participants had an opportunity to spread awareness about PWS amongst attendees to a local suicide prevention walk that coincided with the Idaho PWSA event.

Altogether, the day was a great success, and plans are already in the works to have another fun event next year!

Zach finishes his 13K!

On October 28, 2017 Team HopeFull held its annual Halloween 13k in Endicott, NY to benefit people living with Prader-Willi syndrome. Among the runners was 19-year-old Zachary Reals, an avid runner who happens to have PWS.



First Place finisher Zachary Reals

Zach has been running since junior high school. He was on his school's varsity track team and enjoys long distance running most of all. Now that he's in college, he runs 5ks for fun as often as he can. The Halloween 13k was his longest race to date, and he placed first in his age category, males 19 and younger, with a time of 1:15.

Zach says that his running goal is to complete a marathon. He says he knows it takes a lot of strength and courage, but he believes that God will help him get there.

~ Tammy Reals
Liverpool, NY

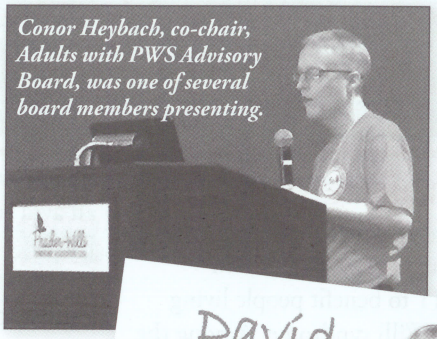
The website for Team HopeFull is: http://www.teamhopefull.com/
Rachel and Shawn Johnson, founders

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

Building Hopes, Dreams and Self-Esteem

This panel discussion, featuring Brooke Fuller and Conor Heybach, Co-Chairs of PWSA (USA) Adults with Prader-Willi Syndrome Advisory Board, was designed to give conference attendees a sense of the hopes and dreams of individual Advisory Board members and present ideas for how we can work together to help our loved ones with PWS live their best lives.

Joined by other Advisory Board members Andy Maurer and Shawn Cooper, Brooke and Conor gave insightful and moving presentations, reminding us all that no one is better situated to advise us on the hopes and dreams of someone with PWS than the person herself. As Conor said, if you want to know what we need, "just ask us!"



Conor Heybach, co-chair, Adults with PWS Advisory Board, was one of several board members presenting.

Advisory Board member hopes and dreams included:

- "the opportunity to make my own decisions, in spite of having PWS"
- that "everyone [would] understand how each individual with PWS feels and how he or she lives each and every day"
- that "everyone with a disability [would] be respected"
- "medication that would control appetite and hunger"
- "a cure for PWS"
- "being able to live on [my] own."
- Conor also relayed some Advisory Board advice on self-esteem, including:
- Always be true to yourself
- Define yourself as more than someone with PWS
- Embrace your talents and qualities
- Surround yourself with people that make you happy and take advice from those who love you.

Other panel members were David Agarwal, Patrice Carroll, Mary K. Ziccardi and Carol Hearn, who facilitated the panel. Carol gave a brief presentation regarding person-centered planning and one-page profiles – two of the tools that families, professionals and persons with PWS (in each case, the "focus person") can use to help the focus person build self-esteem and make progress toward realizing his or her hopes and dreams.

"Person-centered planning" is an ongoing process undertaken by a group of people to listen to the focus person and help him plan for his future. When done well, this process enables group members to view the whole person, not just his disability, and helps the focus person exercise as much control over his life as is reasonably possible regarding such questions as: Where will I live? How will I spend my working hours? How will I spend my leisure hours? Who will I spend my time with? What are my hopes and dreams? How can I make progress toward achieving my hopes and dreams?

The "One-Page Profile" is a simple tool that provides a brief introduction to the focus person and can be adapted to a variety of uses – such as looking for a job, looking for staff, looking for a roommate, or starting a new school or activity. Elements usually include a picture of the focus person, some basic facts (such as contact information), and sections designed to communicate the information that is relevant to the purpose. For instance, when looking for staff, one might include sections on "What people like and admire about me," "What's important to me," and "How best to support me."



David

What people like about me

I have a playful sense of humor. I love to joke around!

I am kind, and I care about other people.

I respect other people and their things.

I am a hard worker. I like to finish whatever I am working on.

I am a good cook, and I like to help plan meals.

I have a happy attitude toward life.

Quick facts about me

- I live in Minneapolis, MN with my parents, Carol & Tim
- I have 2 older sisters, Jessica & Maryellen
- The best way to contact me is through my mom, at: [phone number, email address]

Things that are important to me

- My family
- My girlfriend & other friends
- Being around people who like me, who are kind to me and who "get" my sense of humor
- Knowing my schedule ahead of time
- Knowing my meal schedule and what the meal will be, and helping with food buying and preparation
- Taking pictures of my food
- Watching TV, recording TV shows, watching DVDs and playing video games
- Reading and writing books (ask me about my book, "David Hearn and the Sorcerer's Cat")
- Playing games, like SORRY and Skip-Bo
- My current favorites (for instance, right now, my favorite movie is *Frozen*; my favorite TV shows are "Once Upon a Time" and "The Voice;" my favorite books are the *Little House on the Prairie* books; and my favorite singer is Grace Vanderwaal)

Things to know to help support me

Because I have Prader-Willi syndrome, I need to maintain a low-calorie diet, and I should never have unsupervised access to food.

I like to have at least two things (other than my beverage) at each meal. So, if only one thing is planned (for instance, a sandwich), I need help to identify at least one other thing (for instance, a piece of fruit) to be my second thing at that meal. I sometimes get worried if I don't have a second thing.

I need reminders to help me stay on track so I can accomplish what I need to do. For instance, I need reminders to shower regularly and to do my laundry.

I like to exercise but I need reminders to get out there and do it!

My spine doctor says taking regular walks is good for me because I have scoliosis.

The best way to motivate me is to make an activity a game or a race of some sort. For example, my mom and I have a race in the morning to see who can brush teeth first after finishing breakfast.

I often have trouble making decisions, even about things like what to eat for dinner. I'm usually OK with whatever food, activity or other thing is suggested, so long as I don't have to decide.

Sometimes I get really shy when I am meeting someone new. It helps me loosen up if you talk to me about my favorite movies or TV shows.

In addition to alerting the reader to important medical precautions (such as, "I must not have unsupervised access to food," or "I have severe asthma and use an inhaler," etc.), the one-page profile can help ease communication barriers that might otherwise get in the way. For instance, the one-page profile for Carol's son, David (age 25, with PWS), includes a current list of his favorite movies and TV shows, as well as the statement, "Sometimes I get really shy when I am meeting someone new. It helps me loosen up if you talk to me about my favorite movies or TV shows."

More information about person-centered planning and one-page profiles can be found on the PACER website, www.pacer.org. The following websites also have information on how to conduct effective person-centered planning: www.personcenteredplanning.org; and https://mn.gov/dhs/ (on the MN DHS website search materials entitled: "What does person-centered mean for me?"). If you'd like emailed pdfs of the *Building Hopes, Dreams, Self Esteems* slide presentations or the sample one-page profiles discussed during this conference session, please contact the national office. ■

~ Carol Hearn

Professional Provider Day at National Conference 2017

By Barb Butler, Development & Outreach Director - PWHO

On Thursday, November 16, with 75 professionals in attendance, Tony Holland, MD, psychiatric advisor for UK PWSA and President of the International PWS Organisation IPWSO, kicked off Provider Day with a presentation on mental health and problem behaviors in PWS, from assessment to intervention. His three objectives were: to provide a framework that enables a better understanding of behavioral and mental health problems; to consider how understanding can lead to informed interventions; and to consider the limitations of knowledge and how research seeks to address such gaps.

Next, the team from AME Community Services, Inc. - Lynn Garrick, RN, nurse consultant and program director and Falone Aced Schulz, Program Coordinator - spoke on managing rectal picking in the residential setting. They offered the group practical daily support tips for staff to serve clients in their group homes.

PWSA (USA) favorite B.J. Goff, Ed D, led a lively discussion on families and providers working together. She shared the two major concerns of parents who place a child in residential programs - communication and staff training. In addition, B.J. provided handouts on ways for providers to work with families in the concern areas and offered up do's and don'ts for improving parent-provider relationships.

In the afternoon, the Prader-Willi Homes of Oconomowoc team of Marguerite Rupnow, Director of Operations, and Barb Butler, Development & Outreach Director, discussed GUT: *G.astronomy, U.niform, T.ransformation - How to implement the Science of Good Eating into our Resident's diet.* The speakers shared their company's journey to improve the diet and nutrition of the meals at PWHO. The presentation spotlighted recent research on gut health and then focused on implementation of new menus, meal prep, food ordering, serving utensils and a team nutrition binder that are used in all the homes for consistency.

Kayla Cox and Gina Sheehan of Latham Centers wrapped up the speaker presentations. Their topic - *Transforming a Residential Program with Positive Behavioral Supports* - included data and testimonials on the implementation of their program and its goal of developing a behavior management system to understand what maintains an individual's challenging behavior.

The afternoon closed with roundtable group discussions on key topic areas that have been most requested by providers. Some of the topics included: The New Workforce, Challenges with Food, Aging, and Social Media. Table facilitators gave a report from the day's discussions.

Special thanks to our co-chairs and leaders of the day: Patrice Carroll, MSW, Director of Services, Latham Centers; and Mary K Ziccardi, Regional Director, The MENTOR Network. ■





Above: Patrice Carroll, Latham Centers greeted many with her smiling face.

Left: Barb Butler, Oconomowoc Homes presented at a session during Professional Provider Day.



CHUCKLE CORNER

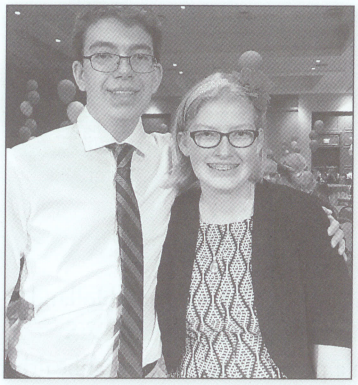
At age 8, our son Aaron was very aware of his sister Ali's (age 6) PWS, and very protective and conscientious about keeping an eye out for her. Ali had never stolen food but it was something we were hyper-aware of anything not normal. One day condiments were under the bathroom sink Aaron and Ali shared: ketchup, mustard, mayonnaise, relish, bottles of salad dressing! I thought to myself, "OMG, it's starting…Ali is beginning to steal food!" Upset, I immediately told my husband Mitch. He thought the whole thing was odd and couldn't quite understand why she would choose condiments. We decided to share the news with Aaron (we included him in things regarding Ali).

As I told him the story, he had the strangest look on his face. After several moments, Aaron said, "Mom, remember that day last week when I was stomach-sick, threw up, and stayed home from school?" I said yes, but I didn't see what it had to do with Ali stealing food. He turned bright red and admitted: "Well, I wasn't really sick that day. I didn't want to go to school because of a test. So I put a bunch of condiments in the toilet to make it look like throw-up. It worked pretty well because when you looked, you agreed that I should stay home for the day." He went on to apologize for worrying me and apologized for his antics.

I could not have been happier! I gave Aaron the biggest hug and thanked him for his honesty and willingness to "come clean" in order to defend his little sister! ■

~Rachel Cohen
Weston, CT



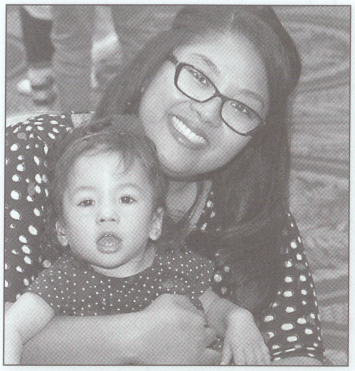


It was amazing to be a part of this conference and to share this experience with my daughter and granddaughter. Thank you so much!!









I gained more knowledge and perspective to help me improve my work as a professional provider.



Feeling connected.

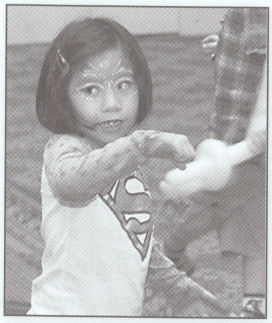




I really enjoyed the topic about Shut Up About Your Perfect Children. It really made you think. And the session on Saturday, Building Hopes and Dreams – what a great inspiration to hear and know people with DD can accomplish so much.



Connecting to an exclusive, caring community that gets it!



We will be back.



Excellent information on the sessions I attended. Have not been to a convention for 15 years.



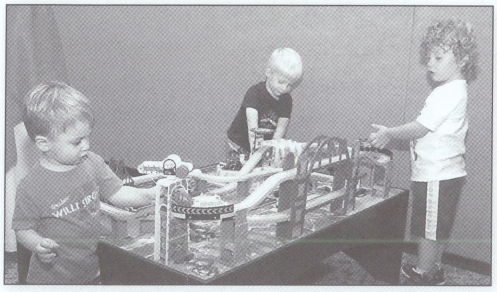


Support and fellowship.

Love feeling empowered by being part of such a great community.







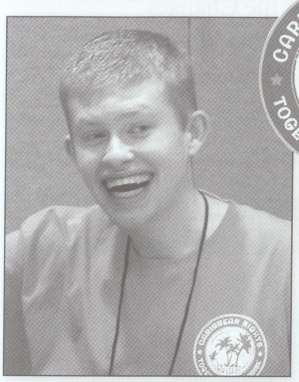
My children make friends and see friends that otherwise they wouldn't.

I LOVE the national conference and my daughter looks forward to it immensely.









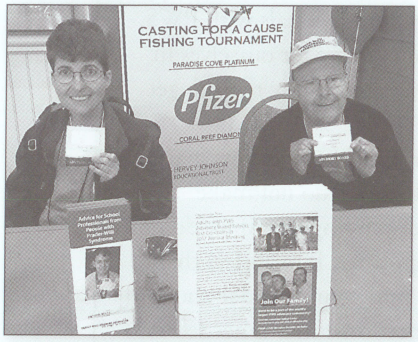
Snapshots: Memories from National Convention – November 2017

Enjoy photos from the 2017 PWSA (USA) national convention. Comments indicate the children were not the only ones who loved their time!

Safe place for my daughter (YAP – Age 14). Fun activities not food oriented – huge social opportunity for her. Respite and education for me – camaraderie with other parents.

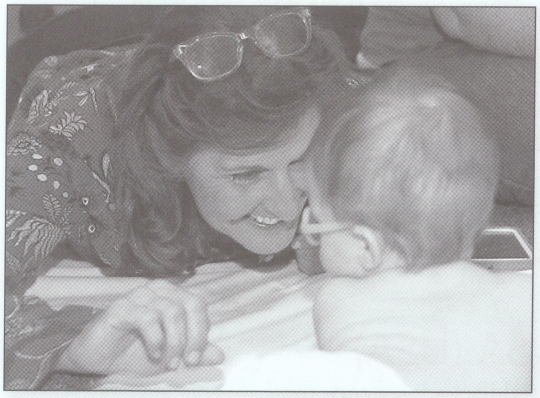
Loved presentations for caregivers! Please do more! Loved the alternative approaches!





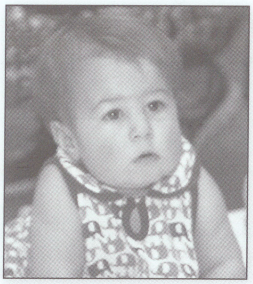




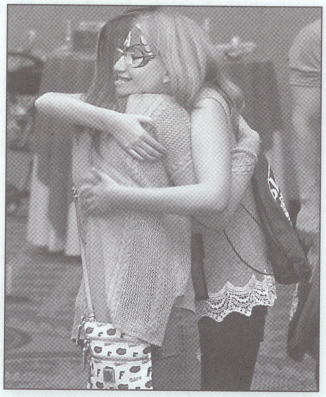


Like hearing the latest research updates.

Five Pillars a wonderful step toward continued growth of PWSA (USA).

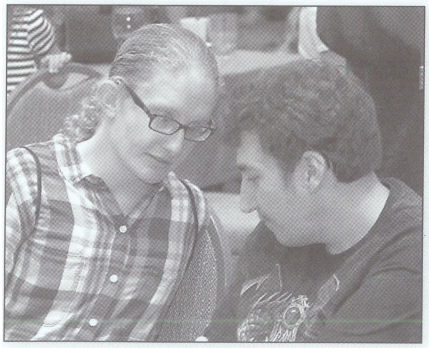




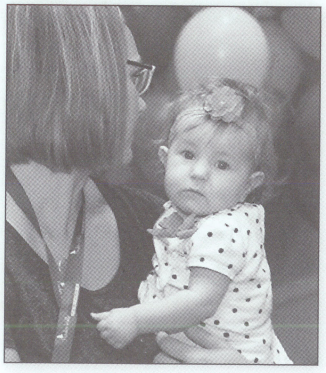


Scientific was <u>very</u> informative.

I always walk away with great reminders or new ideas.







Hold these Dates for a Great Experience

We look forward to seeing you at the

2019 National Convention
October 23-26

Changes Health and Wellness In-Patient Program

By Stacy Ward, MS, Crisis Intervention and Family Support Counselor, PWSA (USA)

Nexus Children's Hospital, formerly known as Healthbridge, in Houston, Texas, is once again accepting children with Prader-Willi syndrome in their Changes program. Nexus Children's Hospital offers a safe, structured environment for children, ages 3-21, with established weight control problems, including Prader-Willi syndrome (PWS). Addressing comorbid medical issues and behavioral complications characteristic of individuals with PWS, the Changes Health and Wellness in-patient program aims to help young patients who have found traditional outpatient programs unsuccessful. The program incorporates low-calorie diets, set daily schedules, individualized physical training regimens, and behavioral health support for both the patient and family members.

To learn more about the Changes program at Nexus Children's Hospital call 855.729.0855 or go to their website nexuscontinuum.com. ■

Parent Mentor

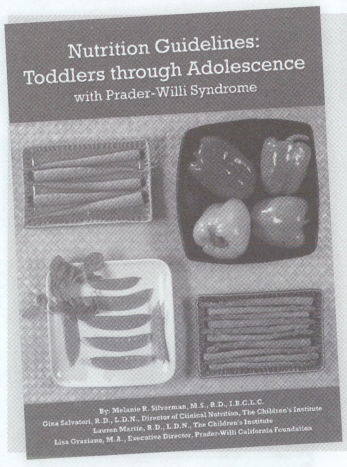
Burned Out

By Kathryn Lucero, PWSA (USA) Chapter Leader and Parent Mentor

The 2017 National Convention was such an awesome experience, this year I was not only an attendee, but also a speaker. My breakout session was about ***taking care of yourself***. As parents and caregivers of individuals with PWS, it can be time-consuming, draining, and emotionally depleting and for many reasons we tend to not care for ourselves in the manner we should. I discussed the implications about not caring for ourselves and how to implement easy tools to get us back on track.

Many of us make excuses for not caring for ourselves. The biggest excuse is TIME. That four-letter word haunts many of us and is a word that tends to be overused. TIME is NOT what is holding us back, it's ourselves. We do not make ourselves a priority and when we do, there is an element of guilt that goes along with that. Understanding that if we do not take the reins on our life we will not be around long enough to enjoy and see those we care for grow up. It takes less than five minutes to do something that makes us feel good. Pick up a pen or even your smart phone, find your calendar and put YOU time in as an appointment. You would not cancel a doctor's appointment, so don't cancel time that is needed for your health. Find one thing that you love doing and do it at least one time per week. This particular thing does not have to take long, and you can build up your time as you start making you a priority. Journaling, going outside to breathe in fresh air, a short walk, tinkering in the garage, meditation are all things that could take less than five minutes.

My take home message was simple, Make YOU a priority. Taking time out for ourselves should not cause us anxiety but quite the opposite, it should bring us joy and a little peace to our chaotic lives. ■



A Great Publication from PWSA (USA)

https://www.pwsausa.org/product/nutrition-guidelines-toddlers-adolescence-pws/

Nutrition Guidelines: Toddlers Through Adolescence With PWS

(2015), by Melanie Silverman, MS, RD, Gina Salvatori, RD, LDN, Lauren Martin, RD, LDN, and Lisa Graziano, MA. Provides parents and caregivers with the basic nutrition knowledge they need to create the healthiest environment possible. Softcover, 18 pages. ***$7.50*** ■

Dental Care for Children and Adults with Prader-Willi Syndrome

Compiled and Reviewed by B. Dorn, RN, Bobbi Pogrant, Dr. T. Hughes, DDS, and Dr. K. Wachter, DDS

Children and adults with Prader-Willi syndrome (PWS) of all ages face lifelong challenges in the area of dental health. People who have Prader-Willi syndrome have decreased, thick and sticky saliva that adheres to teeth and harbors bacteria that can cause decay and periodontal disease. Some also breathe through their mouth which may result in the development of narrow arches and crowding of teeth. Many experience severe tooth grinding with increased tooth wear. There are many steps that can be taken to prevent or minimize problems as well as promote good dental health in everyone with PWS.

Begin Dental Care and Good Habits Early

Before Teeth Appear:

- Wipe gums after feeding with gauze, a soft wet washcloth or finger toothbrush pads. This will help get rid of the sticky coating called plaque that can cause tooth decay.
- Getting your baby used to having his mouth cleaned as part of his daily routine should make it easier to transition into tooth brushing later on.
- For children who are fed via feeding tube, oral health is just as important to keep the mouth clean.
- Consultation with an Occupational or Speech therapist may be helpful in addressing any oral weaknesses and concerns.

When Teeth Appear:

- As teeth start to appear, brush teeth twice a day with water and a SOFT-bristle toothbrush.
- Use fluoridated water. If your water supply is not fluoridated or if your family uses purified water, ask your dentist if fluoride supplements should be considered. (Fluoride tablets - 1mg per day.) Check labels on bottled water to see if they contain fluoride.
- Use fluoride toothpaste after each meal and at bedtime starting at age 3 years – use only a small, pea-size amount for younger children. Make sure they spit it out – minimize swallowing. Ingesting too much can cause stomach upset. Ask the dentist about use of fluoride rinses.
- Schedule first dental appointment within six months after the first tooth erupts, or by their first birthday, whichever comes first. Persons with PWS should see a dentist at least every 6 months – life long.
- As permanent teeth grow in, the dentist can help prevent decay by applying sealant to the back teeth, where most chewing occurs. This protective coating keeps bacteria from settling in the hard-to-reach crevices of the molars.
- Sealants can also be applied to chewing surfaces in adulthood. This does not prevent decay along the gum lines so proper brushing continues to be important.
- Parents and caregivers need to teach, assist, supervise and inspect to make sure brushing is done and no food is left behind – especially along the gum line. Encourage to brush on the inside and outside of teeth, as well as the tongue to dislodge bacteria that can cause bad breath.
- Teach, perform and encourage flossing. There are many flossing devices available on the market.
- Avoid foods that are soft, sticky and sugary (raisins, gummy anything).
- Make sure persons with PWS are receiving proper (not excessive) amounts of water daily. This provides moisture and helps to rinse teeth when there is a low production of saliva.
- Use a humidifier at night to help alleviate dry mouth symptoms.
- If the dentist notices high, narrow arches resulting in crowding of teeth, request referral to an orthodontist.
- If you see or hear grinding of teeth, have it evaluated right away. A bite guard (worn at night) could be lifesaving for the future of his/her teeth.

Help for Some Challenges with Oral Health:

- Oral health care, like other personal care routines you may help with, takes patience and creativity. Establish a daily dental routine by using the same time, place, and position. Start with small steps, until the child gets used to you working in their mouth.
- If tooth brushing causes distress, experiment with positioning, times, places, distractions and rewards.
- A small child may be cradled in the arms or brushing can be done standing behind the child with the head supported or from a seated or kneeling position.
- Use two people to brush teeth – one to brush while the other distracts or encourages.
- Brushing teeth in the bath may be easier.
- Use distractions such as music, singing or their favorite television show.
- Provide rewards. Use stickers, tooth brushing charts which can be downloaded online and other incentives.
- Let the person pick out their toothbrush; get him/her excited about brushing their teeth.
- Let them choose a new toothbrush monthly to keep them interested. Include a new toothbrush on their monthly shopping list.
- Make things fun to encourage cooperation. ■

Through the Eyes of a First-Timer

By Jessica Patay, Palos Verdes, California

I waited until 36 hours before the trip to actually tell Ryan (age 14) we were going on this trip. Otherwise I would have suffered a barrage of nonstop chatter and questions for days or weeks.

Ryan has not been on an airplane in 3 ½ years. Not because he is scared of them. Not because he has a history of meltdowns on them. We just don't travel much or very far with him, as a whole family. His anxiety increases anytime we take him completely out of his routine and food schedule. It's just not worth it. For now.

Because of that, my apprehension in taking him alone (without my husband, Chris) was high, I had a dose of cautious optimism also residing in me.

What if something random triggered him into a meltdown on the plane full of 200+ passengers?

What if he became completely insecure and untrusting about his travel-trip-food-schedule?

What if he had "behaviors" at the YAP Program with all those cute and young volunteers?

WHAT IF?

And yet:

What if this special one-on-one trip with me actually soothed him?

What if he viewed this trip as "highly preferred" and was therefore on his best behavior?

What if having NO SIBLINGS to take my attention nor BUG him, actually decreased his anxiety and mine?

It's a beautiful, sometimes even miraculous thing, when your special kiddos exceed your expectations. Ryan completely surprised me on this trip.

Ryan was a champ! Even with the flight delays and NO FOOD served on the plane, (excuse me American Airlines!), he was calm. Flexible. He handled his first Uber ride, first plane ride to Florida, first huge convention, and his first trip with JUST ME beautifully. He was EASY. Yes, I just said that, and its forever sharp-ied on my heart. For me to see that in the first 24 hours how well he was doing, completely made my apprehension dissipate.

For me, as a mom, living out this PWS Story, I loved the convention. It offered so much practically and personally.

First of all, on a practical note, all the sessions offered were incredibly valuable. I liked the choices and speakers. Was the information overwhelming at times? Yes. But helpful. The convention appeared to be a well-oiled, well-staffed machine, with the KINDEST, most helpful volunteers.

Secondly, to be with other moms and parents who "get it" and "get you", without miles of explanation, is comforting and transformative. I believe in the power of gathering and the power of community. It is life-changing to know and feel you are not alone. I'd even love to see a MOMS-only sharing session and a DADS-only sharing session in the future.

We have a wealth of support that is priceless and unending in PWSA (USA). I cannot wait for 2019!! ■



Firat-timer Ryan enjoys playing a game with veteran attendee, Justice Faith Rickenbach.

From Washington to Florida - Convention or Bust!

By Linda Torgerson, Silverdale, Washington

My name is Linda and my husband Jerry and I live in Washington. We have two daughters: Leah age 31, and 29-year-old Kristin, with PWS. She was diagnosed at age 2 ½. Shortly afterwards, I attended a PSWA (USA) conference in Seattle. It was the first time I had seen another person with PWS. The conference was uplifting but overwhelming; I was still trying to understand the syndrome with the limited information at the time.



Kristin, at age 8

For the next 27 years, we as a family did the best we could by creatively problem-solving our lives with PWS as we went. Interestingly while in junior high, my daughter coincidentally met two other girls in her class with PWS! Wow! We invited those families to our home for a meet and greet. It was such an amazing experience to see how much we had in common. ***It was so refreshing to have someone else understand*** the food-related meltdowns and the unusual things we dealt with, including the school system. And we "survived". We purchased our home about eight years ago with Kristin's long-term future in mind. Our split-level home is split in two with a door that locks from my side to keep food secure but giving her the most freedom possible. She has her own apartment downstairs and my husband and I live upstairs. Doing this was really one of the best things we have done; it works well for all of us as Kristin enjoys her space and we enjoy ours. She joins us for dinner about half the time; other times her food is brought down to her. It is always her choice and she likes it that way.

I was also extremely delighted to hear and learn about the Parent Mentoring program. What a life-changing program.

Fast forward to 2017. It was time to attend the PWSA (USA) convention. I wanted to see and learn of the types of progress and changes that had occurred since 1990, plus had great hopes of making connections with parents and more. Did I ever! My biggest surprise was the unbelievable early diagnoses being made and the numerous new medical breakthroughs for the young babies, and also older children! There were so many babies at convention and they were ALL thriving!

I was also extremely delighted to hear and learn about the Parent Mentoring program. What a life-changing program. Long overdue, this could have been so helpful when my daughter was younger, but so grateful this is helping so many of us now. We can't wait to get started.

In closing, Kristin and I met the nicest parents, families, and caregivers, as well as children and many adults with PWS. It was a VERY uplifting time for both of us. Our goals are to: connect with the chapter here, engage with the Parent Mentoring group, and most of all, return in two years to further the relationships we started, and continue creating new ones. We can't wait to see you again and meet more of you! Blessings- ■



Mother Linda, with daughter Kristin, are ready to celebrate at the PWSA (USA) National Convention galas!

Access PWSA (USA) via App on mobile devices!

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. ■



Chapter View

The Chapter Relations Committee held their annual Chapter Leader meeting on November 15th - 16th at the Caribe Royale Orlando Suites and Villas in conjunction with PWSA (USA)'s 34th National Convention. Thirty-four participants from the following twenty chapters were present at the meeting, as well as the national board members and office staff attendees.

~Arizona ~California ~Colorado ~Florida ~Georgia ~Idaho ~Iowa ~Louisiana ~Michigan ~Minnesota ~Montana ~New England ~New Hampshire ~New Mexico ~New York ~Ohio ~Pennsylvania ~Tennessee ~Texas ~Wisconsin

Beginning Wednesday, attendees spent the morning discussing a myriad of topics related to Board Operations, such as how to set up a board, the creation of bylaws, time management, membership, database management, social event planning, fundraising and raising awareness. After lunch, the PWSA (USA) Development team discussed their goals for 2018 and various aspects of fundraising. Later Wednesday afternoon, Kathryn Lucero presented on Self Care and everyone discussed respite and sibling involvement. The meeting closed with a discussion on how one diet doesn't fit all, the type of specialists and therapists recommended to members by the chapters, and what PWS clinics currently exist.

That evening Parent Mentors joined Chapter Leaders at a fun welcome reception at the Convention Center. Attendees enjoyed hors d'oeuvres and beverages while laughing, sharing stories, and getting to know one another.

On Thursday, the Chapter Leaders and Parent Mentors groups joined together to learn about the State of the Association, Family Support, Education, Medical Affairs, Development, the Global Registry, and Research. The two groups then separated. Following, the Chapter Leaders heard about successful advocacy efforts in various chapters, such as New York and Ohio. Additionally, Tom Conway from the Advocacy Committee shared their proposed advocacy plans for the upcoming months.

The day's session closed with a presentation regarding placement both in and out of state. Everyone seemed excited to share ideas and learn from each other throughout the two days!

I'm thrilled to announce we've also had four individuals reach out expressing interest in starting chapters in their state! Stay tuned to learn more about where these new chapters will be located! I am so proud of the excellent work and growth we are doing. ■

By Crystal Boser, Chapter Relations Chairperson, PWSA (USA)



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

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

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

The Gathered View (ISSN 10 77-9965)
Sara Dwyer, Editor
Lota Mitchell, Andrea Glass, Denise Servais, Kathryn Lucero

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Friday, March 23rd, 2018
Courtyard by Marriott
Bradenton, Florida

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, or at 941.487.6729.

Visit the following link to learn more: http://bit.ly/2IYlTAFhurdle





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