## The Gathered Vie



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

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

#### **CEO View**

## **Education and Learning -**Valuable and Specific Information You Can Use

While you might be reading this when many schools are on summer break, education and learning about Prader-Willi syndrome, and how to best address the issues the syndrome presents, is going on at full speed.



Education is one of PWSA (USA)'s Five Pillars of Support and one of our most comprehensive initiatives. "Education" is very broad-based and encompasses many audiences and activities:

- Informing the public about PWS, including all the communications during the recent May Awareness Month;
- Familiarizing medical providers and school professionals with the needs of the PWS community;
- Training service providers including residential care facility
- Providing parents and caregivers with information to empower them to meet the needs of their loved one with PWS; and
- Alerting legislators to the particular challenges faced by individuals with PWS and their families.

Information and resources distributed by PWSA (USA) have been, and continue to be, fundamental to our working together to Save and Transform Lives. Providing awareness across the country helps empower those with PWS to live their best lives, such as through increasing awareness to encourage peer group acceptance while in school, and employer education to facilitate more opportunities for greater independence as adults.

You might say that "Learning" is the flip side, or receiving end, of education. We want to offer you a multitude of formats and opportunities to learn all that will improve the health and well-being of your loved one with PWS, and of your whole family. There are many other ways to absorb valuable information beyond being in a class or reading a manual. Consider how you can gain very useful, "real life" insights through:

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### A Message from Our Chair: A Lifetime of Support from PWSA (USA)

It has been an honor for our family to have been connected to this association, in one way or another, for just about the entire four decades since our daughter Kate was born with Prader-Willi syndrome.



The Kane family

Now, as Chair of your Board of Directors, working to continue to expand the vital Family & Medical Support services that our organization provides is a way to "pay back" for all the help the Kane family has received over the years. We certainly took advantage of the wide array of programs and resources in place and the many connections we made to enhance the quality of life for our daughter, and for all of

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The third featured of five icons is part of our Five Pillars of Support. By definition, ed-u-ca-tion \ ,e-j\u00e3-'k\u00e4-sh\u00a\n\: is the action or process of educating or of being educated also: a stage of such a process

Education = capturing knowledge. Learning and comprehending Prader-Willi syndrome (PWS) can be overwhelming to the uninitiated. Searching for information online often presents a broad (and often misleading) array of contradicting data and articles. To understand and learn more visit https://www.pwsausa.org/ browse, use the search tool and see stories, resources and information. Learn more about this rare syndrome. We want to hear what you learned reading this issue and visiting our website.

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- Exchanging experiences with other PWSA (USA) members at state or regional chapter events;
- Participating in our age-based and other specialized Facebook groups via https:// www.pwsausa.org/family-support/
- Connecting with friends, long-time or brand-new, at our national convention

   such as in between and after the extremely informative presentations and workshops; and
- Embracing resources we offer that range from our professional Family & Medical Support staff, including assistance with Individual Educational Plans and handling complex medical scenarios, to the recently expanded Residential Care Database (see page six).

You may want to take advantage of other ways to learn about issues ranging from medical and clinical best practices to financial planning, and from behavioral management tips to support for caregivers, through other avenues. For instance, the PWSA (USA)

online store has a library of informative publications for sale that are available to current members for 20% off. (The store is holding a half-off summer sale on all logo merchandise and apparel, so be sure to check that out too!)"

Of course, *The Gathered View* stories and articles cover the gamut of subjects, and our website www.pwsausa.org has both archived copies from years past and a wide range of topics covered in accumulated PWSA (USA) blog posts. Watch for upcoming webinars, and remember that you can view past webinars, also via our website. Also, please let us know if you'd like to be emailed issues of our specialized newsletters *School Times* and *Residential Times*, with all their targeted and timely content.

Learning from the experience of others who have gone before us can be especially powerful, which is the model brought to life by our dedicated Parent Mentors. Our largest volunteer group, this cadre of parents are great resources

you can tap and benefit from the knowledge and strength that those with children with PWS older than yours have gained.

Education and learning are lifelong priorities for us all. Please access our resources to make learning easier for "you and yours." Lastly, let us know of topics, or methods of sharing information, we might provide to help your loved one with PWS maximize his or her education, as well as to help you gain all the information you need.

> Best regards, Steve Queior

#### Our Chair, continued from page 1

our family. Along the way we have been privileged to meet many people we now include in our PWS family.

PWSA (USA) is unique. From the moment of diagnosis, our Family & Medical Support team offers hope and guidance to families as they transition through each stage of their child's life.

This all starts with the information, support, and the individual parent mentor we provide to the family with a newly diagnosed child. From then through adulthood, whether it's reassurance during a medical emergency, advocacy during the school years, or help securing safe and supportive residential care for an older child, the PWS community turns to PWSA (USA) in their times of greatest need. PWSA (USA) is the only organization in the world that provides such a comprehensive support community. And the support is provided at no charge to the individual family.

Now we need you. We rely on the generosity of donors to make this critically needed work possible. This month the six-week PWSA (USA) Family & Medical Support fundraising campaign starts, and I invite you to join those who have invested in this drive in the past to make a positive difference.

Your gift will ensure that help is available when our families need it. Please read the messages you'll soon receive about both how much funding is needed and the important ways dollars raised are used to help families and their loved ones. Your assistance allowing us to help all, whether they 2, 15, or 50 years old, is most appreciated.

**Your role** helping us do even more, together, to *Save and Transform Lives* is key. Regardless of size, your gift this summer is important. Thank you for all your past and future support!

Jim Kane Chair of the Board, PWSA (USA)



## "Providing Homes with a Heart"

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

Contact us

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



## 2019 Convention

#### **Conference Session Spotlight** What do all these test scores really mean?

Learn how to understand psychological and neuropsychological test scores, how to interpret test data and understand standard scores, T-scores and scaled scores. What do these scores mean and what and how do they measure? Dr. Tyson will cover gold standard evaluations and teach parents how to request specific tests and why they are so necessary to gain a full clinical picture. Her presentation will provide tips and tactics on how to interpret and understand how some data can be misleading and what to look for in an evaluation. Additionally, she will talk about diagnoses that often co-occur with PWS, what should be evaluated and how to obtain the best outcomes for your loved one.

#### Presented by Karen Tyson, Psy.D.

Karen Tyson, Psy.D., is a Pediatric Neuropsychologist and the Chief Clinical Psychologist at the LD-ADHD Center of Hawaii. She has a Doctorate in Clinical Psychology and post-doctoral specialty training and certification in neuropsychology. She is a nationally recognized expert in the area of learning disabilities, ADHD and Autism. She is on faculty for the Institute for Special Education Advocacy at the William and Mary School of Law and is called on to testify in court for learning disabled students across the United States. Her clinic, the LD-ADHD Center of Hawaii, has multiple offices on Oahu and also on the Big Island. She specializes in learning disabilities, ADHD and Autism and conducts exhaustive neuropsychological evaluations to assist families and schools in better understanding a child's strengths and deficits. She is also an active researcher. Current research

## Gastrointestinal Complications and Gastroparesis in Prader-Willi Syndrome

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

Prader-Willi syndrome (PWS) is a disorder that is hallmarked by symptoms of intellectual disability, low muscle tone, and hyperphagia. Choking, gastroparesis (a slow emptying of the stomach), gastric distention and rupture, severe constipation and bowel obstruction occur in a disproportionally high number of persons with PWS. It is believed these conditions occur because of the slowing of the contraction (peristalsis) of the esophageal, stomach and intestinal muscles. Because of this delay, food does not pass through the gastrointestinal (GI) tract normally, especially if taken in large amounts, which increases the risk of blockages, dilation and distention.

Binge eating, the size of the "bite" and type of food being consumed influences the risk for choking which can frequently be fatal without intervention. Frequently persons with PWS do not realize they have food lodged in the esophagus and can potentially aspirate the food particles which can lead to a choking episode that progresses to an airway blockage. This situation will require the Heimlich maneuver and emergency medical management to prevent a fatality.

Another complicating fact is that persons with PWS are unable to sense when their stomach is full, so they can not regulate the amount of food they consume, which increases the chance they will overeat and become distended which could lead to gastric complications. If the stomach is stretched to the point that the blood supply to the stomach wall is cut off, tissue can die or become necrotic. This weakness of the tissues could allow the lining of the stomach to tear (perforation) allowing fluids to leak into the abdominal and chest cavity. This

is a life-threatening medical emergency and requires immediate diagnosis and treatment or the person will not survive.

The usual symptoms seen in gastroparesis include abdominal distention or bloating, abdominal pain, heartburn, vomiting and regurgitation of stomach fluid into the mouth. These symptoms can be very difficult to detect in persons with PWS. If vomiting occurs or there are any signs of acute abdominal illness, a person with PWS should be evaluated by a health care professional immediately.

#### Ways to prevent these medical and life threatening emergencies:

Small quantities of food at frequent intervals (three small meals and 2 snacks)

Increase liquids during and between meals; water is best and encourage sips between bites of food, "Pace and chase"

Avoid raw fruits and vegetables, steam and/or mash foods as appropriate

Soft foods are preferred, cooked cereal, smoothies, soups, and canned fruit in natural juice.

Schedule meals as early as possible to allow for digestion prior to bedtime. Stay upright after meals and promote exercise.

If swallowing issues or gastroparesis are suspected, an evaluation by a Gastroenterologist is recommended ASAP. Typically a Gastric Emptying Test will need to be done to evaluate for gastroparesis. If choking is a problem, they will most likely do a swallow study. These disorders can be treated and the symptoms minimized with early identification and interventions, but it important to monitor persons with PWS closely and provide strict food safety to avoid complications and possibly fatal outcomes.

studies include gender differences in girls with autism as well as a reverse longitudinal study of the effects of

Pitocin on the brain and possible correlations with Autism Spectrum Disorder.

# PWSA (USA) Attends/Exhibits at PENS 2019 National Conference

The Pediatric Endocrinology Nursing Society (PENS) conference is designed for the continuing education of Pediatric Nurses and Pediatric Nurse Practitioners specializing in Pediatric Endocrinology. The goal of the program is to promote high quality pediatric endocrinology nursing practice by providing attendees with the latest information on endocrine



Mary Burr sharing info at PENS, April 25-28 in Long Beach, California

DESTINY PWS —
Phase III Clinical Study
Soleno Therapeutics, is currently conducting/
recruiting in the U.S. and the U.K. for phase III

#### What is being studied?

This study is evaluating Diazoxide Choline Controlled-Release (DCCR), a once-daily oral tablet, to see if DCCR can reduce hyperphagia. The study also evaluates the effects of DCCR on overall body composition. The safety of DCCR in patients with PWS as well as the effect of DCCR on BMI, waist circumference, lipid parameters, patient's health-related quality of life, caregiver burden and various PWS behaviors are also assessed.

#### Why we believe DCCR may work

In a previous study with DCCR in overweight or obese patients with PWS ages 10-22, there were improvements in hyperphagia, lean muscle mass, decrease in body fat mass, and reductions in waist circumference and aggressive behaviors.

#### **KEY eligibility criteria**

Eligible participants must be four years old or older, have genetically confirmed Prader-Willi syndrome, be hyperphagic, and have a caregiver with the participant at least 4 hours a day from 6 months prior to the first study visit and throughout the length of the study. Participants must be on a stable regimen of medications for at least three months prior to Visit 1.

#### What does this study involve?

This 15-week study has seven clinic visits. Participants are monitored at every visit for safety using physical exams, blood work and questionnaires. Participants need to fast at least 8 hours prior to every visit for fasting blood tests. Questionnaires for the parent/caregiver are required, an ECG, DXA scans, urine tests as well as a diet, physical activity and sleep assessment. The double-blind, placebocontrolled study has 33% of patients receiving placebo (a tablet with no active drug in it); there is no guarantee participants will receive the study drug during this study. At the end of the trial, each participant who successfully completes this study has the option to enroll into a safety extension study where everyone will receive DCCR.

#### Study Locations –

More information and sites currently recruiting participants is available at: http://bit.ly/2X4VQwj-PWS-DCCR.

For any questions, please contact: https://soleno.life/dccr/ or info@soleno.life

practice trends and research findings.

Attendees were from pediatric endocrinology practices from all over the USA, Canada and Australia. Presentations were divided into General Sessions, Diabetes Management and Basic and Advanced Endocrine Practice Issues. There were approximately 200 attendees, half of which were Pediatric Nurse Practitioners.

Two preconference workshops were offered: a diabetes-focused session, and a research workshop partially funded by a grant from PWSA (USA). During the conference there were two PWS sessions offered aimed at helping endocrine providers better understand the specific needs of our special population. The first presentation was packed with useful clinical tips for a successful research visit for the person with PWS. This presentation was given by a pair of nurse providers at Seattle Children's Hospital who have identified the need to educate research clinicians that the PWS population may require a modified approach when being asked to participate in a research visit. The topic has become an issue because of the increased number of research studies in the PWS population that are starting to recruit subjects. The second session was presented by nurse practitioners at nationwide Children's Hospital in Columbus, Ohio. They described how their practice developed a survey to screen children and young adults with PWS for the risk and or

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#### **2019 Convention News Conference Session Spotlight**

#### **Psychiatric Medications**

This lecture will describe when, why and

how to use psychotropic medications in persons with PWS. The most commonly used medications will be identified, and their action in the brain will be described. Target symptoms and potential side effects will be discussed. The role of the parent in the treatment process will be emphasized.

#### Presented by Janice Forster, MD

Janice Forster, MD, is a developmental neuropsychiatrist who has been working with children, adolescents, adults with PWS and their families for over 30 years. She has clinical experience

with all levels of severity of the syndrome and across all living situations, from family to group home to inpatient hospitalization. Because she has presented across the USA and around the world, Dr. Forster has a "world's-eye view" of how the syndrome is managed. More recently, she has become involved in research exploring the developmental phenomenology of PWS and the efficacy of interventions to reduce stress in fathers of adolescents with PWS. She is "one-half" of the Pittsburgh Partnership (www.pittsburghpartnership.com), established 15 years ago with Dr. Linda Gourash, for clinical consultation and education of professionals, families, and caregivers. In addition to serving on the Clinical Advisory Board of PWSA (USA), Dr. Forster is also on the Clinical and Scientific Advisory Boards of the International

Prader-Willi Syndrome Organisation (IPWSO.)

Pens, continued from page 4

occurrence of choking. They presented the results of their screening; 18% of those screened had choked at least once and of those who choked 50% required a resuscitation intervention; specifically the Heimlich maneuver. Based on these results they changed their practice to include teaching their families the Heimlich during routine visits to the endocrinologist.

The PWSA (USA) exhibit booth was manned by Medical Coordinator Mary Burr, D.N.P., C.P.N.P., and Lisa Graziano from the California Chapter of PWSA (USA). Booth traffic was high and there were many questions from the attendees regarding the care of children and young adults with PWS. Overall, the consensus from our visitors was positive and they were overwhelmingly appreciative of the support and resources offered by PWSA (USA) and its state chapters. An additional perk of exhibiting at the conference was the opportunity to exchange contact information between PWSA (USA) and the providers and their respective practices. The hope is that gathering this information in similar venues will help PWSA (USA) to establish a more robust and current listing of PWS providers nationally.

## Mayor Howard Recognized for **PWS Awareness Month**



The Howard Family

Every year PWSA (USA) celebrates May Awareness Month to help bring attention to the needs of the PWS community. This year staff, volunteers, and PWSA (USA) chapters worked together to spread awareness and increase education by sharing resources, information, and personal stories via email, social media, and outreach events.

This year, the Howard family brought a little extra attention and plenty of fun to the effort when their daughter, Emily, was named "Mayor" of Columbia,

Kentucky, for the month of May. In addition, May was recognized as PWS Awareness Month for the city.

Emily's mom, Mary, is the President of the Kentucky chapter of PWSA (USA). Says Mary, "We held our first On the Move walk in May, too. Everything we do, from hosting an

event, to introducing our local officials to our community, helps create a more understanding and supportive environment for individuals and families living with PWS. By working together to raise awareness, we can help others understand how they can help empower those living with PWS."

PWSA (USA) thanks the Howard family and the entire PWS community for making this year's PWS Awareness Months one of the best yet. Together, we are Saving and Transforming Lives!



#### ZEPHYR PHASE 2B/3 CLINICAL TRIAL - NOW RECRUITING!

#### What is LIVOLETIDE?

Livoletide is an investigational drug being studied by Millendo Therapeutics for the treatment of hyperphagia in people with Prader-Willi syndrome (PWS). Livoletide has not yet been approved for use by a regulatory authority.

#### How is LIVOLETIDE designed to work?

Based on prior research in laboratory and animal experiments, livoletide may improve hyperphagia by counteracting a hormone in the body called acylated ghrelin, which stimulates appetite and is associated with other metabolic effects.

#### **Has LIVOLETIDE been tested in PWS?**

Yes. In a 47 person randomized double-blinded placebo-controlled Phase 2 study, livoletide was shown to improve hyperphagia in participants with PWS more than placebo over 2 weeks. There were no serious adverse events (AE) or discontinuations because of AE. The most common AE were injection site reactions, but these were seen more in the placebo group.

#### What happens in the ZEPHYR clinical trial?

There will be more than 35 sites in the US and Europe. Patients will be randomized into 3 groups (high dose, low, dose and placebo) and treated for 3 months, then all patients will receive livoletide for the following 9 months. The primary endpoint will be a change in hyperphagia. To be included in the study, the participant:

- Must have PWS and hyperphagia
- · Must be age 8 to 65
- Must have a primary caregiver throughout the study
- Must have a body mass index of ≤65 kg/m<sup>2</sup>
- May have type 2 diabetes, but HbA1C must be <10%</li>
- May be on growth hormone or insulin, but dose must be stable



For the latest information about ZEPHYR, please visit www.Millendo.com or go to www.clinicaltrials.gov for Clinical Trial NCT03790865



# Exciting New Residential Care Database Project Unveiled

PWSA (USA) is pleased to announce the upcoming release of an exciting new online Residential Care Database designed to help families in their search for residential care placement options. Through the database families can find current information on residential care providers in the U.S. who support individuals with Prader-Willi syndrome. Once complete, families will have easy access to basic provider contact information, as well as information on provider funding and finances; care issues specific to PWS; staff training; daily vocational, recreational, and socialization activities; and health. For the first time ever, this much-needed information will be available to families through a convenient, easy-to-use online database, 24 hours a day, 7 days a week. To date, 96 residential care providers have been identified with more being added as they are discovered.

The Residential Care Database is scheduled to launch online August 1, 2019. Until then, updated information on identified residential care providers is available from PWSA (USA)'s Family and Medical Support Team.

PWSA (USA) is very excited about this two-phase project and the impact it will have on families' decisions regarding the residential care placement of their loved ones with PWS.

Note: Availability of openings in these programs isn't known, and some programs might not have any openings at all.

Disclaimer: The Residential Care Database is for general information purposes only, and information is being gathered and shared in good faith. PWSA (USA) makes no representation or warranty of any kind, express or implied, regarding the accuracy, adequacy, or completeness of the information. Parents and caregivers must do their own "eyes-on" investigation and determine if programs are a good match for their loved one's needs. Under no circumstances will PWSA (USA) be liable for loss or damage of any kind incurred as a result of use of this information. The provision of the information does not constitute an endorsement of any of the facilities. Use of any of the information is "at your own risk."

PWSA (USA) has updated a handout titled "Questions Families Should Ask Potential Providers of Residential Services" designed to help parents and guardians investigate and select providers who meet the individual needs of their loved one with PWS. (add link to website location) The Residential Care Database will serve as another "tool in your toolbox" in finding the right place for your loved one to reside.

#### **PWSA (USA) FIVE PILLARS OF SUPPORT**











## Transition Planning and Resource Guide

For Parents and Guardians of Young Adults (age 15) with PWS

(2015)This will help you answer questions about a wide range of topics including but, not limited to,



vocational evaluation and transitioning from school to work, residential living options and personal health education. Compiled by: Kate Beaver, MSW, and Barb Dorn, RN, BSN \*P-13, C,S \$25.00 Use link below to order http://bit.ly/2j5tMktPWSAUSATransition

### 24/7 PWSA (USA)

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

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

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



http://bit.ly/2CsjHsnPWSAmobileapp

#### 2019-2022 Board of Directors OFFICIAL BALLOT

#### **Voting Instructions:**

- 1. Review the candidates' statements printed on the Slate of Candidates.
- 2. Cast your vote on the Official Ballot, voting for six (6) candidates only. Insert the ballot into the Official Ballot Envelope.
- 3. Print and sign your name on the Official Ballot Envelope. Affix postage. Mail it to PWSA (USA) postmarked no later than August 17, 2019.
- 4. If you receive The Gathered View only in an electronic form and were not provided with an Official Ballot Envelope, please mail your ballot to: Julie Doherty, Secretary, PWSA (USA) 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471. In the return address portion of the envelope, print your name and address and the following statement: I am/We are a PWSA (USA) Member in Good Standing Eligible to Vote. Place your signature below this statement.

Deadlines: The deadline for voting is August 17, 2019. Ballots postmarked after August 17 will not be counted.

Confidentiality: Your vote will be kept confidential. PWSA (USA) staff will verify voter eligibility and separate the Official Ballot from the Ballot Envelope before the Ballots are tallied.

Voting Criteria: Voting members must be Members in Good Standing with PWSA (USA). Membership dues must be current and paid in full or a dues waiver granted.

Member Types Eligible to Vote: Each membership type, whether individual, family or professional, is entitled to one vote.

Cast your vote for the 2019-2022 Board of Directors. Vote for six (6) of the candidates listed below.

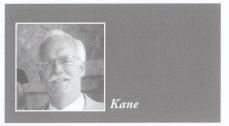
8	Clip along dotted line and mail
2019-2022 Board of Directors	
OFFICIAL BALLOT	
Cast your vote for the 2019-2022 Board of Directors. Vote for six (6) of the candidates listed below.	
☐ Tim Hearn, Esq.	
☐ Jim Kane	
☐ Rob Lutz	er armarina John Col
☐ Matt McCleery	
☐ Denise Servais	
☐ Michelle Torbert	
	New Jersey and American

#### Board of Directors 2019-2022 Slate of Candidates



## Timothy S. Hearn, J.D. Minneapolis, Minnesota

Tim is a senior partner with the law firm of Dorsey & Whitney LLP in Minneapolis and has served as the firm's General Counsel since the beginning of 2013. He earned a B.A. in American History from Brown University in 1978 and a J.D. from Harvard Law School in 1983. Tim joined Dorsey & Whitney upon his graduation from law school and has spent the last 36 years advising primarily medical device, pharmaceutical and software companies in connection with raising capital, buying and selling businesses and general corporate governance issues. Tim also served on the Board of Directors of Special Olympics Minnesota and the Board of Directors of World Voices, a Twin Cities based choral ensemble specializing in global music. Tim and his wife, Carol, who is also an attorney and a past chair of the PWSA (USA) Board of Directors, have been married for 36 years. They have two daughters, Jessica, 32, of Mannheim, Germany, and Maryellen, 30, of San Francisco, California, and a son, David, who is 26 years old and was diagnosed with PWS at the age of 4. David is currently living at home with Tim and Carol, attending a day program run by Lifeworks Services, Inc. and engaging in afternoon activities with staff from Hammer Residences, Inc. At the end of June 2019, Tim will retire from the practice law with Dorsey & Whitney and will commence the next stage of his life. Among other activities in retirement, he hopes to use his analytical and problemsolving skills in serving as a member of the PWSA (USA) Board of Directors and working to address the needs of PWS individuals and their families.



#### James G. Kane, M.B.A. Baltimore, Maryland

Jim is a recently retired real estate executive, whose experience includes public accounting, finance and over thirty years in the real estate industry. Acting as property manager, Vice President and partner of a private company, Jim was responsible for all the business activities of a commercial portfolio of over 2,000,000 square feet of retail, office and industrial space. Jim and his wife Kit have been married for almost 40 years and are the parents of Kate, 34 years old and Molly, 30 years old. Kate was diagnosed with Prader-Willi syndrome (UPD) when she was five. Kate has had a fairly typical life for a young lady diagnosed with PWS in the early 1990's when many of the medical advances known today were as yet unavailable. Kit and Jim have experienced the trials, tribulations and joys of helping Kate battle the syndrome and the system. Kate currently is very happy in a structured living environment. Jim has been actively involved with PWSA (USA) for many years. Having served as the Treasurer, Board member and Board chair, Jim has seen the organization grow into the dynamic service resource it is today. If elected to the board. Jim hopes that he can help PWSA (USA) progress to new levels of "Saving and Transforming Lives".



#### Robert Lutz Bryn Mawr, Pennsylvania

Robert Lutz is the Chief Business Officer of Strongbridge Biopharma, a biotech company that is developing pharmaceutical drugs for rare diseases. In his current role and in his 15-year career in the pharmaceutical industry, he has experience with the people and processes that are developing drugs for rare diseases. Rob received his MBA from the Kellogg School of Management at Northwestern University. Rob and his wife Debra have been married for 23 years and have two daughters ages 19 and 16. Their eldest daughter, Isabel, was diagnosed with PWS at 6 months old. The family has been an active member and supporter of PWSA (USA) since her diagnosis. Isabel is in the 12th grade at the local public school, lives at home and her passion is horseback riding. For 11 years, Rob has served on the PWSA (USA) Board over time and has experience on the Research, Finance, and Fund Development Committees. Rob is committed to helping PWSA (USA) accelerate the development of therapies for PWS and support families with education, conferences, chapters, and crisis support.

There is a choice you have to make, in everything you do.

So keep in mind that in the end, the choice you make, makes you.

- Philip B. Bliss

#### Board of Directors 2019-2022 Slate of Candidates



#### **Matthew West McCleery** North Chatham, Massachusetts

Matt McCleery is 49 years-old, has been married to his wife Buffy for 20 years and is the proud father of 3 boys aged 15, 12 and 12 - one of whom has Prader-Willi syndrome and is a residential student at the Latham School on Cape Cod.

Matt was trained as a lawyer, but has spent his entire career involved with the financing of ocean going cargo ships. He is the owner of Marine Money, a publisher and organizer of 19 ship finance conferences from offices in Singapore, Athens and Connecticut. He is also a director of Blue Sea Capital, which advises on ship financing transactions. He is the author of The Shipping Man, a novel about a hedge fund manager who purchases an old freighter from a Greek shipowner.

Together with Buffy, Matt is a founding member of the Latham School Parent Group and serves on the board of directors of Latham Centers. He is also an organizer of the Latham / Mac Pact PWS Conference and was a founding member of the SEPTO of Guilford, CT. Matt is a strong believer in the power of information sharing and networking to improve the lives of people with PWS and their families and he would welcome the opportunity to be of service to PWSA (USA) - an organization he admires and for which he is very grateful.



#### **Denise Servais** Lake Elmo, Minnesota

A dedicated speech-language pathologist (SLP), Denise graduated from the University of Virginia with a Master of Education in Communication Disorders. She has been working as a SLP for over 20 years in a variety of settings with different ages, from early childhood to geriatric. Denise is a member of the American Speech and Hearing Association, and is a regular contributing writer for The Gathered View. Denise lives with her husband of 23 years, Jeff, and their three girls Maddie (17), Maya (15), and Mallory (10). Maya was diagnosed with PWS at the age of one month. In her free time, Denise enjoys singing, traveling, and spending time with her family. Denise and her family are grateful for the support they have received from the PWSA (USA) community. Denise believes that now is the right time to pay it forward. She feels that she can use her time and skills as a speech therapist to help other families who may need help like her family has received in the past.



Torbert

#### Michelle M. Torbert Homestead, Florida

Michelle served as President of the PWSA (USA) Florida chapter from 2007-2015 and is a current chapter board member. A 2009-2018 member of the PWSA (USA) Board of Directors, Michelle served as Board Chair from 2015-2018. She is currently Chair of the 2019 National Convention, serves on several committees, and is a Parent Mentor.

Michelle and husband Tommy established the Casting for a Cause fishing tournament which ran from 2008–2017, raising over \$1 million for PWSA (USA) and the Florida chapter.

From 1981-1991, Michelle worked as a police officer for the City of Homestead. She and Tommy formed Torbert Produce and Farms in 1988. Michelle is active in her church and has served on numerous community boards. Married for 33 years, Michelle and Tommy have four "boys" ranging from 24-29 years of age and the Princess Leslie with Prader-Willi syndrome, who will turn 22 in August.

Michelle would be honored to serve another term on the PWSA (USA) Board of Directors, continuing to help and support families and their children.

Love recognizes no barriers. It jumps hurdles, leaps fences, penetrates walls to arrive at its destination full of hope."

- Maya Angelou

## **Bringing Hope**

By Kristi Rickenbach, mother to Justice age 15 with PWS, board member, PWSA (USA)



"Optimism is the faith that leads to achievement. Nothing

#### can be done without hope and confidence." ~ Helen Keller

There are things that happen in our lives that we have no control over-things we wish we could change. These "things" come in many forms and can devastate a person or an entire family. We may not be able to control all aspects of our lives but what we can control is our reaction to them.

When we received our daughter's diagnosis one month after her birth, our world turned upside down. Our perfect little family was suddenly thrown into a new world where doctor appointments and therapies ruled. This world was more unknown than known. We grieved for the baby we had dreamed of. We grieved for the future we felt she may never have. We grieved for our four other children; their lives were forever changed too. We grieved and then one day, we didn't.

#### "Life is 10% what happens to you and 90% how you react to it." ~ Charles R. Swindoll

We could have fallen into a deep, dark place but we knew that would not have changed anything. Instead, we decided to bring hope to this diagnosis. We have taken what we know and have shared that hope wherever possible.

Recently, Justice and I were asked to speak to the entire genetics department at our local children's hospital. Our message was simple- bring hope.

We felt this room full of geneticists and genetic counselors did NOT fully understand the impact their words can have on families to whom they give life-changing diagnoses. Handing those parents a list of "this is what your child will never do" or the dreaded list of "all children with this diagnosis will



suffer from..." is traumatic. There are things that newly-diagnosed families need to know about every diagnosis, but not everything, certainly not all at once. Instead, new parents need to hear "congratulations, you have a beautiful baby"!

Simply, parents need to understand their child's syndrome will come with some challenges and that there IS hope. Studies and trials are being done and there are many doctors and researchers fighting to improve the lives for all children diagnosed with Prader-Willi.

Our family's message? "Our" children are not textbooks. OUR children are unique individuals who happen to have a diagnosis of a rare genetic disorder.

Our daughter Justice Faith explained it so eloquently to the room full of people, "We all have something; mine just happens to have a name." She explained

that "PWS is only a small part of who I am and it does not define nor limit me." The room was very quiet after she spoke, I don't think they expected such a well-thought-out response from Justice. The listeners own personal textbook biases had made it difficult for them to believe that she was able to carry on a conversation and stay on topic. Following her remarks, most questions were directed to her.

This was one of many opportunities Justice has had to speak publicly of her diagnosis, bringing her message of hope to many people. Her dream of being a motivational speaker has begun. She wants to encourage and bring hope to many, especially those working for, or living with, health issues.

Sharing our story and offering hope has personally brought me healing I didn't even realize I needed. It has also given Justice a platform to share her feelings about living with PWS. Most importantly, bringing awareness offers opportunities to make a difference for future families waiting nervously in the NICU. We are so proud of our daughter, who is lighting the way by educating the public, as well as the medical professionals.

#### CARbetocin Efficacy and Safety Study in PWS

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



CAREPWS

www.levotx.com/care-pws

www.clinicaltrials.gov - NCT03649477



By Stacy Ward, M.S.

The Individuals with Disabilities Education Act (IDEA) requires that students with disabilities have a free appropriate public education (FAPE) available to them. One that is designed not only to meet their unique disability-related needs but also to prepare them for further education, employment and independent living. This includes transition planning which according to the IDEA must begin no later than the first Individualized Education Plan (IEP) in effect when the student turns 16. The transition plan must be included in the child's IEP and updated annually thereafter.

#### So, what is transition planning?

Transition planning is a coordinated set of activities for a student with a disability designed for implementation within a results-oriented process that:

- Is focused on improving a child's academic and functional achievement.
- Successfully facilitates the movement of a student from school to postsecondary education and activities.
- Should begin early in the child's educational career but no later than when the child turns 16.

#### Federal Employees!

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

PWSA (USA) CFC ID # is 10088

To learn more click or visit

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



Data should drive all aspects of plan development and reflect assessments completed to measure foundation skills (academics, independent life skills, communication skills and technological skills), integrative skills (social skills, self-determination skills and personal values) and application skills (career exploration and planning, job acquisition and post-secondary education and training). Ensure assessments are current and measure aptitude and present levels of performance across multiple domains, identifies your child's goals, interests, preferences, values and needs as they relate to obtaining their goals.

## Parent Role in Facilitating Effective Transition Planning

As a parent, your role in the transition planning process is to ask questions of

yourself and the IEP team including:

- Does the IEP reflect your child's interests, strengths and preferences?
- Does the IEP set your child up for success as an adult?
- What are the steps needed for your child to be as independent as possible?
- Do the IEP goals help build the skills and knowledge your child needs to manage post-secondary life?
- Does every goal have a legitimate purpose for your child's future?
- Is your child's transition plan flexible enough to adapt to changing needs as your child moves through the school years?
- What post-secondary goals might appeal to your child? Employment, education, or something else?

#### **Types of Transition Plans**

 Many students will qualify for vocational rehabilitation, a federal program with varying levels of qualification and services. Be sure to check out your state's vocational rehabilitation programs.

#### **Sample Transition Timeline**

**Elementary school** Discover child's interests and strengths

Middle School Child can articulate their dreams and goals for their future

Ninth Grade Child engages in self-exploration and explores the process of

career decision-making

**Tenth Grade** Child begins to research career interests, narrowing their focus

to a cluster of careers and related skills

Eleventh Grade Develops skills associated with the career cluster of interest

Twelfth Grade Enhance those skills by engaging in work-related learning

experiences and finalize post-secondary plans

Completion of Transition Plan

Successful transition to post-secondary life.

Transition planning is crucial for your child's future. Make sure your child's IEP Team is not going through the motions. If you feel discussions about your child's future are not meaningful and/or substantive, bring that to the IEP Teams attention. Also remember to include your child in every step of the transition planning because it is their plan and future after all.

#### Encourage your child to aim high and think big!

We hope you find this publication and our materials helpful; consider a donation to PWSA (USA) to assist in developing more resources like this. Please visit our website, https://www.pwsausa.org/

## Florida Walk and Conference

By Catt Pudney, PWFA President The PWFA Conference/On The Move Walk 2019 was held April 26-27 at Westgate Lakes Resort in Orlando.

Friday started off with a bang! The "Meet and Greet" for families and speakers grew to over 70+ people attending! It was a fabulous time getting to know families and presenters. Families attended from out of state as well as abroad. We could not have asked for a better night!

On Saturday the kids/adults with Prader-Willi syndrome (and their siblings) attended YIP and YAP programs with many fun activities and fantastic volunteers. This included people from ARC who came to help.

Conference presenters were Hannah Stahmer, RD, (who has worked with Dr. Miller and specialized in Prader-Willi diets) who gave a FANTASTIC presentation about sugar and how it affects the body. Occupational Therapist/Certified Hippotherapist Sandy Wainman (with 25+ years of experience) spoke about the benefits of Hippotherapy, and Pediatric

Endocrinologist Dr. Jennifer Miller was our final speaker. Dr. Miller gave a presentation on current research studies, proving we have come a very long way in the world of PWS giving hope to families (new and old). The event concluded with our annual fundraising Raffle and Walk.

Thank you all. As the new PWFA President, I could not be prouder of our chapter! I cannot give the other officers, board members, volunteers and all of those who attended, enough credit. Without all of you, this would never have been possible! We cannot wait until our next event!



Dr. Miller with Zoe and Tressa Pringle, and Chloe Kirkpatrick.



## **Texas Spring** Conference

By Susie Reisenbigler, Executive Director, TXPWA

On Saturday, April 13, the TXPWA conference was held at Spring Creek Presbyterian Church with over 100 parents, caregivers, grandparents and siblings registered. Childcare was provided and each child registered was assigned a 'buddy' who was a nursing student. Thank you to sponsors including Millendo Therapeutics, Soleno Therapeutics, Levo Therapeutics, Pfizer, Zafgen and Nexus.

Presentations with Q&As were given by Dr. Ann Scheimann (gastrointestinal issues), Melanie Silverman, MS, RD (nutrition), Dr. John Cassidy, (how inpatient settings may improve significant, multiple handicapping conditions), Dr.

Linda Gourash (skills for noncompliant, disruptive behavior). The day included updates on clinical trials, breakout sessions by Patrick Jones (technology keeping your family safe and working with educators), Cindy Yelverton (transition services), Maria (Mariki) van Aleman. Vuuren (Schroth Therapy Method for Scoliosis), Hope

Amador (correct brace-fitting demo), Gayle Fisher, M.Ed (building a positive ARD) experience), and Michele K. Goldberg (government benefits and guardianship).

During breaks and lunch, attendees visited vendor booths. Congratulations to Sophia Burgos and Stacy Henderson: winners of the \$500.00 drawings.

The next TXPWA conference will be Saturday, January 30, 2021. Share your



Sophia Suico drawing with Naomi



Drs. Linda Gourash (left) and Ann Scheimann offered their expertise.

topic requests with us; we want to hear from you. Thank you to the amazing volunteers, parents and professionals united for this precious cause: the kids with PWS, who are loved so much.

■ The TXPWA understands navigating PWS is a difficult journey. If you're in need of respite and can find a camp, TXPWA may be able to help with the cost. Contact us for more information at executivedirector@txpwa.org.

## **PWSA-WI Hosts Ninth** On The Move

On Saturday, May 11th, PWSA-WI, Inc. held its Ninth Annual On The Move Walk-A-Thon at Roosevelt Park in Watertown, Wisconsin. Though the weather was on the cool side, all 357 participants (their larg-



A very happy Greg B. hugging Kim S.

est crowd yet!) and sponsors enjoyed a beautiful walk, delicious lunch, and camaraderie with friends out on the dance floor.

#### **Upcoming Chapter Events:**

#### Oregon/Washington - On the Move Walk/Fun Day July 13, 2019

Stroller-friendly, water park fun and more! in Renton, WA http://bit.ly/31QwfXoPWS-OR-WA for details/to register

#### **Wisconsin - PWS Sparkle and Shine Gala and Dinner** August 17th, 2019

in Nashotah, WI http://bit.ly/2N50Tcq-PWSgalaWI Email: progdir@pwsaofwi.org or call 920-733-3077 for more details.

#### **Wisconsin - 19th Annual Charity Golf Benefit** September 29th, 2019

The Oaks Golf Course, Cottage Grove, WI http://bit.ly/31QbprwGOLFpwsWI for details/register

#### Delaware - Inaugural 5K Walk/Run

November 17th, 2019

Milton, DE Please join the Delaware PWS Chapter at our 5k Walk/Run! http://bit.ly/2N21mfwDEPWS5kPWS-DE





## \$10,000 Grant from the **Penguins Foundation**

The Pittsburgh Penguins Foundation made a \$10,000 grant to the Fifth Annual Clint Hurdle "Hot Stove" Dinner in honor of Clint's daughter, Maddie, who has PWS. This year's event was the most successful yet with total donations to PWSA (USA)'s Family and Medical Support Program at just over \$248,000. Clint, his wife Karla, son Christian, and daughter Maddie, stopped by the Penguins locker room to receive the check on behalf of PWSA (USA).

"We are so very thankful and grateful," Hurdle said. "Not just for the Penguins Foundation, but for the people who are involved in Maddie's life. They care about Maddie. They don't care that her dad is the manager for the Pirates. It's what you all do to help, raise awareness, provide funding. It's another way we've been humbled by the love and support that we have in our great community here in Pittsburgh."

PWSA (USA)'s Family Support and Medical Program provides a lifetime of support in areas such as behavior management, nutrition education, crisis intervention, and advocacy. Without the program, many families would have nowhere else to turn for the information and resources they need to empower and support their loved one with PWS.

On behalf of the entire PWS community, thank you, Pittsburgh Penguins, for your support!

Monday, Audrianna (my daughter with PWS who is 17) and I were at the social security office getting things straightened out. When we were leaving, she announced to everyone in the waiting room "I have an electrical disability." She meant intellectual.

> - Submitted by Janis Williams Lawton, Oklahoma

## Meet Ruby G. Plummer Volunteer Coordinator

Meet Ruby Plummer – a vital member to the organization as she shares a bit about herself. What attracted you to the Organization?

My first and primary career has been working for nonprofit organizations, which began following graduation with a Bachelor of Science degree from the University of Wisconsin.

I was asked to consider working for PWSA (USA) 5 years ago. The focus would be the Volunteer program, in which I was well-versed.

#### What have been your duties and responsibilities?

As Volunteer Coordinator I report directly to the CEO, and am responsible for planning, organizing and directing the volunteer programs and efforts associated with the national PWSA (USA) office. Briefly, the purpose of my position is to organize, coordinate, and manage the recruitment of volunteers requested by staff. Promoting positive reciprocity for staff and volunteers is vital to the health of our people. Other areas include

managing our association's (as hosting agency) activities in partnership with AARP's Senior Community Service Employment Program.

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working and presenting on internship programs (for both field and credit) with college students is exciting. We are accepted and used by New College here in Sarasota, and requested by State Colleges of Florida.

Subsequently, I have been asked to activate Bereavement mailings for the Medical Coordinator. This involves

developing a generic Bereavement Packet mailed to those who have recently lost a loved one, and defined procedures for both programs, at the request of the Medical Coordinator. I also do Death Study mailings for the Medical Coordinator.

#### What do you like best about your job?

Diversity. Recruiting and orienting volunteers is so rewarding. Their orientation gives them knowledge of PWS and shares how to enhance their information needs. Close attachment to PWSA (USA) mission and objectives is very important too. Working with individual staff members to make a solid successful match for requests is a great win when the relationship supports the needs. The Bereavement and Death Study work is a definite highlight of my work.

#### What is the favorite memory of your working with the Association?

Working with Carolyn Loker was fulfilling. Procedures for the Bereavement and Death Study programs were established and followed. The professional guidance, partnering and appreciation were great.

#### What are the best parts about volunteering with PWSA (USA)?

Easy. I'm helping an organization that "Saves and Transforms Lives." I believe that volunteering is almost part of one's DNA as the happiness and fulfillment derived makes volunteering a very important part of one's life. Reciprocity is clearly seen in those that receive and those who give freely of their time to help others. I am honored to be a part of this organization.

## Thank you

Paving the way for Advances in Treatment and Health for PWS (PATH) study is a four-year natural history study using the PWS Global Registry powered by National Organization for Rare Diseases' (NORD) registry platform. The information gathered through the PATH study will inform the development of clinical trial design for potential new treatments for years to come.

With the help of all of you, our organization, FPWR, and other partners have reached the required enrollment numbers for this study - thank you very much! There are several other clinical trials still recruiting participants; to find a complete listing go to www.clinicaltrial.gov. Stay tuned for updates on PATH and all the PWS-related clinical trials.

Consulting services available.



**Our Mission:** to enhance the quality of life and empower 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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Andrea Glass, Denise Servais

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