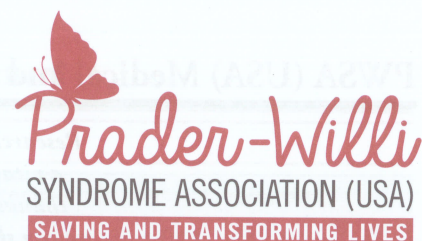


The Gathered View

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



CEO View By Steve Queior, PWSA (USA)

Research, Chapter Activities, and Matching Dollars – All Blooming this Spring!

As Rob Lutz of our Research Committee points out in this issue, numerous clinical trials are coming online this year. Both his article and the fact-filled chart included in it are must-read items for the PWS community, as we work to ensure that these studies are populated with participants.

His article, and the links to the pharmaceutical firms provided, will let you see if the individual with PWS that you know, love, and care for might meet the criteria for a study that could help develop more effective drugs available or new treatments.

Also, we all should read about the research (page 8) titled *High Levels of Caregiver Burden in Prader-Willi syndrome*. Evan Farrar represented PWSA (USA) on the research team that executed this study over the past 18 months. In addition to the study's specific findings, we feel good about the fact that having caregiver burdens quantified and summarized in a highly credible paper will help us advocate for insurance coverage and/or other forms of support that could address the costs of providing care.

And the research activity of 2018 does not stop there: Another key article in this issue discusses research and results regarding the use of vagus nerve

continued on page 4

Join us on

MAY 1st - May 2nd

Noon to Noon

COMMUNITY FOUNDATION
OF SARASOTA COUNTY
PRESENTS

2018
**Giving
CHALLENGE**

Be The One

PWSA (USA) is thrilled to announce that we will be participating in the **24-Hour Online 2018 Giving Challenge** again this year from 12 noon on May 1st to 12 noon May 2nd. In 2016, we were able to raise a total of over \$100,000 in donations and matching gifts thanks to the generous PWSA (USA) community! This year, we are challenging our entire commUNITY to get involved and help us meet our goal of \$125,000! The best part? **All gifts from \$25-\$100 will be matched!** That means, each and every donor can make their mark and "Be The One" to help Save and Transform Lives of individuals with PWS and their families. Go to www.pwsausa.org to learn more.

Volume 44, Number 3 ~ May-June 2018 ~ Our 44th Year of Publication

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

Trials, continued from page 3

INFORMATION AND LINKS PROVIDED BY COMPANY SPONSORS:

GLWL:

The primary objective of this clinical trial is to evaluate the efficacy of GLWL-01 given in capsules at doses of 450 mg twice a day, compared to placebo, in reducing hyperphagia-related behaviors in male and female patients with PWS. This medication has been shown to be safe and well tolerated at doses up to 600 mg given twice a day for 28 days in patients with Type 2 diabetes. Side effects were mild and moderate, and generally related to the gastrointestinal tract.

Multiple study sites are currently active: For the latest information on this clinical trial and the list of sites, visit the page on the clinicaltrials.gov website: <http://bit.ly/2J6NYQpGLWL>
<http://bit.ly/2Hax470GLWLresearch>

Insys Therapeutics:

Insys Development Company, Inc. is conducting a clinical trial to determine if the use of cannabidiol (CBD) is safe

and effective in the treatment of Prader-Willi syndrome. To determine if CBD is effective in Prader-Willi, the trial will be evaluating in children between 8 and 17 years old whether the use of CBD provided as an oral solution can help control continual feeling of hunger regardless of food intake and the effect of CBD on compulsive behaviors. After completion of the study, patients will be offered the opportunity to enroll in an open-label, long-term safety study. For more information, a description of this study including the location of the sites that are enrolling patients is available at <http://bit.ly/2EWPn9yInsys>.

Levo Therapeutics:

Carbetocin is an investigational drug that was created to have effects in the body like oxytocin. Carbetocin is not approved in the United States, but is approved in some other countries for treatment of women with excessive bleeding after giving birth via caesarean section.

Carbetocin has been studied by Ferring Pharmascience Center for the treatment of PWS in a Phase 2 study at Vanderbilt University, University

of Florida and Winthrop University. Further development, including the Phase 3 study, will be pursued by Levo Therapeutics. Plans for the Phase 3 study are subject to change.
<https://www.levotx.com>.

Millendo Therapeutics:

Millendo Therapeutics is preparing to initiate a Phase 2b/3 study for livoletide (AZP-531) with clinical sites in both the US and Europe. Millendo recently acquired Alize Pharma and is continuing the development of livoletide in PWS. Livoletide is an analogue of unacylated ghrelin, that counteracts some of the effects of acylated ghrelin, commonly referred to as the hunger hormone. Livoletide was previously studied in a double-blind, randomized, placebo-controlled Phase 2 clinical trial with a total of 47 subjects with PWS, demonstrating an improvement in hyperphagia as measured by the HQ at 2 weeks. (<http://bit.ly/2EY7xHZMillendo>)

More information on Millendo and livoletide can be obtained at www.millendo.com. Trial details will be available later in 2018. ■

CEO View, continued from page 1

stimulation (VNS) in Prader-Willi syndrome (page 7).

Shifting from our national office to chapters around the country, the next 10 weeks are among the busiest of the year. With mild weather returning, many state chapters are having outdoor events that help increase awareness and educate others about the syndrome, raise funds to help states provide their programming, and provide fun and fellowship for all.

Please consider supporting these upcoming chapter events - information about them is in this issue and others available on our website - and then become more involved in your state's chapter on a year-round basis. The 33 state and regional chapters of PWSA (USA) are tremendous assets and we

firmly believe that the more we all work with them, the more positive results we'll all see.

**Beginning May 1st,
the 24-Hour
Giving Challenge is
an opportunity to
have YOUR dollars
DOUBLED.**

Last, but hardly least, the absolutely unique opportunity called the 24-Hour Giving Challenge is right around the corner. This opportunity to have dollars by you, your friends, family members, co-workers, and neighbors DOUBLED is not to be missed.

During the 24 hours from 12 noon on Tuesday, May 1st to 11:59 a.m. Wednesday, May 2nd, every online donation between \$25 and \$100 will be matched by a very generous foundation located in the community of our national office. Please mark your calendar and follow the easy steps on our website, social media, and emailed to you.

Together we can generate over \$100,000 in this one-day period, all to help strengthen our Five Pillars of Support: Awareness, Family Support, Research, Education, and Advocacy.

As always, thank you for all your support, and particularly for helping us exceed our goal in the **Giving Challenge**, when you can **Be The One** Saving and Transforming Lives! ■

Constipation in children with PWS

By Kathy Clark, R.N., M.S.N., CS-BC, Coordinator of Medical Affairs, PWSA (USA);
Reviewed and approved by Ann Scheimann, M.D.

Difficulty passing bowel movements (BM) is a common problem in PWS, even during infancy. Very soft daily bowel movements are the goal – no bunny pellets, no liquid stools, no pain or discomfort. Some children will release just a small BM, unaware that there is a bigger load behind – so don't be afraid to ask to see what has been produced. Complete evacuation is the goal.

PWS challenges

Poor motility in the entire GI tract

– from sucking, chewing, and swallowing to stomach emptying, to finally pooping – things just don't move along in a typical pattern. There may be slow spots along this pathway, not just at the exit.

Low muscle tone (hypotonia) – movements such as crawling and walking help the passage of food, but are generally delayed skills for children with PWS.

Time – Parents and children are so busy with the many therapies and appointments that life is often too rushed to think about the last bowel movement or to take time for the potty.

Sensation – not feeling pain may also mean they miss the “full” signal that it is time to poop.

Gut microbes, probiotics, and fiber – gut microbes may not be typical in people with PWS, so a probiotic is worth trying. PWSA (USA) no longer recommends a high fiber/raw foods diet for persons with PWS because of the risks of fermentation if the digestive tract is not moving well. Fruits and vegetables, softened and in small pieces, are an essential focus of a healthy diet.

Top down, bottom up

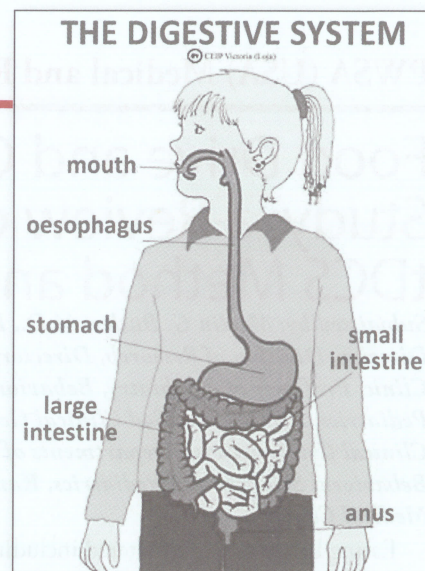
If your child has had constipation, prevention should start at the “top” – over-the-counter medications that will make the food hang onto water, making the BM less likely to dry out. Miralax and milk of magnesia are examples of stool softeners. Stool softeners do not make

the bowels contract or stimulate a bowel movement. Other oral medications, such as senna, activate the colon to propel a bowel movement along. Some families use these medications daily, and others add these only if things are not moving along. Taking these medications by mouth or feeding tube can take 1-3 days to produce results.

The “bottom up” approach is helpful when there is already a backup of stool. Children quickly learn to “hang on” to a BM if it hurts to pass. Stimulating the anus can help release the BM and may bring fast relief. A glycerin suppository, which has no medication, only a lubricant, will stimulate the rectum slightly and can be enough to prompt a BM. Dulcolax suppositories have medication which causes the rectum to squeeze and is a faster therapy. Neither one works unless it is touching the inside wall of the rectum – not stuck right into the BM. Grease up the anus with some Vaseline for your child's comfort in passing the large BM; this will also stimulate defecation. Have them lie on their side to insert the suppository, with their knees up to their chest. If they can wait 10 minutes to push, it is more likely to produce the best results. Drinking a glass of water before sitting on the toilet is also helpful – you may have to use your usual tricks to get them to drink.

Once a child has had lots of constipation bouts, they may lose the sensation that it is time to “go”. They will have to retrain their bowels. Swallowing stimulates a reflex in the colon, so the best time to sit on the toilet is right after a meal. Make it a habit after breakfast. A chart with stickers can be a motivator!

Some parents find abdominal massage is helpful for any age child; there are Youtube videos explaining this technique. Blowing up a balloon or blowing bubbles can help a child relax their bottom muscles while sitting on the toilet. This is



no time for speed or impatience. Bring a book to read together, or play music.



Toilet tricks

Use statements rather than questions (e.g., “It is time to sit on the toilet”, not “Do you need to use the bathroom?”). They may be unaware of the fullness in the colon.

You may need to reward the sitting, even without any results – think sticker charts.

Correct positioning on a toilet is very important for children – and adults. American toilets are poorly designed for good bowel elimination; we are designed to squat when pooping. For a child, or a short adult, the toilet height will never be ideal for good bowel health. The knees should be at least as high as the hips – a true squat is best to open up the muscles that release the BM. A small footstool at the toilet is a good investment – there are toilet footstools, such as the Squatty Potty, which may be very helpful - www.squattypotty.com

Keep their hands occupied so they cannot hold onto the toilet seat. This position can increase muscle tension of the pelvic floor and make it harder to pass the stool comfortably and completely.

Before adding any over-the-counter medication, call your health care provider to discuss the unique issues for your own child. These are just guidelines for a very common problem for children with PWS. ■

Food Drive and Craving Study: a Review of the tDCS Method and PWS

Submitted by: Merlin G. Butler, M.D., Ph.D., F.F.A.C.M.G., Director, Division of Research, Director, Genetics Clinic, Professor of Psychiatry, Behavioral Sciences and Pediatrics, ABMG Certified Clinical Geneticist and Clinical Cytogeneticist, Departments of Psychiatry & Behavioral Sciences and Pediatrics, Kansas University Medical Center

Eating behavior can be altered including decision-making and cue-induced food craving in healthy adults by stimulating regions in the prefrontal cortex, although the mechanisms underlying hyperphagic behavior is not fully understood.

Transcranial direct current stimulation (tDCS) is one of the emerging non-invasive, safe and painless methods which administers a weak electrical current to the forehead that

penetrates the skull and affects brain/neuron functioning, thereby influencing cognitive or thinking processes (Nitsche and Paulus, 2000; Fregni et al., 2008; Boggio et al., 2009; Goldman et al., 2011). Our goal was to assess the value of applying tDCS to the prefrontal cortex area to activate the inhibitory regions controlling brain pathways to lower food craving and hyperphagia

in Prader-Willi syndrome (PWS). We conducted a multicenter pilot double blind, sham-controlled transcranial direct current stimulation during mid-day for 30 minute sessions to the right dorsolateral prefrontal cortex (DLPFC). DLPFC is a key brain

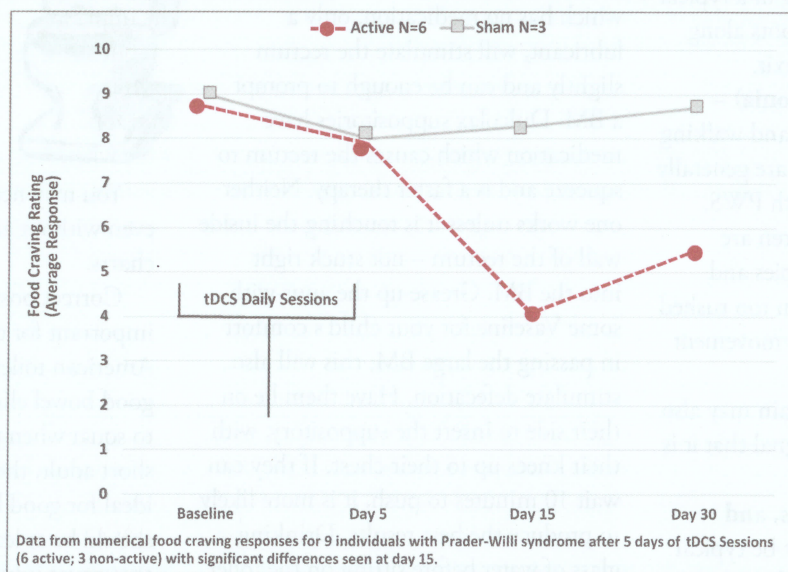
structure for the regulation and processing of food motivation and satiety signals crucial for integration of incoming sensory information for food stimuli (Rolls, 2005). PWS is also associated with reduced cortical and grey and white brain matter with reduced brain signaling compared with healthy controls (Holsen et al., 2012; Honea et al., 2012; Zhang et al., 2015).

We studied the food drive and craving in 10 adults with PWS, 11 obese adults and 11 healthy-weight adults in five consecutive daily sessions of active or non-active tDCS treatments. Standardized psychometric instruments assessed food craving, drive and hyperphagia by self-report and caregiver assessment over 30 days in our study. Baseline differences were observed in severity scores for the Three-Factor Eating Questionnaire (TFEQ) and the Dykens Hyperphagia Questionnaire (DHQ) for PWS compared to healthy weight controls while obese participants were more similar to the healthy weight controls. Active tDCS treatment in PWS was associated with changes from baseline in TFEQ Disinhibition-

Factor II (at 30 days) and Total Scores (at 30 days) and participant ratings of the DHQ Severity (at 5 days) and Total Scores (at 15 days). Our pilot study supported sustained effects of tDCS to reduce food drive and behaviors impacting hyperphagia in PWS beyond the five consecutive days of treatment without any recognized safety issues (Bravo et al. 2016).

Transcranial direct

current stimulation may represent a straight-forward, low risk and cost method to improve care, management and quality of life in PWS but further testing of this device is required for treatment of hyperphagia in PWS. ■



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Research in Progress: The Use of Vagus Nerve Stimulation (VNS) in Prader-Willi Syndrome (PWS)

By Anthony J. Holland, M.D., CBE (United Kingdom), President, IPWSO

From Observation to Understanding

The challenge in terms of new treatment development for hyperphagia, and for behavioral problems and mental ill health, is a lack of understanding of the underlying causes. However, a combination of the use of new technologies such as neuroimaging, observational studies, and findings from clinical trials are providing insight into why these problems commonly affect people with PWS.

Why the Vagus Nerve?

The vagus nerve has many important biological functions. The left and right vagus nerves run from the brain stem through the neck to the chest and abdomen, linking, for example, the hypothalamus and the gastrointestinal system. This provides part of the feedback loop that enables the brain to accurately regulate food intake. It also regulates cardiac and respiratory functions, and facilitates our complex and multifaceted response to threat. This latter role described by Dr. Stephen Porges is what he has named the Polyvagal Theory.

Why Vagus Nerve Stimulation (VNS)?

Stimulation of the vagus nerve from a surgically implanted device has a long history as a treatment for epilepsy and for depression. There have been incidental observations that people who have had VNS for epilepsy have lost weight. Given this observation and the role of the vagus nerve in the regulation of eating behavior, we undertook a trial of VNS in three people with PWS. In the treatment of epilepsy, the implanted stimulator is programmed to switch on and off continually over time and may take months to have an effect. The hypothesis in this first study was that VNS from such an implanted device would lead to an increased ability to control food intake and to weight loss.

Early Findings

As reported (Manning et al, 2016), contrary to our predictions, VNS had no marked effect on hyperphagia or weight but some weeks into the active stimulation phase, two of the three people with PWS and their parents reported a marked improvement in behavior. As this study was investigating the effects of VNS on hyperphagia, behavioral data had not been collected; however, the two participants and their parents reported such improvements that both asked that the VNS continue. These benefits have been maintained over five years.

A Second Trial of VNS Using an External Device

This serendipitous observation provided an important lens to focus on the reasons for such behaviors, and also led to the need for a more systematic study to collect behavioral data

before and during treatment using VNS. There are now vagus nerve stimulators with rechargeable battery and controls, which are about the

size of a mobile phone, which are worn externally. The battery pack is connected by wire to an electrode worn in the left outer ear for four hours each day (see photograph). This type of VNS is referred to as transcutaneous VNS (tVNS). The use of this external device has been the subject of a second study involving six participants. The findings of this study are now being collated and they will be the subject of a paper in the near future. As with the implanted devices, improvements in behavior are being seen, but there remain some concerns about compliance and the optimum treatment protocol. Benefits take many months to become apparent, and it has been difficult to encourage some people with PWS to persevere using the device each day. However, as those who have persisted have felt the benefits, they then keen to continue. Working with Dr. Stephen Porges, we are also investigating how VNS is working in order to better understand the underlying dysfunction that puts people with PWS at risk for temper outbursts, and to be able to target those most likely to benefit.

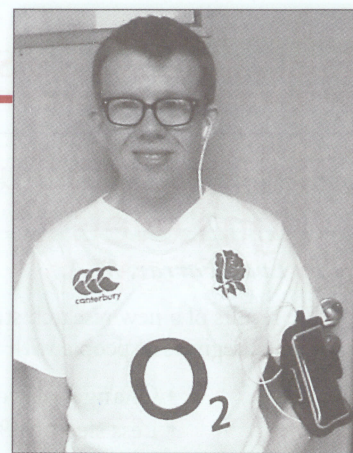
Where Next?

The increased propensity to temper outbursts in people with PWS is at least partly due to a biologically determined abnormality of the autonomic nervous system and, in turn, of emotional regulation. We are now studying the use of other types of transcutaneous stimulation, which may also be effective but perhaps easier to use. Although we have not observed any direct effect on eating behavior, as emotional regulation has improved, our participants have become more accepting of food regulation. After we fully analyze the data, the findings will be submitted for publication and any further research needed can be conducted and recommendations made about the use of such devices for children and adults with PWS. ■

Acknowledgements

We would like to thank the participants, their families, and others caregivers for their support, and the Dunhill Medical Trust, Sam's Foundation, the UK PWSA, and the Foundation for Prader-Willi Research for funding these studies.

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Subject, age 26, demonstrating an external VNS device.

New Research Study Documents High Levels of Caregiver Burden in Prader-Willi Syndrome

By Evan Farrar, M.A.

The results of a new research study, published in PLOS ONE, reveal high levels of burden on caregivers in the PWS community. Caregivers of people with PWS, to varying degrees, can experience:

- Changes at work (88%)
- Less sleep (61%)
- More mood disruptions such as feeling anxious (94%) or depressed (77%)
- Increased challenges in marital and romantic relationships (89%)

The study, "High levels of caregiver burden in PWS," is the first published research developed by the PWS Clinical Trial Consortium (PWS-CTC). The PWS-CTC is an international, collaborative research consortium gathering stakeholders from pharmaceutical industries, academia and patient organizations to facilitate the development of clinical trials in PWS. The consortium is supported and funded by patient advocacy groups including PWSA (USA), the Foundation for Prader-Willi Research, Prader-Willi France, the International Prader-Willi Organisation, industry partners and experts from Academia (for more information see <https://www.pwsctc.org/>). It is also the first study to directly measure challenges faced by caregivers of people with PWS, making it a unique and important contribution to understanding the daily challenges faced by caregivers. The study was based on the responses of 142 caregivers from the United States.

The study is a clear example of how research can inform providing family support to the PWS community. Stacy Ward, a PWSA (USA) Crisis Intervention and Family Support Counselor, explains, "The PWSA (USA) family support program will use the results of the caregiver burden study not only to develop new resources that will support caregivers, but to engage caregivers differently based on their needs identified in this survey. The mission of our family support program is to provide meaningful practical support and the results of this study will help us to do that more effectively."

The Caregiver Burden study also has two other important outcomes:

1. It points to the need for additional study of the caregiver experience in the PWS community.
2. It validates the experience of caregivers who often feel the burdens they face are unique to their specific situation. The study suggests this is not the case, helping caregivers know they are not alone in the experience of caring for a person with PWS.

To learn more about the caregiver study and to dig deeper into its results, you can read the entire research article at <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0194655> ■

Note: Evan Farrar represented PWSA (USA) on the caregiver burdens research team and is listed as one of the study's authors.

Newly Updated for 2018!

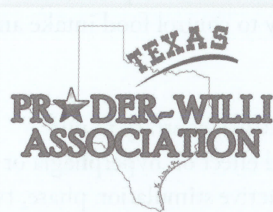
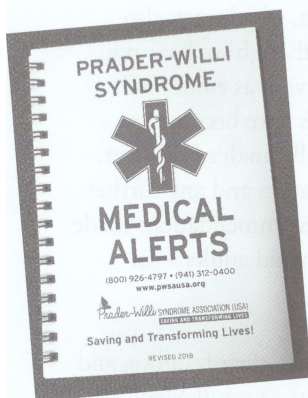
Medical Alerts

by PWSA (USA)

20% member discount

For parents/caregivers! Share crucial medical information and the GI lifesaving chart to doctors, ER staff, EMTs and all caregivers. The content was written by our medical professionals. **It's imperative that**

this pocket-sized medical booklet be with you at all times. The lifesaving booklet (\$3.00 ea) includes the foldout G.I. algorithm chart to help direct ER medical staff what to look for and do, when GI problems are presented in PWS. visit: <http://bit.ly/2qzBEACMedicAlertPWS> for purchase. ■



Eighth Annual Charity Golf Tournament

Cypresswood Golf Club, Spring, TX,
Monday, May 21, 10AM Shotgun Start

Get in on the fun! Play a round and/or be a Tournament Sponsor! Spotlight your company by donating an item or service to our event raffle or live/silent auctions. For more details visit <http://praderwilligolf.wix.com/pwsgolf>. Thank you for helping TXPWA! **Sponsored by Molly's Pub benefiting the Texas Prader-Willi Association (TXPWA)** Donate via PayPal www.txpwa.org ■



Clint gives a great presentation, and the 2018 Hot Stove dinner was no exception!

A delicious dinner, great music, baseball, and great company perfectly describe the 2018 Clint Hurdle "Hot Stove" dinner! Through the kindness and generosity of attendees, donors, and sponsors, over \$79,000 was raised to help fund PWSA (USA)'s Family Support program! Funds raised will go directly into providing information and resources to the PWS community, such as: school assistance; behavior management and modification; nutrition education; crisis intervention; legal, and legislative advocacy; medical intervention; and so much more. Just as importantly, awareness about Prader-Willi syndrome was raised and attention brought to the needs of the PWS community. In all senses of the word, the event was a great success! ■



This Pirate is a favorite, especially for young Pax!

Many thanks to all who donated, sponsored, and attended!

Fourth Annual Clint Hurdle "Hot Stove" Dinner a Great Success!



Pirates players past and present lent their support for the Hurdle family and PWSA (USA)!

Special thanks to all who supported the event including our event sponsors:

Helton Foundation
Continuum IT Management Platform
Dawn Allard
Seminole Hard Rock Casino
Pirates Charities
Vanguard
the Hurdle family



PWSA (USA) staff, Clint and Maddie Hurdle and friends celebrate another successful Hot Stove dinner. The event raised over \$79,000 for PWSA (USA)'s Family Support program. More than 130 people attended the 2018 Hot Stove dinner, enjoying live music, delicious food, and excellent company!



Maddie Hurdle with her grandparents, Clint Sr. and Louise Hurdle.



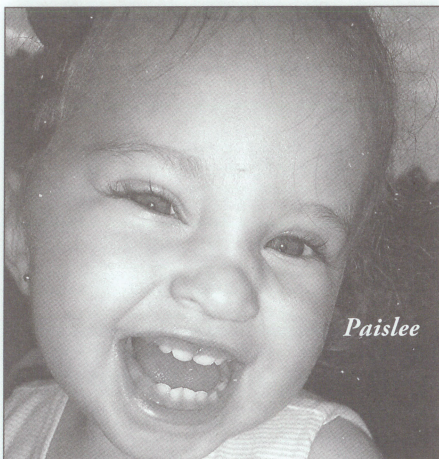
The silent auction was a sports fanatics delight with autographed jerseys, baseballs, bats, and more!



The Pirate Parrot was a favorite, especially with the kids!

Editor's comment: "Sometimes you meet someone who sees a silver lining in everything. Brittnee Peterson is one of those people. Here is her story."

Just before I learned I was pregnant with Paislee, our daughter Olivia (3 mos.) passed away. Olivia had 1p36 Deletion Syndrome. I vowed to give all of our troubles to God so I could enjoy my pregnancy and enjoy my "rainbow baby" after she was born. During pregnancy with Paislee, she showed a lot of the same issues that Olivia did, small at each gestational milestone, low amniotic fluid, etc. I declined all of the testing, including an amniocentesis. I wanted to be able to enjoy my pregnancy with her; I gave it to God. She was born at 39 weeks via scheduled caesarean, with no complications, and weighed a tiny 3 pounds 10 ounces. The NICU performed genetic testing, but missed the PWS.



Paislee having PWS makes her who she is, personality and all. As you know, most kids/babies with PWS are the most loving babies. She came in a time of my life that was hard as I struggled with depression after my daughter passed away. Paislee is the most loving child I have ever met. She can walk into a room and brighten everyone's day. I needed her to be the easy baby that she was. So with this being said, I am so thankful for the life that God has blessed us with, Prader-Willi and all.

Paislee had all of the delays that many

kids with PWS do. She didn't crawl until 24 months, didn't walk until 30 months. She still doesn't talk. As a baby she never cried. She aspirated all the time; I must have changed her formula 10 times! She had PT, OT and ST, however, none of the therapies seemed to help. Still no answers, so we changed pediatricians. Dr. Rihka Chadalawada ordered more genetic testing but had already told us to research Prader-Willi syndrome. Paislee had begun gaining weight for

I started reading about Prader-Willi syndrome and suddenly everything made sense.

no apparent reason. Her calorie intake was about the same. Also, I started reading about Prader-Willi syndrome and suddenly everything made sense. Within seven days, we got the genetic test back. Paislee had PWS. This all happened in October of 2017, and I took up the search for Facebook groups. I called PWSA (USA), who plugged me into the Facebook Groups, and watched as my Facebook Messenger BLEW up! I saw that there was a national convention just a few weeks away. I knew I had to find a way for us to make it to the convention. Before I knew it, we had flights and everything booked. Thanks to PWSA (USA)!

The convention was amazing! I get the chills and want to cry happy tears every time I think about it. I learned so much, Paislee and I both met lifelong friends. I cannot wait until 2019!

When leaving the convention, I knew I had to start an Alabama Chapter.



This is now a reality: we are an official chapter! I want families in Alabama to have that same feeling that I had in Orlando; that they have people that love them and know exactly what they are going through. I want to share resources and doctors. I was shocked when I received the list of disconnected families and individuals in Alabama. Many are not on social media, nor actively involved with PWSA (USA); there were many adults with PWS that have never met another person with PWS. THIS ALL HAS TO CHANGE. If you live in Alabama, please join us for our first meeting to be announced soon.

I want families ... to have that same feeling that I had ... that they have people that love them and know exactly what they are going through.

Brittnee and Albert Peterson live in Pelham, Alabama. Please contact her at Brittneepetersonpusalabama@gmail.com. She would love to hear from you! ■

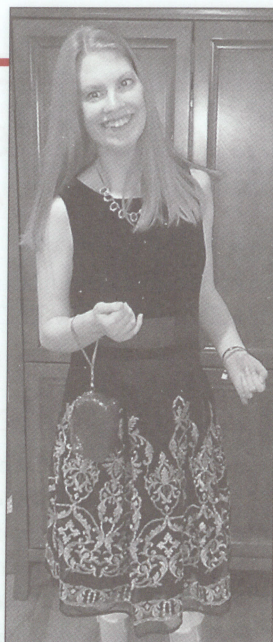
An Amazing Grandmother

This submission is to honor my sister Maureen O'Neil on her 70th birthday and her unconditional devotion to family. For the last 18 years she (along with her husband Chip), has made a lifesaving difference for twin granddaughters Kate and Meghan, who have Prader-Willi syndrome. This is the shared glimpse of their lives together, submitted by Doris Feirer.

Kate and Meghan were born in New Jersey, on November 19, 1999. It took two weeks to receive the diagnosis of PWS from the hospital; they had other problems as well. Kate left the hospital in February, 2000. Meghan came home around Easter. Maureen remembers visiting the hospital in the morning on the way to work to hold them. The girls' mother Cathy had early intervention support come to help the girls with their respective developmental issues. We learned about growth hormones, which they started right away. The girls were able to grow and do not have the short stature associated with PWS prior to growth hormone treatment. At age three, Maureen took Meghan (Meg) to hippotherapy which helps with hip movements, to enable her to walk more normally. We remember her being able to walk down the aisle with her walker at the wedding of Maureen's son. When the girls started school, Maureen helped during vacations and days off. As they grew, new health issues arose. When Meg had her foot surgery, Maureen stayed with her for six weeks to help with recovery and begin therapy. Maureen became involved in PWSA (USA), and attended conventions to learn more about what could help her granddaughters. As a quilter, she also created and donated quilts for convention auctions. During summers, Maureen was able to send them to Camp Sunshine, a special needs day camp in Ridgewood. The girls loved camp, its fun activities and stayed with Maureen those nights. They had fun packing lunches and getting ready for each exciting day. Maureen also was involved in some camp fundraising.

The girls love to visit the IHOP in Clifton, NJ. All the employees there always make a fuss about them and the girls basked in the attention. Kate is the more voracious reader, preferring books to TV. Both girls are without a doubt social butterflies and love to dance. They attend West Milford High School, are in the 11th grade, active in the Color Guard and their community Special Olympics.

As special vacation holidays, Kate and Meg regularly visit



Meg



Kate

in August with Maureen and her husband in Florida. When each girl was sent on a "Make a Wish" trip to Disney, Maureen went to help with the girls. Kate and Meg enjoy shopping for new sneakers and clothes, and they all enjoy going to the bookstore during their special times together. This has become a special time for the girls.

Meg recently had major back surgery for scoliosis. Maureen spent five weeks with her in the hospital, then the rehabilitation that followed. The follow-up and continued therapy was at her home before Meg was cleared to go to camp.

Most recently Kate and Meghan were among the 100 guests who attended the Feb. 9 Tim Tebow-sponsored "Night to Shine Prom", hosted by St. Catherine of Bologna Church in Ringwood, NJ. They were so happy to get dressed up and had the time of their lives! (see photos)

In closing, this story shares the wonderful love and support of a special grandmother and her grandchildren, plus hope and joy to other families and grandparents of children with Prader-Willi syndrome. ■

In follow-up to a March/April 2018 awareness article, I attended presentations on Prader-Willi syndrome given by two Ashley Hall students; also attending was Nichole Carey, (mathematics teacher whose niece has PWS).

Biology teacher Allison Bowden includes a section on genetic disorders in the ninth grade curriculum. Both Miss Wickie Fort and Miss Mia

Rogers gave thorough reports including data, studies, and supporting reference information. Feedback was inspiring to see these young women prepare well and ask questions; they may be our next generation of medical professionals "Saving and Transforming Lives"!

Madison Whelpley, a 2018 Ashley Hall graduate, will be attending Clemson University, and I look forward to future presentations on PWS. ■

~ The Editor



Teacher Allison Bowden with student Mia Rogers.

Exciting Updates to the Wyatt Special Education Advocacy Training

By Evan Farrar, M.A.

PWSA (USA) is proud to announce the newest webinar training module for the Wyatt Special Education Advocacy Training (WSEAT):

Free Appropriate Public Education (FAPE) for Students with PWS: The Legal Keystone

Presented by Perry A. Zirkel, Professor Emeritus of Education and Law at Lehigh University. Perry has a Ph.D. in Educational Administration and a J.D. from the University of Connecticut, and a Master of Laws degree from Yale University. Dr. Zirkel has written more than 1,500 publications on various aspects of school law, with an emphasis on legal issues in special education.

This important new module covers:

- The crucial concept of a *Free and Appropriate Public Education* (FAPE) - its dimensions, overlaps, and remedies
- **A review, for the first time ever, of PWS-related case law**
- Key “take-aways” and references
- Downloadable FAPE-related resources

More WSEAT Resources for YOU! Yes, the WSEAT now includes:

- Tip sheets for parents, medical professionals, PWSA (USA) chapter leaders, and others, to equip every audience to get the most out of the WSEAT.
- An expanded and updated additional resource section. Now people can dig even deeper into special education advocacy issues of interest.

The WSEAT is the Prader-Willi syndrome community's one stop shop for special education advocacy. It is free and available 24/7 at <https://www.pwsausa.org/wsear-webinar-series/> ■

Note: Evan, formerly a PWSA (USA) family support counselor, is a WSEAT consultant.

Ninth Annual Hunter Lens Golf Tournament

Join us! On Saturday, June 2nd, 1:00pm, at the Back 9 Golf Club (<http://www.thebacknineclub.com/>) in Lakeville, MA come have fun to support Hunter and our worthy cause. All proceeds are being donated to Prader-Willi Syndrome Association (USA). In 2017, we raised over \$30,000 (8 year total: \$130,000+). **Thank you for your generosity.** These

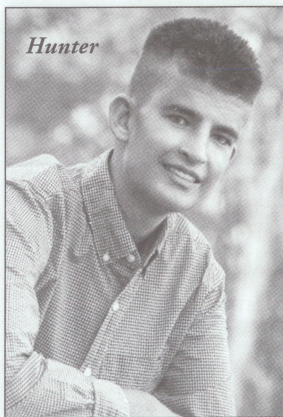
proceeds help promote and fund research, provide education, and offer support to enhance the quality of life of those affected by PWS.

Help us continue to raise awareness and support for this worthy cause in many ways:

- Come join us for fun, laughs, 18 holes of golf, plus dinner, raffles and a silent auction.
- Non-golfers: please join us for a great dinner, drinks, raffles and a silent auction (4PM).
- Not able to join us, but want to help? Donate online by clicking the link below, or send a check directly written out to PWSA (USA) and mail it to Jon Hunter at 22 Beechtree Drive, Lakeville, MA 02347.
- Also, if you would like to donate raffle items such as gift baskets, sports autographs / tickets, trips, restaurant gift certificates, etc. for the silent auction, please email Lori and I directly. Last year the auction provided MUCH of the profits of the event and all generosity is greatly appreciated.
- Pass this on to anyone you feel may be interested in playing or donating as well!

Donation and Registration: <https://www.firstgiving.com/pwsausa/hunterlensgolfouting>

Thank you for supporting Hunter and PWSA (USA). ~ Lori and Jon ■



Organization View

Advocacy Update

By Thomas Conway, Esq., Advocacy Committee Chair, PWSA (USA)

The following is a summary of recent legislative and administrative issues that are important to the Prader-Willi syndrome community.

State Legislation Regarding Prader-Willi Syndrome

Through the efforts of the Prader-Willi Alliance of New York, the New York State Chapter of PWSA (USA), New York State has enacted legislation that will ease access to needed supports for those with Prader-Willi syndrome. Previously, eligibility for supports through the New York Office of Persons with Developmental Disabilities (OPWDD) was based on several criteria, with a low IQ score and limited adaptive (self-help, community living, communication) skills being the foremost considerations. The new law acknowledges the reality of Prader-Willi syndrome and makes the diagnosis of PWS the primary consideration in determining eligibility for support and services, rather than a test score.

On April 2, 2018, the Governor of Colorado signed legislation adding Prader-Willi syndrome to the definition of an "intellectual and developmental disability" for the purpose of receiving services and supports. Congratulations to the Prader-Willi Syndrome Association of Colorado for its tireless efforts in advocating for the enactment of this law. Colorado is now the ninth state to have enacted this important legislation.

Affordable Care Act

Recent Congressional attempts to repeal provisions of the *Affordable Care Act* (Obamacare) would have dramatically impacted the ability of persons with pre-existing conditions to obtain health insurance coverage and would have reduced expenditures for Medicaid by hundreds of billions of dollars. As a result of an unprecedented lobbying effort by patients and patient advocates, including members of the

PWSA (USA) Advocacy Alert Network, the proposed legislation failed to become law. We anticipate future proposals by Congress in this area and we will continue to oppose any effort aimed at stripping protections for persons with pre-existing conditions and/or cutting funds for the Medicaid program which is vital for our community.

Orphan Drug Act

In 1983, Congress enacted the *Orphan Drug Act* (ODA), which allows drug manufacturers to claim a tax credit of fifty percent of the costs of qualified clinical research and drug testing of drugs for rare diseases, defined as diseases affecting fewer than 200,000 Americans. Since its enactment, the ODA has played a critical role in the development of drugs for rare diseases. More than 3,500 potential treatments have been designated as orphan drugs, and more than 500 orphan therapies have been approved by the FDA. In the decade before the incentives provided by the ODA, only ten medicines were developed for rare diseases.

In its proposed *Tax Cuts and Jobs Act* (TCJA), the U.S. House of Representatives completely repealed the ODA. PWSA (USA) joined with over 200 other patient advocate organizations in opposing the proposed repeal of the ODA. In the final version of the TCJA enacted by Congress and signed by the President, the tax credit for drug manufacturers to develop orphan drugs was reduced from 50% to 25%. Although our lobbying efforts did not result in a complete restoration of the ODA, they played an important role in ensuring that the ODA remains in effect.

Medicaid Formulary Access and State Concerns Regarding Medications Approved Via FDA's Accelerated Approval Program

PWSA (USA) joined with 125 patient organizations representing persons with rare diseases in a letter to the State Medicaid Directors in every state expressing concerns regarding patient access to innovative new medicines. The

letter addresses recent efforts by some states to create formulary restrictions limiting coverage for drugs for patients participating in the Medicaid program, as well as efforts to restrict coverage for drugs granted approval through the FDA's Accelerated Approval Program. ■



In Remembrance

It is with sadness that we share the passing of Louise Greenswag, who dedicated her life to improving the lives of those with Prader-Willi syndrome and their families. Louise had a special gift of communicating the difficult realities



and critical behavioral management techniques in a supportive manner. Her pioneering work underpins today's standards.

Louise organized and co-edited the first definitive PWS textbook: *Understanding Prader-Willi Syndrome* in 1988; she served on the PWSA (USA) board of directors from 1985-1997 and co-organized the first international conference on PWS in The Netherlands in 1991, giving rise to IPWSO, the international PWS organization. Louise generously and often shared her knowledge and expertise at decades of U.S. conferences, chapter meetings, and globally traveled to train families and professionals on the special needs of PWS.

In her memory, a Louise Greenswag Memorial Fund has been established at PWSA (USA) to celebrate all that she has given us. Click <http://bit.ly/2zNEb1Cpwsausa> and select "in memory of" ■

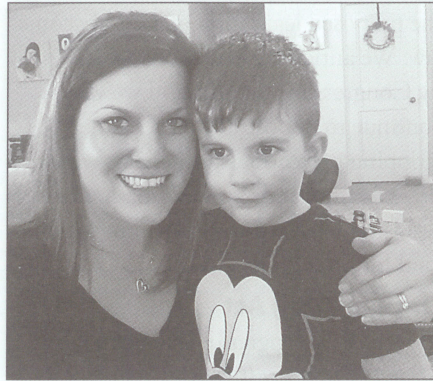
Giving Back

By Kathryn Lucero

Giving back to the PWS community is something many of us enjoy doing by ways of fundraising, volunteering in various capacities, and becoming a vital part of the organization. Some volunteers enjoy the relationships that develop when meeting another family. The Parent Mentor Program was created to give back in a big way.

A Parent Mentor is someone who provides support throughout the journey of a newly diagnosed individual and their family. A Mentor's "job" is not done when the child hits a certain age; they are part of that family's life. It goes beyond being discharged from the hospital, and the tough times of therapies, feedings, etc. Parent Mentors provide support, encouragement and resources to the families and a life changing bond between that mentor and each family is typically made.

We are looking for mentors! Could you be one? All resources that may need to be given to the new family are provided by PWSA (USA), who works hand in hand with mentors to provide them with resources and education to share confidently the support to their families.



Kathryn with son Ronan.

This year, the Parent Mentors will meet in Tennessee, with lots of exciting news and speakers on the agenda. These meetings allow mentors to meet one another, share ideas and experiences, and build lifelong friendships.

If you are curious to learn more or interested in becoming part of the Parent Mentor Team, please contact Diane Seely at dseely@pwsausa.org or contact the PWSA (USA) national office. Thank you!

About the Author:

Kathryn Lucero is the proud mother of four-year-old Ronan and supportive wife to her husband Armando. Her journey began on January 21, 2014 when their son Ronan was born and later diagnosed

with Prader-Willi syndrome. Kathryn became active with PWSA (USA) in early 2015 when she realized that there was not much support in her home state of New Mexico. Kathryn wanted to help other families who felt the weight of the new diagnosis, and is able to provide them with support and encouragement. During this time, Kathryn also was enrolled at the Institute for Integrative Nutrition. To receive her Integrative Health and Wellness Certification, she was given the opportunity to "Intern" for PWSA (USA). She began writing articles for The Gathered View beginning September 2015 and through her articles, reached and bonded with other families going through similar circumstances.

Kathryn connected with the Parent Mentor program that provided encouragement and support to her and her family. She quickly was able to do the same with other families in the community. Kathryn now balances being: a Chapter Leader for New Mexico (while living in CO), a Parent Mentor, a PWSA (USA) Brand Ambassador, but most importantly, her role as Ronan's mom. Kathryn considers herself a strong advocate for those with PWS and will continue to make a footprint in the hearts that she reaches. Thank you Kathryn. ■

Nexus Children's Hospital Announces Program Restart

Changes Health & Wellness Program reopens to treat underserved pediatric population

Nexus Health Systems restarted their national Changes Health and Wellness program in January, 2018, at Nexus Children's Hospital, in Houston, Texas. The program offers support and treatment for patients with Prader-Willi syndrome (PWS), providing care for patients with other weight management-related illnesses.

"Our inpatient program is one of the only available in the country for children with PWS," said Dr. John W. Cassidy, Nexus Health Systems Founder, Chief Executive Officer and

Chief Medical Officer. "We provide a safe, structured environment where these children and their families learn behavior management strategies and coping skills."

The program's safe, structured environment addresses medical and behavioral complications of patients with PWS. Individualized physical training and behavior support is among services available for children, while family members receive education and training to continue successful management at home.

Nexus Health Systems President Erin Cassidy explained that services for this patient population can be difficult to find. "My hope for the recommencement of our program is that we'll be able to provide treatment that delivers great outcomes for our patients and their families. We were able to help so many patients when our program ran previously, and I have confidence that our multidisciplinary team can do the same this time, too." ■

Our Mission:

To enhance the quality of life
of those affected by PWS.

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Dec. 1; Feb. 1;
Apr. 1; June 1;
Aug. 1; Oct. 1

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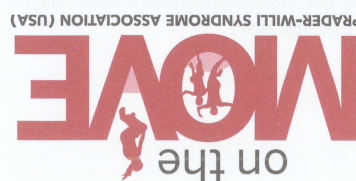
Photo: Clint Hurdle, wife Karla,
daughter Maddie, and son Christian.

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2018 Florida *On the Move* Walk
PWSA of Florida
<http://bit.ly/2JjaEYb>OTMFlorida
May 20, 2018 at 9:00 a.m.
Ninth Annual PWSA New England
Walkathon
PWSA of New England
<http://pwsane.org/>
May 26, 2018 at 4:00 p.m.
2018 PWSA Alabama Spring Fling
PWSA of Alabama
<http://bit.ly/2GVxGNS>Alabama
June 2, 2018 at 1:00 p.m.
Ninth Annual Hunter Lens Golf Tournament
<http://bit.ly/2IRMQA4>HunterLens
June 9, 2018 at 10:00 a.m.
2018 Michigan *On the Move* Walk for
Prader-Willi Syndrome
PWSA of Michigan
<http://bit.ly/2HzrEPY>OTM-MI

for Chapter Events



It's Time to Get

2018 Medical Alerts booklet!

NEW...

See page 8

- April 21, 2018 at 12:00 p.m.
Strategy Session PWSA of Georgia
<http://bit.ly/2EJTzjD>PWSGeorgia
April 28, 2018 at 3:00 p.m.
2018 Tennessee Family Day Pool Party
Tennessee Prader-Willi Association
<http://www.pws-tn.org/events>
May 12, 2018 at 9:00 a.m.
Eight Annual *On the Move* Walk-a-Thon
PWSA Wisconsin
<http://pwsaofwi.org/events/>