The Gathered View

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

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

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

Angel Drive

Thanks to Our 2018 Partners in Hope

Angel Drive is a great success. Many thanks to:

State Chapter Partners in Hope Leadership Circle

GOLD	SILVER	BRONZE
Georgia	Arizona	Maryland/Virginia
Minnesota	Florida	Utah
Ohio	New England	
Texas	New Jersey	
Wisconsin	Oklahoma	

Thank You!

The 2018-2019 Angel Drive campaign kicked off on Giving Tuesday in November of last year, 24 incredible hours during which hundreds of donors came together to make gifts in support of the Prader-Willi syndrome community. Over the next several weeks hundreds more individuals answered the call, and together raised $150,000 to date, funds that will be used to ensures all PWS families have access to the programs and services they need to live their best lives.

This year's Angel Drive saw our state chapters participate like never before. Twelve chapters were inducted into the Chapter Partners in Hope Leadership Circle by making gifts of $1,000 or more. Their combined gifts, totaling $50,000, were pooled together and used as a special matching gift incentive for individual donors throughout the campaign. Their generous contribution helped create extra excitement and played an important part in making this year's

PWSA (USA) FIVE PILLARS OF SUPPORT



Every Gift Matters…Thank You!

PWSA (USA) is the only organization that provides the comprehensive support, tools, and resources families need to thrive in the face of a rare genetic condition. Donor gifts received during the 2018-2019 Angel Drive will help pay for the programs and services the PWS CommUNITY has come to rely on. Regardless of size, your gift will make a real and meaningful difference by ensuring PWSA (USA) can continue to provide the hope and support families need, when they need it. Thank you for

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2019 PWSA (USA) Convention Speaker Announced

We are pleased to kick off our 2019 PWSA (USA) Convention Friday morning, October 25th, with keynote speaker Rick Guidotti. An award-winning photographer for 20 years, Rick collaborates globally with nonprofit organizations, hospitals, medical schools, educational institutions, advocacy groups and communities. His objective is to promote a more inclusive and compassionate world where all differences are understood and celebrated. Guidotti's work has been published in numerous newspapers, magazines and journals as diverse as *People, the American Journal of Medical Genetics, The Lancet, Spirituality and Health, the Washington Post, New York Times, Atlantic Monthly and LIFE Magazine.*



Rick Guidotti

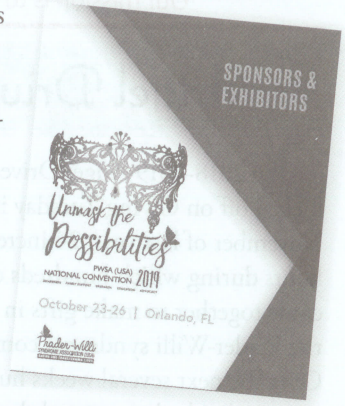
Rick is also founder and director of POSITIVE EXPOSURE (PE), an innovative arts, advocacy and education organization. Visit his site: https://positiveexposure.org/ **See the dates shown on page 2 and mark your calendar! Convention registration begins soon!**

To see more convention info, make your hotel reservations under the PWSA (USA) discounted rate, etc., visit the website http://bit.ly/2LswNekPWSA2019 to click on the reservations link, or call the hotel: 1-800-823-8300. ■

Volume 44, Number 1 ~ January-February 2019 ~ Our 44th Year of Publication

Levo Therapeutics is the Top 2019 Convention Sponsor

We are very excited to announce that Levo Therapeutics, Inc. will be the Platinum Sponsor for the upcoming National Convention. Led by CEO Sara Cotter, the firm is enrolling participants in its Phase III clinical study of intranasal carbetocin for the treatment of PWS. PWSA (USA) is deeply committed to providing education about PWS, support to those affected by the syndrome, and truly understands the value of meeting in person. The PWSA (USA) National Convention is a biennial event where nearly 1,000 people from around the world gather to attend. It is an event unlike any other that boasts three different conferences which give families, researchers, scientists, and professional providers the opportunity to obtain the best and most up-to-date information on PWS while also making lifetime connections with the PWS CommUNITY.



Becoming a PWSA (USA) 2019 National Convention sponsor, advertiser, or exhibitor will afford you the opportunity to network and build relationships with both PWS professionals and individuals living with PWS and their families. Please email Devon Young at dyoung@pwsausa.org for more information or visit: https://www.pwsausa.org/2019-pwsa-usa-national-convention/.

Thank You to Levo Therapeutics, our 2019 PWSA (USA) National Convention Platinum Sponsor. ■

Angel Drive, *continued from page 2*

Angel Drive

your kindness and generosity this year and every year!

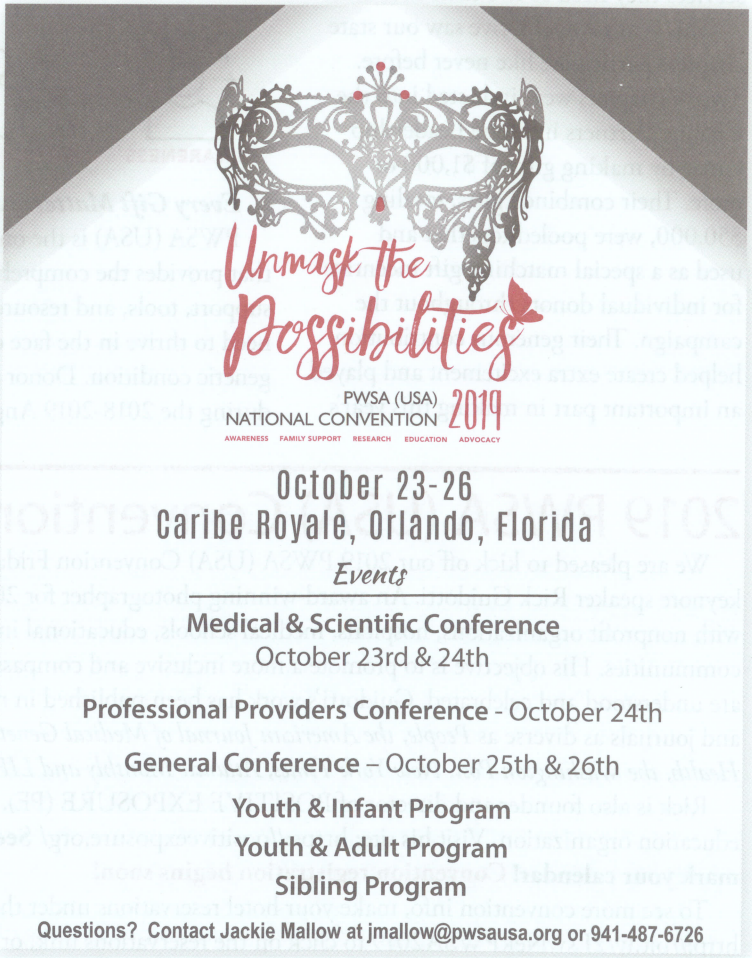
Other Ways to Support PWSA (USA) in 2019

The upcoming year is already shaping up to be a busy one, and we're inviting you to join us at one of the many events and conferences that will be held across the country…Be sure to check out the Chapter and Events section on page 8 and the Clint Hurdle "Hot Stove" Dinner save-the-date on page 16 (back cover) to learn more! And, as always, be sure to check out the PWSA (USA) Facebook page to keep on top of all the great events, programs, and news that happens throughout the year! Visit us at www.facebook.com/PWSAUSA/. ■

"I've seen and met angels wearing the disguise of ordinary people living ordinary lives."

~Tracy Chapman

Watch for our regular updates on what's to come as we Unmask the Possibilities.



2019 Convention registration will begin soon!

Opportunities to Help PWS Research

Research is one of PWSA (USA)'s Five Pillars of Support and also a vital component to the treatment of Prader-Willi syndrome. We urge all families/caregivers to consider enrolling their loved one with PWS in a clinical trial.

It is important for our community that enrollment in these studies is completed as soon as possible. However, clinical trials involve risks and labor - please consult with your physicians and refer to the following resources for more background on participating in clinical trials.

"Never in its history has there been so much interest in Prader-Willi syndrome (PWS). From the root causes of hyperphagia and metabolism flaws, to the long data-gathering programs, to simple behavior management strategy improvements, this work provides exciting hope for a bright future for all our families and for those with PWS, whose age is across the entire spectrum."

- Jim Kane, Chair of the Board PWSA (USA)

Levo Therapeutics

This is a Phase III randomized, double-blind study with an 8-week, placebo-controlled period designed to test the effectiveness, safety, and tolerability of LV-101 in participants with PWS.

Effectiveness will be measured using both caregiver-reported and clinician-reported measures of hyperphagia (extreme hunger), obsessive and compulsive behaviors, and anxiety. Safety and tolerability will be measured by adverse events, laboratory tests, and physical exams.

After the 8-week placebo-controlled period, there will be a long-term follow-up period of 56 weeks during which all participants will receive active treatment with LV-101. At Week 8, participants who were randomized to placebo in the placebo-controlled period will be randomized to one of the two LV-101 doses, administered three times per day before meals.

Age Eligibility:
7 to 18 years

University of Florida
Gainesville, Florida
Principal Investigator: Jennifer Miller, MD
Contact: Beverly Giordano
352-294-5280
bgiordano@peds.ufl.edu

Vanderbilt University School of Medicine
Nashville, Tennessee
Principal Investigator: Ronald Cowan, MD
Sub-Investigator: Elizabeth Roof
Contact: Hailee Hunt 615-343-0915
hailee.m.hunt@vanderbilt.edu
https://clinicaltrials.gov/ct2/show/NCT03649477

Soleno Therapeutics

DCCR Efficacy and Safety Trial in young children and adults with PWS

Protocol title: *A Randomized, Double-Blind, Placebo-Controlled Study of Diazoxide Choline Controlled-Release Tablet (DCCR) in Patients with Prader-Willi Syndrome.*

- DESTINY PWS (C601): Multi-center, randomized, double-blind, placebo-controlled, parallel arm study in patients with PWS (Phase III)
- C602: Open label safety extension study
- PWS patients 4 years and older are eligible
- Patients will be randomized in a 2:1 ratio to DCCR or placebo
- All patients completing C601 are eligible to screen for C602

Active Enrolling Sites

- Children's Hospital Colorado – Aurora, CO
- Children's Minnesota – St. Paul, MN
- Rady Children's Hospital – San Diego, CA
- Seattle Children's – Seattle, WA
- Stanford University – Palo Alto, CA
- University Hospitals Cleveland – Cleveland, OH
- University of Florida – Gainesville, FL

Upcoming Sites*

- Baylor College of Medicine – San Antonio, TX
- Boston Children's – Boston, MA
- Nationwide Children's Hospital – Columbus, OH
- NYU Winthrop Hospital – New York, NY
- NICHD / NIH – Baltimore, MD
- University of Kansas – Kansas City, KS
- University of California – Irvine, CA
- University of Utah – Salt Lake City, UT
- Vanderbilt University - Nashville, TN

**Sites will be added to www.clinicaltrials.gov NCT03440814 as soon as they are able to recruit subjects.*

Age Eligibility:
Ages 4 and above

Please visit: www.clinicaltrials.gov
NCT03440814
Contact: C601 Project Manager
650-353-2051 or Email:
C601ProjectManager@soleno.life
http://bit.ly/2R688SdSolenoPWSA

You represent all that is good, wholesome, ethical, and moral in an organization.

When you have a cause you feel strongly about, awareness, advocacy and fundraising become a natural fit. For 13 years, two families have hosted a Christmas "party with a purpose": supporting a group or cause in need. Over the years, rather than bringing a plate of cookies, a toy for a needy child, or a gift for the hostess, guests of this joyous gathering now contribute to a very friendly fundraiser for PWSA (USA). The eight-year-old son of one family (the two husbands grew up as childhood friends) was the catalyst of this heart-warming annual event. Read below a fine example of the good works of how two families created a festive vehicle to support PWSA (USA).

This letter was received by Neemah and Ryan Mayhugh of Shaker Heights, Ohio:

"We admire your work and your diligent efforts to improve the world around us. I am honored to present you with these contributions and hope that it will help provide you with the resources you need to continue your endeavors. Attached you will find twelve (12) checks made payable to your organization totaling $1,615.00.

After recently hearing about PWSA (USA), we spent some time researching the concept and purpose driving the organization, and found ourselves deeply connected to your cause. You are addressing real problems in our society, and because we admire the integrity and efficiency with which you use your resources to establish services and directly support your target populations.

We know that your organization goes above and beyond the call of duty. You represent all that is good, wholesome, ethical, and moral in an organization. You can be assured that your efforts are greatly appreciated not only by us, but by most members of this community. We look forward to seeing the continued progress you will make in the near future." ■

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

CFC® Combined Federal Campaign *Approved Charity*

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://www.opm.gov/cfc/index.asp



"Change how you see, see how you change"

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

Navigating the PWS world allowing options within limits

By Patience Ergish, MS, RD, LDN, Clinical Dietitian, Monroe Carell, Jr. Children's Hospital at Vanderbilt and Jessica Duis, MD, MS, Vanderbilt University School of Medicine, Director, Prader-Willi Syndrome Comprehensive Clinic at Vanderbilt

It can be difficult for your loved one with Prader-Willi syndrome, and your family as a unit, to ease back into a healthy lifestyle after the holiday season. First and foremost, make a commitment to healthy habits as a family and commit to lifestyle changes. We present some tips to help get you started:

Limit added sugars

An easy place to start is limit the amount of added sugars in the diet. You can start by decreasing "sweets" such as candy, sugar-sweetened beverages, especially juices, cookies, and cakes. Next, take it one step further and begin looking on the Nutrition Fact label for "Added Sugars." Be sure to also check the ingredients list for sugar or syrups. The ingredients are listed in order of largest to smallest amount. If sugar is one of the first several ingredients, then it likely makes up a large portion of the food item. You will want to look for foods with very small amounts or no added sugars to offer instead.

Watch portion sizes

Portion sizes are a top spot where extra calories can make it into the diet. A portion is how much you plan to eat of a food at a meal. Portion sizes can be controlled by using smaller plates to serve meals. You can use visual tools to help measure the amounts given. For example, half a cup is about the size of your cupped hand and 3 ounces is the size of your hand. You can also monitor portions by filling your small plate with non-starchy vegetables that do not provide as many calories and give some extra fiber.

Add more nutritious carbohydrates such as vegetables and whole grains

Non-starchy vegetables can be a great lower calorie option to fill a plate. They can be lower in calories, but also tend to have fiber. Fiber is what gives fruits, vegetables, and whole grains their structure. Foods rich in fiber tend to fill you up and support digestion. You can check food labels for dietary fiber. While it is important to increase fiber in one's diet, make sure to increase slowly over a week or two and drink plenty of fluids to avoid any discomfort.

Drink more water

Drinking plenty of water each day is another easy change to make. This helps with making sure you stay hydrated each day. Individuals with PWS prefer not to drink plain water, so "spice" it up. Some suggestions are to find zero calorie flavored waters with natural sweeteners or make your own! There are some great infused water recipes that add vegetables such as cucumber or fruits, such as watermelon and apples, or herbs, such as mint.

Involve the whole family

The whole family can benefit from many of these tips, but also it is more fun and successful when everyone is involved working toward the same goals. Involve your child/adult in the routine and planning. Create spreadsheets together with goals such as drinking a glass of water with dinner and reward with stickers for each time the goal is met. It is key to keep things positive and find an age-appropriate, non-food reward to keep everyone motivated. Make it fun!

Remember Prader-Willi is a genetic drive

Remember Prader-Willi is a genetic drive, not a moral issue. Individuals with PWS do not feel satiety and therefore they should not be disciplined for "food-seeking" as it is hard-wired in their brain. Revealing food-sneaking occasions should be encouraged and meals for the day should be modified to avoid excess intake of calories. Good days and positive behavior should be rewarded.

Exercise – it's good for you

It can be difficult to get your child motivated to get activity on a regular basis. Find something they love such as dancing and encourage regular (even if short) bursts of activity every day.

Seek advice from a professional

While these are great steps to make, a Registered Dietitian can help with these strategies and setting individualized goals for you. A dietitian can work with you to set appropriate goals for limiting carbohydrates, counting calories, and getting enough exercise. They may also set a "net carbohydrate" goal to help with monitoring intake. Net carbohydrates are the total carbohydrates in a food minus the dietary fiber. A dietitian is part of a multidisciplinary team of doctors that specialize in care of people with PWS. ■

Editor's comment: "Often you read of a journey filled with obstacles on a path to happiness. Nikkita Tarnauskas is one of those people. Here is her story."

Residential placement for my son has been a journey filled with tears, frustration, fear and faith. Born in 2000, and weighing just five pounds, Christopher had failure to thrive. Diligence and much research led to his eventual diagnosis of PWS at age four.

Like most moms, my life mission was to find Christopher the best support possible.

My search for services and medical care was long. We zigzagged across the nation, moving from state to state to state to state desperate for quality educational and medical services. It seemed there were always obstacles (never mind MY coping mechanism was emotional eating). In addition to the opposition many PWS parents face, I felt discrimination because I was African-American, overweight and single. Who was I to challenge doctors and teachers? I felt judged with one glance, sometimes feeling I was treated as if I was overreacting. The doctor didn't order X-rays, so I refused to leave until they did. Christopher's arm was broken in two places, and the elbow was dislocated from a fall.

Christopher always came first. Days started with prayers begging for help; some nights ended with me crying (while eating a family-sized bag of Doritos). Struggle and sacrifice eroded friendships and relationships. I became so aware of how many activities in our society are based on food. I began working from home. Locating good childcare because of his needs, or staff not familiar with PWS, was challenging. Christopher and I enjoyed time together at the library and the movies. Reality: even with my isolation and loneliness, I WAS my son's advocate.

As my son's advocate, I celebrated every victory! Sometimes I doubted if I had the strength to find my voice, especially when times were tough. When school bullying occurred, my son, whose smile lights up my world, would cry and beg to stay home. My happy, confident, friendly, little boy had become angry, withdrawn and depressed. Once imaginative and creative, he turned into someone I didn't recognize. I vowed to bring joy back to my Christopher. Chris had weighed 450 pounds and was nearly immobile. His weight was life-threatening, following many years of improper and ineffective placements, and unhealthy weight gain. Once active in Special Olympics for years, he battled a long recovery following his leg surgery in 2014. Multiple infections then caused significant weight gain, immobility and hospitalizations.



2018 Athlete of the Year

With research, I discovered an amazing school with a program for Prader-Willi syndrome. With prayer, support of family, friends, strangers, and faith, a miracle occurred, allowing us to move to the state where this school was located. *Something I visualized for 13 years became reality.* Christopher enrolled nine months later.

Although we'd been praying for this, it was the hardest thing I'd ever done. There was no room for my ego; I feared for his life and Christopher was ready to give up. As he hugged me goodbye, he said I was the best mother he could've ever asked for and he would be fine. It was time for both of us to find happiness, health, love and grow our family.

Upon arrival at Latham, Chris was saddened by his inability to keep up with his peers. With the support of a walker, Chris could only manage to slowly navigate the Latham campus. Since his placement, Christopher has changed.

Challenged by Latham's clinicians, teachers and nurses, Chris gradually began to take larger strides and walk farther distances than he believed possible. And, he learned new coping skills to deal with his frustrations.

The Latham staff carefully evaluated Chris' condition and set him on a path to a healthy weight. Now, after more than two years, Chris has lost almost 200 pounds, his calories have been increased from 1,200 to 1,400, and he is impressing staff, family and friends with his courageous attitude.

Back in 2016, Chris was asked each day to walk up one set of stairs without the help of his walker; it become a daily test. How many steps could he walk up without losing his breath; how many times did he have to stop; how long would it take for the entire flight? Then, one day, everything changed! He smoothly glided up the steps. A huge moment was realized – he did it! Chris said aptly, "Every day that I am here, I am one step closer to becoming the kid that I want to be." Chris, his fellow students, and the staff celebrated. He is full of energy and happiness.

He continues to prosper and lose unhealthy weight, while being surrounded by caring friends and staff. Chris' optimism and enthusiasm have proven instrumental in his success. He now says to his staff, "Every

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The Game

By Denise Servais, mom to Maya, with PWS

Recently, I attended my 9th grade daughter's annual IEP meeting at the high school. This is Maya's (PWS) first year at the high school and she has been handling the adjustments of being in a new school fairly well in terms of her behavior. Change of any kind is hard for Maya. When it was her DAPE (adapted PE) teacher's turn to talk at the IEP meeting, she said, "As you know, Maya refuses to attend DAPE and we have done everything we can think of to get her to try it. We should think about taking it off the IEP." No! I thought. Maya has always loved DAPE before high school and the exercise has been good for her. I knew if Maya gave it a chance, she would participate and like it. I had talked to Maya about it earlier several times and told her how much fun she would have. At the high school, DAPE is now under a program called ***Unified PE***, because it includes neurotypical students to help out as partners. These neurotypical students sign up for the class as an elective and generally have a desire to be with their peers with disabilities. "But it's ***(Unified PE)*** not called DAPE!" Maya persisted, and refused to consider it further.

There was one thing that we still had left to try. I call it "The Game." I'm sure there is a more formal term for it, but it is essentially a collaborative problem-solving approach where the main objective is to have everyone win and Maya feels like she is making the final decision. While there are times when I will directly include Maya into the problem-solving part of the collaboration, there are also times when I will not, such as when the mere talking about subject upsets her (i.e. participating in DAPE).

The IEP team and I came up with a plan. Maya loves her SLP (Speech-Language Pathologist) so the school had Maya and her SLP "run an errand." As they were walking down the hall, they walked past the gym where DAPE was occuring. The SLP stopped to watch and commented to Maya that whatever was happening in the gym looked like a lot of fun. Maya's older sister (in 11th grade) arranged to have one of her friends, Parker, who was one of the participants, come up and greet Maya. He asked Maya to join them sometime. Maya accepted and, as they say, "the rest is history."

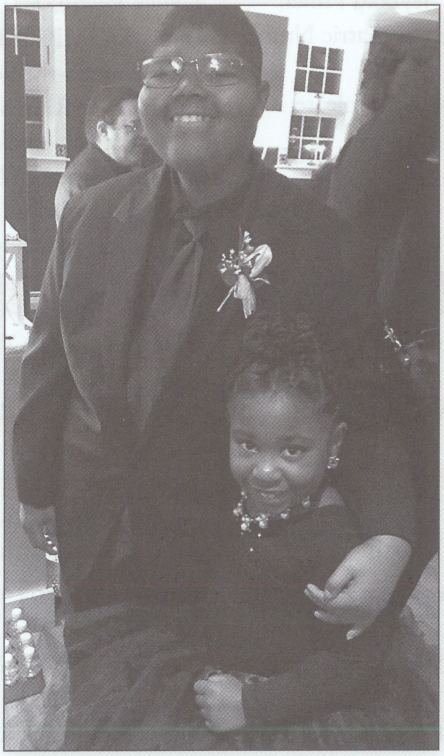
A couple of weeks ago, Maya and I were sitting in an office with her PT and an orthotist. They both agreed Maya needed a different kind of supportive shoe. The PT suggested a new type of shoe (which "ties" on with magnets) on the market that she believed would be a good fit for Maya. The PT gave Maya choices of colors and Maya choose blue, her favorite color. As the orthotist was measuring her foot, Maya started to become agitated. "I don't want a new pair of shoes, I'm not wearing new shoes!" Maya exclaimed (the magnet closures were the catalyst). As the PT and orthotist exchanged uncomfortable glances, the orthotist asked me if he should order the shoes. I calmly looked at him and nodded subtlety. It was time to play "The Game" again. ■

Christopher's Journey, *continued from page 6*

pound that comes off I feel better and healthier."

For the first time in years, Chris is able to move without the support of his walker. He has befriended everyone on campus, and is thriving; he even has a girlfriend! He is learning how to play the piano and performed at the Latham Centers Fall Cabaret in front a large audience. He loves dancing and participating in performing arts.

He once again joined Special Olympics track & field and basketball teams, and now also participates in soccer, football and bowling. This October, he received the 2018 Massachusetts Special Olympics Athlete of the Year. I could not be more proud. His smile and warm energy are contagious. Chris is flourishing.



Christopher at his mother's wedding with pal Madison

For the first time, he's living LIFE. He lost almost 200 pounds, gained friends and once again loves school. His secure food environment allows more opportunities of a life of inclusion. After years of fighting to find the right placement for my son, we found home. His Prader-Willi syndrome is no longer a debilitating flaw, but rather a challenge that he can overcome with consistency, a routine, family support and the experience of the Latham Centers Staff.

Remember: Believe that you have the right to ask for help and education for your child. Remember: every time you hear the word "No", you're simply one step closer to "Yes!"

Likewise, one of these steps was when my son proudly walked me down the aisle at my wedding last year. Dreams can come true. ■

Reviewed by Patrice Carroll, Latham Centers' Manager of PWS Services

PWSA Michigan Conference

By Rikka Bos, Development and Chapter Relations Specialist, PWSA (USA)

On Saturday, October 27th, PWSA of Michigan held its biannual conference in Kalamazoo, Michigan. The event was provided to individuals and families free of charge thanks to the generosity and support of PWSA of Michigan, Prader-Willi Homes of Oconomowoc, and Bronson Methodist Hospital. Parents and children, extended family members, support staff and professional providers were among the 110 in attendance at the all-day event. Of those 110 attendees were 12 families with children ages birth to four, and families from six states and Canada.

Several presenters spoke on a variety of topics, such as reinforcing positive behavior, education advocacy, disability benefits planning, and current research initiatives in the Prader-Willi syndrome field. Clinical professionals were also available to caregivers of children ages birth to four during special breakout sessions during which questions could be answered and expert guidance provided.

Speakers and clinicians included: Pete Mulder - Program Manager-Disability Network Southwest Michigan; Stacy Ward, M.S., Crisis Intervention and Family Support Counselor PWSA (USA) ; Marguerite Rupnow, National Director of Admissions and Advocacy for Prader-Willi Homes of Oconomowoc; Jim Loker, MD, Pediatric Cardiologist; Janice Agarwal, Pediatric Physical Therapist; Stacey Seybold Hiller, Pediatric Speech Pathologist; and Kathy Clark, Pediatric Nurse Practitioner.

For more information about PWSA of Michigan, please visit: https://pwsami.org/. ■

PWCF Annual State Conference 2018

By Emily Dane, Executive Director, PWCF

110+ parents and professionals, 36 youth and adults, and 17 student volunteers also gathered on October 27th for the 2018 Prader-Willi California Foundation Annual State Conference located at the Doubletree by Hilton in Sacramento. The 2018 theme "Your California Community" focused on the importance of connecting with your local PWS community. Keynote speaker Elizabeth Roof, M.A. covered *Behavior and Psychiatric Issues in PWS* and presented a *PWS Research Update.* Mrs. Roof presented current findings from the Vanderbilt PWS Longitudinal database; this resource holds 15+ years of data collected on characteristics of children and adults with PWS and their families.

The conference featured six educational breakout sessions too, conducted by experts in each subject area: *New Federal Rules Impact Your Future: New Tools to Keep Your Loved One Safe* by Lisa Graziano, M.A., Former PWCF Executive Director; *Food Life & Fads* by Leah Blalock, MS, RD, CSP, CDE; *Using the Science of Gratitude to Help Manage Daily Family Life* by Emily Felt, MPP, CAPP; *Financial Planning: Delivering Your Ultimate P.R.O.M.I.S.E.* by Patrick McGrath, ChFC, ChSNC; *Managing Challenging Behaviors at Home and Team Approach to Care* - Patrice Carroll, MSW, Katrina Fryklund, MSPC, Kara McDowell, M.Ed., and Brittni Kliment, M.Ed. from the Latham Centers in Massachusetts; and *Building a Fun Physical Activity Routine for Children and Adults with PWS* by Daniela Rubin, Ph.D, PWCF Board of Directors.

Halloween-themed projects, games, and activites included Zumba with Rika Matsuda and Haley Kavrell, a craft / fitness activity titled, "Halloween Fitness and Fun" presented by the Latham Centers of Massachusetts, and customized impromptu songs performed by Rodney Dong, PWCF Board of Directors. It was a fantastic day of learning and connecting. ■

UPCOMING CHAPTER EVENTS

Wisconsin - The 8th Annual Snowflake Ball
February 2nd, 2019

Red Circle Inn & Bistro, N44 W33013 Watertown Plank Road, Neshotah, WI.
$20 for individuals with PWS; $25 for members; $35 for non-members. For more information, please visit: https://pwsaofwi.regfox.com/pwsa-of-wi-8th-annual-snowflake-ball

New York - PWANY 29th Annual Conference
May 3rd and 4th, 2019

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

Wisconsin - On The Move Walk-A-Thon
May 11th, 2019

Roosevelt Park Roosevelt Park, 630 S. Main Street, Oconomowoc, WI. egistration starts at 9:00 a.m.; the walk begins at 10:00 a.m. with lunch and dancing to follow.
For more information, please visit: www.pwsaofwi.org, or contact Joshua Escher at progdir@pwsaofwi.org.

Minnesota - 2019 Minnesota Golf Scramble
May 17th, 2019

Majestic Oaks Golf Club, 701 Bunker Lake Blvd. NE, Ham Lake, MN.
For more information, please contact Kristi Rickenbach at kristi_cole@yahoo.com.



Parent Mentor Program Highlights

Submitted by Diane Seely, New Parent Support Coordinator, PWSA (USA), December, 2018

2018 has wrapped up (can you believe it?). It's my hope that we can take these days early in 2019 to breathe in all that we have accomplished. For me, it's somewhat of a tradition to reflect on the things that I've achieved, and then some of the things that I thought I might get to. If I had to choose just one highlight from 2018 - it would be the PWSA (USA) Parent Mentor Workshop held in Nashville, Tennessee at Vanderbilt University.

First, a huge THANK YOU to those who made the weekend successful – PWSA (USA) staff, PWSA (USA) Parent Mentors and of course, Jessica Duis, MD, and the entire team at the PWS Clinic who went above and beyond for our mentors! I LOVE what I do, and it's rewarding to have the caliber of mentors that we have involved in our Parent Mentor Program.

This year, we rolled out a Parent Mentor Program template that is like none other in the United States, while creating robust materials available in our publications such as our *Package of Hope, Grandparent Package, Parent and Educator Packet,* while also connecting families via social media.

Our PWSA (USA) Parent Mentor volunteer team has grown this year alone by 15 new mentors; in addition, we have created our Ambassador Program and an orientation process for all new incoming Parent Mentors and monthly Parent Mentor Webinars. PWSA (USA) supports not just our parents, but also grandparents, siblings, and so many more. It's incredible to know that 161,000 people visited our website across the year and found our Parent Mentor Program to be a lifeline to navigating a diagnosis such as Prader-Willi syndrome.

To further educate our Parent Mentors, we presented free webinars throughout the year:

- *Marriage: In the Midst of Special Needs Parenting* with host Jessica Patay, founder of *We Are Brave Together.* Find out more here: www.wearebravetogether.com
- *PWS Behavior and Mental Health Issues – Information and Tips for Parents* with host Elizabeth Roof. Elizabeth is a Senior Research Specialist and Psychological Examiner and has worked with hundreds of individuals with PWS and families.
- *Special Needs Financial Planning for PWS* with hosts Ivailo Grigorov and Kacy Seitz
- Financial Representatives of Northwestern Mutual

All these webinars are available online. Contact dseely@pwsausa.org for more information.

- Additionally, we hosted our first LIVE Facebook chat with the PWS Clinic team from Vanderbilt University and plan to do more of this in 2019.

2018 was a fun year; full of firsts and ending with new and exciting things to come in 2019. ■

Every Person Matters

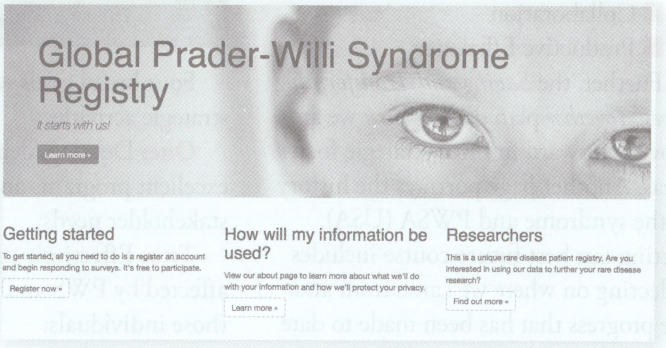
Register Now

Global Prader-Willi Syndrome Registry

You can advance PWS research faster than ever by providing researchers with comprehensive, accurate, and research-ready data that is easily accessible.

Whether your loved one with PWS is 2, 15 or 52, we need your help in making sure they are ALL included to provide a complete picture of the PWS community. This is a great way people with PWS – of ALL ages – can help advance research, develop new treatments and improve the quality of life of the entire PWS community.

The Global PWS Registry is a secure database compliant with U.S. Health Information privacy laws and FDA regulations. To create the most robust PWS registry possible, EVERY person with PWS should



be included in the registry. Through a series of electronic surveys, the registry collects information on a wide range of topics including developmental history, medical complications, and quality of life issues.

If you are a parent or guardian of a person with PWS, please join the movement today to build the Global Prader-Willi Syndrome Registry by visiting www.pwsregistry.org. ■

New Three-Year Action Plan Starts Now

By Steve Queior, CEO, PWSA (USA)

To help the PWS community as much as possible, PWSA (USA) has finalized a new three-year strategic action plan, called *Saving and Transforming Lives, Together*. Access the document at http://bit.ly/2LBeljIPWSAusaStrategicPlan online. This informative brochure is full of easy-to-read information about PWSA (USA) and what's coming in the years ahead.

The *Saving and Transforming Lives, Together* plan includes much more than important goals and objectives. As a result of the hard work of your Board of Directors, staff, and other supporters of our organization last year, there is a shorter and more direct new mission statement, as follows: "Prader-Willi Syndrome Association (USA) exists to enhance the quality of life and empower those affected by Prader-Willi syndrome."

The plan also includes an updated Vision and Organizational Values that convey our principles in the following areas:

- Diversity, Equity and Inclusion
- Trust
- Compassion
- Optimism
- Collaboration
- Productive Efficiency

Further, the *Saving and Transforming Lives, Together* plan depicts how we are moving forward in three strategic focus areas. Another page portrays the history of the syndrome and PWSA (USA). Setting our best future course includes reflecting on where we came from and the progress that has been made to date - through your support and hard work. Our future priorities address needs and opportunities across all of our Five Pillars of Support: Awareness, Family Support, Research, Education, and Advocacy.

Two other absolutely key elements of our approach to 2019 through 2021 are that:

a) we will work to increase the engagement of members of the PWS community – both with each other and our organization, and

b) PWSA (USA) believes taking a life-long approach of caring and support is imperative to assist our loved ones with PWS at every stage of their lives.

> ***"In this life we cannot always do great things.***
>
> ***But we can do small things with great love."***
>
> ***~ Mother Teresa***

Four broad goals will guide our strategic activities:

One: Develop, deliver, and enhance excellent programs and services to meet stakeholder needs;

Two: Effectively support those affected by PWS and those who support those individuals;

Three: Achieve our mission through exceptional governance and organizational excellence; and

Four: Ensure that the necessary resources are obtained and managed to meet the needs of the PWS community.

Infographics included show the number of families helped and how the association "runs lean" which directs as many dollars as possible to key programs and services, rather than administrative expenses.

Another feature is a listing of available information and services, making the document a resource that you may want to keep and refer to over time. These include tools in the areas of **Family Support, Medical and Research, Awareness and Development, State and Regional Chapters,** and **Publications and Electronic Resources.**

The plan reminds its readers to mark the dates for the next National Convention – October 23-26, 2019 – in their calendars. Being there offers life-changing moments for all and you won't want to miss this. Please watch for updates on individual activities and actions in the plan in upcoming *Gathered View* issues.

Most importantly, thank you for all your support as we move forward helping to *Save and Transform Lives* over the next three years! ■

CHUCKLE CORNER

While filling up our car (named Ben) Kimber asked, "mom, what kind of gas does Ben eat?"

Me: "unleaded"

Kimber: "UNLETTUCE GAS?! Mom, one time I ate some salad and I had lettuce gas..."

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

International Caregivers Conference in Munich Brought Advanced Topics, Collaboration among IPWSO Boards

By Mary K. Ziccardi, *Co-Chair, PPCB IPWSO; Co-Chair, PPAB, SEAB board member, PWSA (USA)*

In August 2018, the Professional Providers and Caregivers Board (PPCB), a board of professional providers operating under the authority of IPWSO, was pleased to present its fifth program in Munich, Germany. This conference was specifically directed at meeting the challenges of a career as a professional caregiver.

As featured in past practices, the conference opened with the "Pam Eisen Lecture". The 2018 memorial lecture was awarded to Monika Fuhrmann. Monika, a mother of a young man in his mid-20s with PWS, is a member of the German PWS Association, where her special task is the relations to the international activities in PWS. In her lecture, she gave a very personal view of her way of handling many challenging effects around the situation of having a child with PWS.

Monika, a professional opera singer, often performed at different conferences or events solo, or along with Giorgio Fornasier, IPWSO Advisor, including some of the PWS songs created in collaboration with Pam.

This memorial lecture serves to remind us of the love, respect and appreciation shown by Pam to everyone working with persons with PWS, and of her commitment to encourage collaboration of parents and caregivers.

The conference tradition followed with a "new country" lecture, presented this year by Craig Moore of Australia. Mr. Moore provided updates about the development and vision of works being done there, specifically at Mr. Moore's organization, Interaction.

The conference was organized by the PPCB, and co-chaired by Norbert Hodebeck-Stuntebeck and Mary K. Ziccardi. With extraordinary support of the six other board members, the conference included three days of four different workshop topics. The areas were explored in depth, involving significant interaction from the participants. They featured *Early Intervention, Aging, Friends/Partnerships/Sexuality* and *Self-Determination.* Workshop participants each selected two different topics and were involved with in-depth interactions and conversations with people from many other countries. At the conclusion of the workshops, the workgroup leaders gathered at a marketplace area. The various materials generated during the workshops were made available, allowing all participants to review and discuss with each other and the topic leaders.

Interspersed with the workshop sessions this year were a variety lectures with topics of interest to the entire group of attendees. They included a scientific and clinical overview, an exploration of the impact of trauma in lives of people with PWS, and the value of diagnostics as the basis for therapy and psychological treatments.

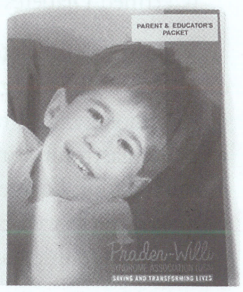
The conference culminated with a collaborative round-table interactive Q&A session. This allowed audience participation with IPWSO Board President Dr. Tony Holland, CSAB Chair Dr. Dan Driscoll, PPCB Co-chair Mary K. Ziccardi and FamCare Chair Georgina Loughan.

In addition to the knowledge gained and shared within the workgroups, the cooperative spirit among the groups operating inside IPWSO, holds much promise for future collaborations. The efforts of the PPCB and conference organizers of the conference are gratefully acknowledged and appreciated. ■

"Pam Eisen, a former IPWSO president, was a loving mother, fierce advocate, amazing author, and world traveler who would go anywhere to reach people who needed resources to care for those with PWS. There is no easy way to say that she is one of the very few on the shortest list of people in my past/current personal and professional life who I could not say no to, ever. She would ask me to do something for someone with PWS and I would think, I cannot or will not do that, and then I would be doing just that. Pam was relentlessly kind in her steadfast belief that caregivers had a very significant and meaningful role in advancing the quality of life for people with PWS. She literally took a piece of my heart with her when she left this world." ~ Mary K. Ziccardi

A must for both parents and teachers!

Packet for Parents and Educators



(2017) Don't miss this information-filled resource packet for parents and educators! You'll learn more about Prader-Willi syndrome, how the syndrome impacts children's learning, and how to work with students of all abilities to ensure their educational success. This resource packet will help parents provide teachers with valuable information to assist in working with students of all abilities. $35. To purchase: shop on our online store at: https://www.pwsausa.org/product/parents-and-educators-packet/ ■

Seattle Children's®
HOSPITAL • RESEARCH • FOUNDATION

The PWS Clinic at Seattle Children's Hospital

The Prader-Willi Syndrome (PWS) Clinic at Seattle Children's is a multi-disciplinary clinic that brings together experts in many specialties to care for children and teens with PWS. The clinic started in October 2014 through the collaboration of specialists in different fields with an interest in helping individuals with PWS, under the direction of Dr. Parisa Salehi.

The clinic meets 18 times per year and provides care to children in the Pacific Northwest and surrounding regions. Some of the issues they treat are obesity, hormone imbalances that can affect growth or sexual development, Type 2 diabetes, difficulty controlling emotions, intellectual disability, sleepiness, and breathing issues during sleep. The clinic's main tenet is that the standard of care for PWS is treatment by a team of doctors trained in many different specialties. They provide access to all the medical care a child/teen with PWS would need in one medical center. Treatment might include hormone replacement, dietary advice, behavioral therapy, sleep studies, and physical therapy.

To meet the varied needs of children and teens with PWS, the Seattle Children's team has specialized training in areas such as:

- **Endocrinology and Diabetes** to care for the multiple hormone problems that often affect babies, children, and teens with PWS providers: Parisa Salehi, MD
- **Developmental Behavioral Pediatrics** to evaluate your child's needs related to the development of the nervous system and provide the right services for you and your family with PWS provider: Anne Leavitt, MD
- **Pulmonary and Sleep Medicine** to conduct sleep studies and treat sleep disturbances with PWS provider: Maida Lynn Chen, MD, Amber M. McAfee, ARNP, and Joanna Wrede, MD
- **Neurology** to evaluate conditions that affect the brain such as seizures with PWS provider: Joanna Wrede, MD
- **Genetics** to evaluate your child for genetic testing and to counsel families with PWS provider: Anita M. Beck, MD, PhD
- **Psychiatry and Behavioral Medicine** to diagnose, treat and prevent problems with emotions and behavior with PWS provider: Soo-Jeong Kim, MD
- **Nursing and Nutrition** to manage your child's diet and help prevent obesity with PWS provider: Cheryl Woods, MS, RDN (Registered Dietician Nurse), CD (Certified Dietician) CDE (Certified Diabetes Educator) and Anne Dulong, RN, CDE

We also coordinate referrals to other specialties outside of our clinic including, but not limited to, gastroenterology, ophthalmology, and orthopedics. This includes working closely with the gastrointestinal Motility Program at Seattle Children's, directed by Dr. Lusine Ambartsumyan, for management of issues related to the movement of food through the digestive tract.

The PWS clinic participates in PWS research and national meetings. This work has led to the following published papers:

- *Salehi P, Leavitt A, Beck AE, Chen ML, Roth CL.* "Obesity Management in Prader-Willi Syndrome." *Pediatric Endocrine Reviews.* 2015; 12(3); 224-238. PMID: 2596220
- *Salehi P, Hsu I, Azen CG, Mittelman SD, Geffner ME, Jeandron D.* "Effects of exenatide on weight and appetite in overweight adolescents and young adults with Prader-Willi syndrome." *Pediatr Obes.* 2016 Apr 13. PMID: 27071367
- *McCandless SE, Yanovski JA, Miller J, Fu C, Bird LM, Salehi P, Chan CL, Stafford D, Abuzzahab MJ, Viskochil D, Barlow SE, Angulo M, Myers SE, Whitman BY, Styne D, Roof E, Dykens EM, Scheimann AO, Malloy J, Zhuang D, Taylor K, Hughes TE, Kim DD, Butler MG.* "Effects of MetAP2 inhibition on hyperphagia and body weight in Prader-Willi syndrome: a randomized, double-blind, placebo-controlled trial." *Diabetes Obes Metab.* 2017 May 29. PMID: 28556449
- *Salehi P, Stafford HJ, Glass R, Leavitt A, Beck AE, McAfee A, Ambartsumyan L, Chen M.* "Silent Aspiration in Infants with Prader-Willi syndrome identified by Videofluoroscopic Swallow Study." *Medicine.* 2017 December; 96(50). PMID: 29390364
- *Salehi P, Lee D, Ambartsumyan L, Sikka N, Scheimann A.* "Rectal Picking Masquerading as Inflammatory Bowel Disease in Prader-Willi syndrome." *JPGN.* 2018 February; Epub ahead of print. PMID: 29470292.
- *Salehi P, Herzig L, Capone D, Oron A, Lu A, Kim SJ.* "Aberrant Behavior Checklist scores in Youth with Prader-Willi syndrome, Trisomy 21 and Autism". Accepted to *AJMG Part A*, pending publication

Dr. Salehi first became interested in working with individuals with PWS after working with Dr. Susan Clark at the CHOC (Childrens Hospital Orange County) PWS clinic; she was touched by the families as well as Dr. Clark's passion for the care of her patients.

Dr. Salehi then initiated a pilot study looking at the effects of Byetta on appetite during her fellowship at CHLA (Children's Hospital Los Angeles), and moved to Seattle Children's after graduating to help start the PWS clinic.

Since its initiation, the clinic has seen more than 70 individuals with PWS from WA, AK, MO, ID, and OR.

The clinic is currently participating in the Soleno trial and are to and is considering participation in other pharmaceutical trials.

The clinic takes new patients up to the age of 18 and accepts most insurance plans* in Washington, also providing financial assistance where needed. Please contact the department administrator at 206-987-2640 for more information.

**might require a prior authorization for out of state areas, specifically those outside of the WWAMI region (Washington, Wyoming, Alaska, Montana, Idaho)* ■

Farewell to Our Founding Father

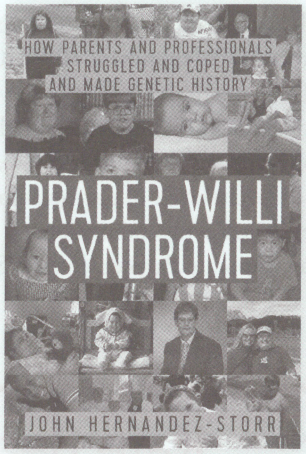
By Janalee Heinemann, MSW, PWSA (USA) Clinical Advisory Board Liaison, IPWSO Advisor

Many members are not aware that the original founders of the Prader-Willi Syndrome Association (USA) were Gene and Fausta Deterling. Gene, 87, died on September 24, 2018. He is survived by his wife, Fausta, daughter, Sara, sons Evan and Curtis (PWS) and four grandchildren. I have known Gene for as long as I have known there was a syndrome called Prader-Willi, so I want to honor him on behalf of all of us. Without his cornerstone to build on, we would not have been able, over time, to develop PWSA (USA) into the world's largest membership association for Prader-Willi syndrome (PWS).

Gene and Fausta's son, Curtis, was born in March of 1971. He was only three-years-old when Gene began the search for other families. In 1975, their family of five drove from Massachusetts to Seattle to meet with Shirley Neason who also had a child with PWS. "Like the Deterlings, the Neasons had initially been told that there was nothing they could do to save their son Daniel from an early death from obesity." *(That quote and much of the information in this article comes from the remarkable historic book on PWS and PWSA by John Storr.)* They also met with dietician Peggy Pipes, and Dr. Vanja Holmes at the Seattle clinic, and created the organization called *Prader Willi Syndrome Parents and Friends.* Shirley became the first editor of our newsletter, *The Gathered View*, and Gene became the first president and key organizer of the association. Two years later, it was renamed the Prader-Willi Syndrome Association. Later, as state chapters were developed, we decided to add the (USA) to delineate the national organization from the state chapters. The Deterling family moved to Minneapolis in 1976 and held the first national conference in 1979 in Minnesota. For the first five years, the Deterling's home was the national headquarters. In 1980, Gene stepped down from the presidency, but took on the new position as secretary/treasurer and remained on the board.

Of course Gene had a full professional life and career beyond his volunteer work with PWS. He was a United States Air Force meteorologist with the rank of Captain, and an electrical engineer and marketing executive at Honeywell Corporation. But his heart and soul were always invested in helping their son Curtis (now 47) and all children and families impacted by Prader-Willi syndrome.

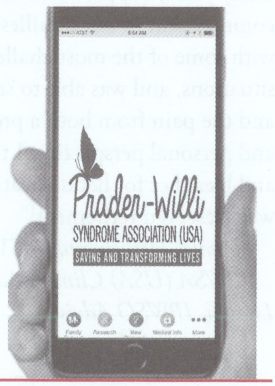
If you have not already done so, I do recommend you buy John Hernandez Storr's book, *Prader-Willi Syndrome ~ How Parents and Professionals Struggled and Coped and Made Genetic History.* This amazing 256-page book gives never-before-told historical facts on the evolution of the medical world working to understand Prader-Willi syndrome entwined with personal stories of the Deterling family's evolution with the syndrome. It gives the reader a true appreciation for the struggles and fortitude of Gene Deterling and the other original pioneers. The book is available through PWSA (USA). Vist or click: http://bit.ly/2POSlSU-PWSAusaGeneticHistory



Carry PWSA (USA) Wherever You Go!

Are you carrying PWSA (USA) in your phone or tablet? You can! Thanks to the Settles family, you can download the **FREE** PWSA (USA) app for mobile devices via iTunes or Google Play. With this app, you will have immediate access to all the important information you need on the PWSA (USA) website with a touch of your phone screen. Forget a handout you wanted to share with a teacher or doctor? No problem. It's all on your phone! Through this app you can:

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



Encourage all the family, friends, and professionals in your child's life to download the app so they can know what you want them to know about PWS and also support the needs of your child at your fingertips.

Link: **http://bit.ly/2CsjHsnPWSAmobileapp**

Welcome Corporate Partners!





PWSA (USA) recently welcomed two new additions to its newly launched Corporate Partners program; *Soleno Therapeutics* and *Latham Centers.* Soleno Therapeutics, is a company developing cutting-edge treatments for rare diseases headquartered in California; Latham Centers, is a residential facility located in Brewster, Massachusetts that offers independent living programs and schooling for children and adults with complex special needs and currently is accepting applications. They both join our first corporate partner; Prader-Willi Homes of Oconomowoc (PWHO). We thank these organizations for their support, and look forward to the continued growth of this program and the positive impact it will have on the PWS community.

PWSA (USA) works with Corporate Partners to coordinate the efforts of PWSA (USA) and corporate leaders, in a collaborative environment, to advance the field of Prader-Willi Syndrome research, patient care, and family support. Positive recognition and other benefits are provided at three different levels of partnership. Both PWSA (USA) and Corporate Partners benefit from the relationship, as each assists the other in achieving its mission.

To learn more about becoming a Corporate Partner, contact Steve Queior at 941-487-6730 or squeior@pwsausa.org. ■

Organization News

Kate Beaver Retiring

"Kate has been a staple in the PWSA (USA) community for many years and had been instrumental in helping my family with several crises. Her love and compassion for my family was always evident with her kind and comforting words she gave me during those trying times with doctors, schools and behaviors. Kate: you will be missed my friend. Enjoy retirement."

Tammie Penta
Board Member, PWSA (USA)

"Having worked with Kate for many years, I appreciated her depth of commitment to our families. She worked with some of the most challenging situations, and was able to see the beauty and the pain from both a professional and personal perspective. I thank her and bless her for her dedication and well-deserved retirement!"

Janalee Heinemann, MSW
PWSA (USA) Clinical Advisory Board Liaison, IPWSO Advisor

For the last 13 years, Kate Beaver has been working as a family support and crisis intervention counselor, promoting a higher quality of life for individuals with PWS by educating anyone seeking information about PWS – family, providers, law enforcement representatives, etc. Kate has helped evaluate environments (home, work, school, etc.) in order to come up with solutions to improve the quality of life for the individual with PWS and those supporting them. Kate will be easing into retirement as she and her husband, Dan, welcome their first grandchild this winter.

Thank you, Kate for all you do for PWSA (USA). Your hard work and dedication have made a huge difference in the PWS community. ■

Stacy Ward, M.S., Crisis Intervention and Family Support Counselor, PWSA (USA)

"Over the past 15+ years, I have problem-solved, collaborated, co-presented, and also laughed and cried with Kate. Her dedication and commitment to all who are impacted by PWS will be missed. Enjoy your retirement and your time with family. (Retirement is great!)"

Barb Dorn, R.N., B.S.N.

"The Georgia chapter has been the grateful recipient of many tireless hours of time spent with Kate, both in crisis and on many regular days. Her retirement comes to us with some sadness and great joy as she will experience with time with her family, spouse, grandchildren.

All the best and a huge thank you. You have touched our hearts."

Debbie Lange, Executive Director
Georgia Association for Prader-Willi Syndrome

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

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

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

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Access our Website: www.pwsausa.org for downloadable publications, current news, research, and more.
The Members Only section requires a password: member20

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

The Gathered View (ISSN 10 77-9965)
Sara Dwyer, Editor
Andrea Glass, Denise Servais
The Gathered View is published bimonthly by PWSA (USA). Publications, newsletters, the Website, and other forms of information and communication are made possible by our generous donors. Consider a donation today to help ensure the continuation of these resources.

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

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

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SAVE THE DATE!

5th Annual Clint Hurdle "Hot Stove" Dinner!

Friday, March 22nd, 2019 at Pier22 in 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 then we'll kick things up a notch with a delicious dinner and 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.

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

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