

The *Gathered View*

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

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

Executive Director View

Did you Know?

PWSA (USA) Services: Unique in Rare Genetic Disease Community

Recently, PWSA (USA) Family Support Counselor, Evan Farrar, was invited to speak at the national conference of the Phelan-McDermid Syndrome Foundation (PMSF). PWSA (USA) has had a long and fruitful association with PMSF (<http://22q13.org>), offering guidance and input as their organization develops a national office in nearby Venice, Florida. PMSF focuses primarily on research so – at this time – does not have a formal family support program.

When Evan returned, he told me that everyone at the conference was so impressed by the depth and breadth of PWSA (USA)'s Family Support Program. They were amazed that we have trained professional staff to offer counseling and support.

This discussion prompted me to reflect on the uniqueness of PWSA (USA)'s Family Support Program in the rare genetic disease community. I always appreciated the value of PWSA (USA) family support services while working at The Children's Institute in Pittsburgh (TCI). I worked closely with PWSA (USA) crisis counselors to admit people into TCI and to support their families after discharge. During over 20 years on the PWSA (USA) Board, I watched these services grow and change over time to meet the increasingly complex needs of people with PWS and their families. But it has only been while

serving as PWSA (USA)'s Executive Director that I've been able to fully grasp the range of family support services we provide to people with PWS, their families, and PWS-related professionals around the country. Many rare disease organizations have developed written and video resources for their communities. None that we are aware of have trained professional staff to talk to parents and professionals when they call the office. **PWSA (USA) has both!**

Presently our Family Support Program includes:

- Two trained **Family Support Counselors** available to help with a range of issues including school advocacy, behavioral problems, obtaining benefits, involvement with law enforcement, and supporting a parent seeking residential placement for their adult child.
- A **Medical Counselor** to offer information about medical issues to physicians and families. This includes facilitating communication between doctors on our Clinical Advisory Board and physicians needing guidance on treating a person with PWS – especially in a medical crisis.
- A **Family Advocate** to speak with parents of a newly diagnosed child to help them understand our support and assistance as they

*Yes, it is good
to give thanks
for our Family
Support Program.*

begin

the journey of raising a child with PWS. This includes sending a Package of Hope which contains helpful and accurate information about the early needs of their child and offering a parent mentoring program which will pair a parent of a newly diagnosed child with a parent mentor for more informal support on a regular basis.

- The **Willet Crisis Fund** that provides for PWSA (USA) school and residential consultants to provide direct assistance and training for crisis situations when a more intense level of intervention is needed. This fund also enables us to assist families who need help with transportation costs for treatment at TCI in Pittsburgh.
- An amazing variety of internationally-respected **written and video resources** on a wide range of topics for families and the professionals who serve them.

Amazingly, all of this is offered at little or no cost – none for calls to crisis counselors. Every year, PWSA (USA) gives away many free publications to families without the means to purchase resources and to professionals without the budget to acquire materials. Nobody is turned away for support services; our goal is to serve anybody who needs

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Executive Director View

Did You Know?, *continued from page 1*

support in the PWS community. We may not be able to answer every question or solve every problem, but we can offer a consistent level of effort and expertise.

This support doesn't go away. We are here for newborns all the way through adulthood – at home, school and beyond. With such level and length of support it is not surprising that others in the rare genetic disease community admire the program PWSA (USA) has built over the years. Yes, it is good to give thanks for our Family Support Program.

It is also good to give thanks for how this all developed. A small group of dedicated parents of children with PWS began the development of PWSA (USA) at a time when there was nowhere to turn. Their profound vision for this association from its beginning included

funding research and creating a family support program, with the goal always to create a better future – and better today – for all living with PWS and their families.

This commitment has remained unshakeable over the years as PWSA (USA) board leadership has been steadfast in making sure parents and professionals in the PWS community have a place to call when they need help – a remarkable achievement for an organization our size accomplished in no small measure due to the financial generosity of the PWS community.

Providing our Family Support Program is costly (approximately 60% of our overall budget), and funding is critical. Our new David Wyatt Crisis and Family Support fund offers a new way to give *directly* to support the Family Support Program. If you believe what we



Watch for the 2014 Angel Campaign.
Each donation will create a ripple of change.

do for families is important and should continue, even expand, please consider a gift to the Wyatt fund. Like the fund founders we have great dreams for our Family Support Program. But they will not come to fruition without your generous support and encouragement.

With thanks for you and all we have accomplished together to support families,

Ken Smith

Executive Director, PWSA (USA) ■

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

ASHG to Honor Dr. Suzanne Cassidy

Edited by Sara Dwyer, Editor, The Gathered View

The American Society of Human Genetics (ASHG) has named Suzanne B. Cassidy, M.D., Clinical Professor of Pediatrics in the Division of Medical Genetics at the University of California, San Francisco, as the 2014 recipient of the annual Award for Excellence in Human Genetics Education.

The ASHG award recognizes an individual for contributions of exceptional quality and importance to human genetics education internationally. Awardees have had long-standing involvement in genetics education, producing diverse contributions of substantive influence on individuals and/or organizations. Dr. Cassidy will receive her award during ASHG's 64th Annual Meeting in San Diego.

Dr. Cassidy is well-known for her clinical and research leadership in Prader-Willi syndrome. She has also played key roles in the medical genetics education of medical students, residents, and genetics trainees as well as of patients and their families. She has developed a variety of education materials, including three editions of the textbook *Management of Genetic Syndromes* and clinical genetics training programs across the country.

"Dr. Cassidy has worked tirelessly to improve genetics education and support patients in a variety of roles – as a

teacher, mentor, physician, author, and advocate. This award celebrates her contributions to science, medicine, and the patient experience," said Joseph McInerney, M.A., M.S., Executive Vice President of ASHG.

Throughout her career, Dr. Cassidy has received numerous honors for her research and teaching, including election to several advisory boards, founding editorship for clinical genetics in the journal *Genetics in Medicine*, and visiting professorships at institutions in the United States and abroad. In addition, she was a member of the founding Residency Review Committee for Medical Genetics when it was first recognized as a medical specialty, and belonged to the American Board of Medical Genetics and Genomics, which accredits genetics training programs and certifies medical geneticists.

Since its foundation, Dr. Cassidy is past chair and continues to serve as a member of the PWSA (USA) Scientific Advisory Board. She also gives tirelessly as president of the International Prader-Willi Syndrome Organisation.

Congratulations on this well-deserved award from the American Society of Human Genetics. This is a very prestigious honor few people ever achieve. ■

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School student-sponsored "Spirit Week" Fundraiser in Greenville, South Carolina.

AN EXCITING NEW CLINICAL TRIAL FOR THE TREATMENT OF PWS BEGINNING SOON

Investigating a New Approach to
Combat Disease-Driven Obesity



Adolescents and adults (12-65 years) with Prader-Willi syndrome (PWS) may be eligible to participate in a phase 3 clinical trial sponsored by Zafgen. This important clinical trial, **bestPWS**, will help determine the effectiveness of a novel treatment for PWS called beloranib. In a phase 2 clinical trial completed earlier this year, beloranib showed a reduction of body fat and hyperphagia-related behaviors (the drive to eat) in a small group of PWS patients. Currently Zafgen has identified 13 study sites within the United States and the enrollment target will be 84 adolescents/adults with PWS.

Eligibility will be determined by study doctors according to the study protocol and will include obese patients with a BMI of greater than or equal to 30, and, less than or equal to 60 kg/m² (or greater than or equal to 95th percentile for ages 12-17). The study will enroll people with PWS living in a family home environment or group home less than half time with a consistent primary caregiver.

Study participants will be randomly assigned by chance to receive active drug (beloranib) or placebo (a matching product that does not contain active drug) – there will be 2/3 chance (66.7%) of receiving drug in the study. Study participation will involve twice weekly injections (which will be administered by visiting nurses at the participant's home) and approximately 8 visits to the study site over 7 months. Patients who complete the study will be eligible to enroll into an optional study extension where all patients will receive active drug (beloranib) for another 6 months. Travel expenses for visits to the study site will be covered.


To learn more about the study and participating study sites, click this [link](#) or go to www.clinicaltrials.gov and type in "Zafgen Prader Willi" on the search bar.

Hope is in the air – this is an exciting new era for Prader Willi research!

Janalee Heinemann, MSW
Director of Research & Medical Affairs
PWSA (USA)
Vice President, IPWSO

Version: 24-JUL-14

GENETIC CAUSES OF PRADER-WILLI SYNDROME (PWS)



EVERY CELL HAS **23 PAIRS** OF CHROMOSOMES

22 PAIRS OF NUMBERED CHROMOSOMES AND **ONE PAIR** OF SEX CHROMOSOMES

EACH PAIR HAS A **MATERNAL** AND **PATERNAL COPY**

EACH COPY HAS 2 ARMS

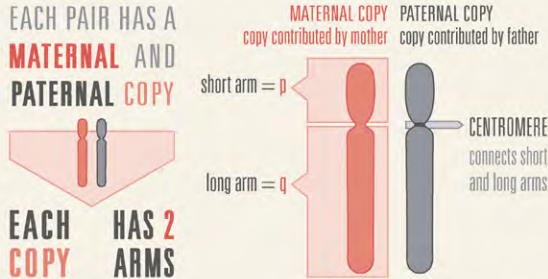
MATERNAL COPY copy contributed by mother

PATERNAL COPY copy contributed by father

short arm = p

long arm = q

CENTROMERE connects short and long arms



PRADER - WILLI CRITICAL REGION LOCATED ON CHROMOSOME 15

15

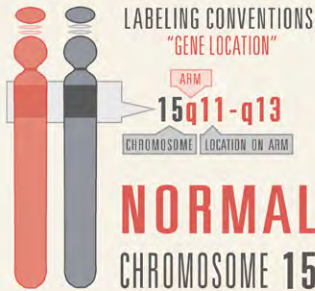
LABELING CONVENTIONS "GENE LOCATION"

ARM

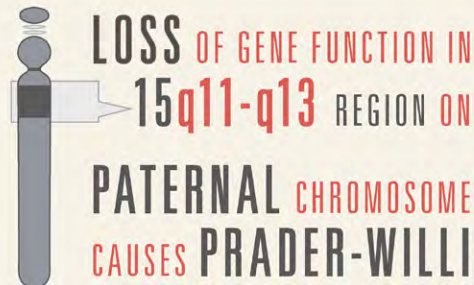
15q11-q13

CHROMOSOME LOCATION ON ARM

NORMAL CHROMOSOME 15



LOSS OF GENE FUNCTION IN 15q11-q13 REGION ON PATERNAL CHROMOSOME CAUSES PRADER-WILLI

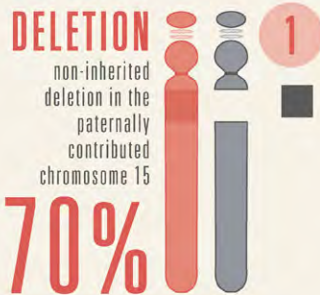


3 GENETIC MANIFESTATIONS OF PWS

1 DELETION

non-inherited deletion in the paternally contributed chromosome 15

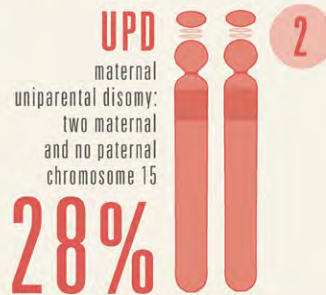
70%



2 UPD

maternal uniparental disomy: two maternal and no paternal chromosome 15

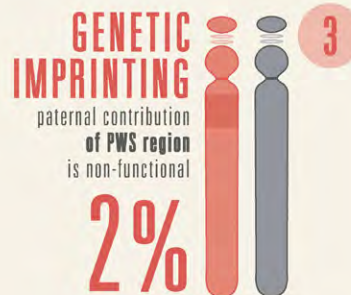
28%



3 GENETIC IMPRINTING

paternal contribution of PWS region is non-functional

2%



PREVALENCE

1:15,000



occurs in males and females **equally** and in all races

hypotonia, hypogonadism, hyperphagia, cognitive impairment

major medical concern: **morbid obesity**

growth hormone was the first drug approved by the U.S. Food & Drug Administration (FDA) for the treatment of Prader-Willi Syndrome

USA
PRADER-WILLI SYNDROME ASSOCIATION *still hungry for a cure.*

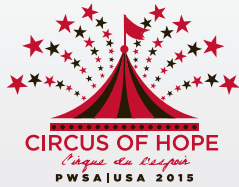
© Elina Mer, **MA** STUDIO

This nice, simple graphic explains the genetics of PWS. It was done by Ivy Boyle's daughter-in-law, Elina.

Ivy, the parent of a son with PWS, is a psychiatrist who served on the PWSA (USA) Clinical Advisory Board in the past. ■

Welcome Aboard

Welcome and congratulations to our two newest board members, Tammie Penta, Tucson, AZ and Denise Westenfield, Eden Prairie, MN, and also to Dan Driscoll, M.D. Ph.D., Gainesville, FL on his re-election. ■



Save the DATE

Mark your calendars for the 2015 PWSA (USA) National Conference. The event dates are November 5-7th at the Buena Vista Palace in Orlando, FL. Details and more news to come!

PWSA (USA) Annual Membership Meeting

The Annual Membership Meeting for 2014 will be held telephonically on Monday, October 27, 2014, at 8:00 p.m., Eastern Standard Time. To join the meeting call, please dial 1-641-715-3395. The participant access code is 1076930#.

Receive updates on exciting developments in research, learn what your Association has accomplished in 2014, and what is planned for 2015. The meeting will last approximately one hour. ■

~ Michelle Torbert
PWSA (USA) Board Chair

Tools to Cope with Stress of Caregiving

Source: *New York Times*
Edited by Denise Servais

All parents endure stress, but studies show that parents of children with developmental disabilities, such as autism, experience depression and anxiety far more often. Struggling to obtain crucial support services, the financial strain of paying for various therapies, the relentless worry over everything – all of it can be overwhelming.

A study published in the journal *Pediatrics* offers hope. It found that just six weeks of training in simple techniques led to reductions in stress, depression and anxiety among parents.

Elisabeth Dykens, a research psychologist interested in PWS, was the lead author of the University of Vanderbilt study. Dykens is the director of the Vanderbilt Kennedy Center and member of the PWSA (USA) Scientific Advisory Board. “Learning to quell distress and anxiety is especially important for parents of children with development disabilities because it’s often a lifetime caregiving commitment,” said Dykens.

Dykens and her team randomly assigned 243 mothers of children with developmental disabilities, genetic syndromes, or psychiatric issues to mindfulness training or “positive adult development.”

The first group practiced meditation, breathing exercises, and Qigong practices to hone mental focus. The second group received instructions on curbing negative thoughts, practicing gratitude and reclaiming an aspect of adult life. Both groups were led by specially trained mentors, themselves the parents of special-needs children.

Part of what makes the experiment innovative is that it was targeted to adults, not their children, and it was not focused on sharpening parenting skills. Instead, parents learned ways to tackle their distress as problems arise.

The results of the study concluded that the mindfulness treatment and positive adult development led to significant reductions in stress, anxiety, depression as well as improved sleep and life satisfaction among participants. But the mothers in the mindfulness group saw greater improvements in anxiety, depression and insomnia than those who received positive adult development training.

Manuals detailing the strategies, mindfulness and positive adult development, are available online for \$200 each (\$350 for both manuals) for parents of special – needs children who want to start groups. The program is called the *Parent Stress Intervention Program Curriculum* and is available for purchase at <http://psip.vueinnovations.com/>. ■

PWS Brochure Announcement

PWSA (USA) is proud to announce the availability of two wonderful new brochures for PWS:

“**Someone You Know Has PWS**” was created more for the general public such as friends, neighbors, and for community events. It is more generalized and “softer” in context; it gives some characteristics and suggestions to the reader about ways to help.

“**Supporting Someone With PWS**” was created for distribution for people who may actually have short term care of the child or adult with PWS such as babysitters or relatives. It gives more details on the issues and strategies on how to manage the symptoms.

Both brochures can be ordered on the PWSA (USA) website under publications, or you can call 1-800-926-4797. ■

Supporting
Someone
with PWS



Whether you are a babysitt daycare provider, teacher or professional care provid it helps to know about Prader-Willi syndrome.

USA PRADER-WILLI SYNDROME ASSOCIATION *will help you to cope.*

Someone
You Know
Has PWS



An introduction to Prader-Willi syndrome especially for babysitters, neighbors, extended family, friends, play-date occasions, and the community

USA PRADER-WILLI SYNDROME ASSOCIATION *will help you to cope.*

A Day in Our Shoes

By Krystal Ellington

My hope in sharing what it's like in our house raising a child with PWS is to let other PWS families realize you're not alone and to spread awareness to those who may not completely understand what Prader-Willi syndrome is.

Our Smiley Kyleigh: "I wanna eat!" I open my eyes groggily and look at my alarm clock...5:30 AM. I slowly crawl out of bed and see my beautiful, brown-eyed girl sitting up in her bed waiting for me to unlock the gate across her doorway that keeps her safe at night (for now) so she won't sneak food while we're asleep. Sleeping-in with a four-year-old with PWS is non-existent as she wakes each morning hungry.

In the kitchen talking with Kyleigh about breakfast as I prepare it seems to reduce the tantrums and anxiety about waiting for her meal.

I never imagined having to count calories and watch what my preschooler ate. Sometimes I worry about God giving her to me since I struggle with food and weight myself; now I'm responsible for making sure Kyleigh doesn't become obese while being restricted to 850 calories a day that she can't burn off well due to slow metabolism. But I tell myself that God doesn't give you more than you can handle, try my best, and take one day at a time.

After finishing breakfast, Kyleigh brings her dishes to me at the sink, already saying she's ready to eat again. I try to redirect her to her toys and asking what she would like to play. Constant redirection is a big part of our day as she frequently complains of being hungry and says she's ready to eat. It kills me to think about how she must be feeling...



starving, never feeling full – and I can't take that suffering away from her. I'd trade places in a heartbeat. No matter how many times we switch activities, keeping her mind off being hungry is a challenge.

I never thought about how food is EVERYWHERE until having a child with PWS... TV commercials, pictures in coloring books, radio

advertisements, food at concession stands at baseball games – the list goes on.

Tears, fits, and screaming are a regular part of our day if she is not given food when she wants it. Setting a timer for the next meal helps reduce the tantrums. A red magnetic timer (her favorite color) stays on the refrigerator, and when she cries for her next meal, we set it together so she can watch the numbers count down. Some days are better than others; we have not learned why or noticed a pattern yet...we just keep praying for a cure.

Our day continues with playing, setting timers, and keeping a close eye on her every move. Everything still goes in her mouth. We have caught her eating lotion, deodorant, and trying to dig in the trash can.

You absolutely CANNOT leave her unattended...not even to use the restroom. Where you go, she goes. Where she goes, you go, especially in or near the kitchen. Kitchens in most homes are viewed as a warm place of bonding while you cook meals and eat as a family, but for the Ellingtons, it's the most dangerous place in the house. No food in the lower cabinets, nothing left on the counters,

every crumb off the floor, the refrigerator in sight at all times when we're in that area.

When she was younger, the refrigerator didn't pose much of a threat because she couldn't open it. Now that she's strong enough to open it and is figuring out more sneaky ways of getting food, it can be deadly.

Most people don't understand how dangerous it is if she would get access to food. "I must have Prader-Willi, too, because I'm hungry all the time!" I can't count how many times people have said that, and I want to scream! Yes, some of us have issues with food and feel hungry. BUT we feel full after eating, AND we can throw up if we eat too much. Individuals with PWS NEVER feel full, and they cannot throw up if they eat too much.

I have become paranoid about leaving her with anyone whose house isn't "Prader-Willi proof," which makes outings alone as a married couple very difficult when you only have a few homes where you feel comfortable leaving her. Thank goodness for a supportive family!

Our evenings start winding down after supper, which must be at about the same time each night--or you don't want to be in our little yellow house at 5:30 PM! After supper we play a little and listen for her to say, "I wanna take a nap" around 7:00 PM. We read her a story, kiss her goodnight, and thank God that He blessed us with such a happy, beautiful girl to call our little miracle. While she comes with many challenges and has her moments, she has a way of lighting up every room she enters.

I know God has special plans for her, and I tear up thinking about how much she has progressed. Since she was a baby going through challenges of low muscle tone and delayed milestones, she has been a fighter...and so have we. Every milestone she reaches is like saying, "Take that, PWS!" And we'll continue fighting...because we will not let it win. ■

Employee Spotlight

Debi Applebee Business Manager

By *Andrea Glass*

Debi Applebee is behind the scene at PWSA (USA)'s office in Sarasota, FL, ensuring that our association runs smoothly and efficiently. She is a caring individual with three children, ranging in age from 11 to 24. When you speak to Debi, you are instantly aware of her warm and caring nature. She believes in giving back to society and has chosen many charities to work for over the years. She had been a lead fundraiser for the American Cancer Society, Breast Cancer 3-Day and a volunteer at PWS fundraisers, including "Casting for a Cause" and the Wisconsin chapter annual golf

benefit. Although she is a paid employee at PWSA (USA)'s National office, you would not be surprised to find that she spends many extra hours of effort on our bi-annual conference. Besides being at the conference, Debi also runs the PWS store during conference and throughout the year; orders items for sale (shirts, book and pamphlet reprints) and other merchandise sold to support the organization. In her administrative management role at our National office, Debi is constantly looking for ways the office can save. Negotiating leases on office equipment, utilities, and insurance policies is a challenge she truly enjoys.

Debi also helps the effort to raise additional funds. Fundraising in each state means compliance with that state's fundraising laws. Deb is responsible to

ensure compliance for all state fundraiser activity and maintain chapter renewals and also applies for grants to fund PWSA (USA) through various charities. Outside auditors rely on Debi to pull records and files, track volunteer hours, reconcile conference expenditures, and produce payroll records. Compliance is complicated and is necessary to maintaining non-profit status.

A huge supporter of the "Pay it Forward" theory, Debi has been a perfect addition to our National office team. In her spare time, Debi enjoys cooking, baking, time outdoors, hiking, biking, visiting her hometown in Maine and travelling to new places. ■



Counselors Corner

Change: A visit to Korea blooms with success

By *Kate Beaver, MSW, CSW, Crisis Intervention Counselor*

In 1988 we adopted a beautiful special needs baby from Korea. She was extremely small and very "soft". At the time we knew she had special needs, but it wasn't until she was six years old that we heard the words "Prader-Willi syndrome". When Hana was ten, we were finally able to have the insurance company pay for growth hormone.

Needless to say, early treatment and intervention were not a part of Hana's life. Learning how to best work with Hana was difficult because it did all come a little later in her life. As a family, we worked very hard to make up for lost time by implementing positive behavior support plans, limiting the food, and just trying to stay consistent. The year she went on growth hormone she grew 6" and developed some muscle mass. At that time, I felt life was always going to be hard for her and for us.

Hana is now 27 yrs. old and has turned into a beautiful, funny and smart young woman. This summer we decided to take her back to Korea, so she could see where she was from, and to have the experience of looking like everyone else. The good part? We have a friend who is teaching English as a second language there whom we were able stay with for part of the time. We have always done family vacations with Hana and her brothers, but usually it was to one location and there were four of us keeping tabs on Hana. I wasn't sure how things would work out traveling together in a country so far out of

our comfort zone, plus with an adult with PWS. But we did it and as it turned out, we had the best opportunity to see Hana in a different light. She was a great traveler! We traveled by bus, train, car, and stayed in Korean hotels and hostels, besides staying with our friend. We ate Korean food, visited the countryside as well as a few bigger cities and, all through this, watched Hana take it all in and blossom. There were no behaviors and the food was tasty as well as healthy, cheap and limited. I think we all actually lost a few pounds!

Hana definitely rose to the occasion. With the language barrier, people didn't notice so much the lack of Hana's social skills; she still said hello to strangers. She tried to ask them questions, wanted to order more food, and no one seemed to mind. And those that did understand her were kind and understanding.

One of the biggest things I came away with from the vacation was that our children continue to develop and grow, even in small ways. For me, it was a great opportunity to see Hana as an adult who could (and did!) handle change successfully. She is not the same little girl who I have a tendency to sometimes see. As for Hana, one of the many things she was able to take away from the trip is: if you ask her now if she is short, she will say, "No, I'm Korean." That's my girl! ■



PWS and Theft

By Katherine Crawford, PWCF Family Support Coordinator and Lisa Graziano, M.A., PWCF Executive Director with input from Elizabeth Roof, Ph.D.; Senior Research Specialist, PWS Research Project, Vanderbilt University; Janice Forster, M.D., Child & Adolescent Psychiatrist, The Pittsburgh Partnership Specialists in PWS; Evan Farrar, Crisis Counselor, PWSA (USA)

■ Megan stole a bag of chips from another student's lunch.

■ Kirk took money out of his father's wallet to buy candy from a vending machine.

■ Walter went into his brother's backpack and took one of his comic books to trade for food on the bus.

■ Eloise went into her mother's room and took some jewelry to sell at school to get money for a candy bar.

■ Isabelle was given recess detention after she took a star eraser from her teacher's desk.

There are many reasons for theft amongst children and adults with PWS. Like all things in the spectrum-world of PWS, not everyone with the syndrome has the same degree of symptoms, including the theft of food and non-food items. For those who are impacted by this challenge, this article is for you.



Food-Related Theft

Food-related theft is a well documented challenge with Prader-Willi syndrome. Parents and care providers who live with a high food drive individual know that theft can be a recurring concern. Within food-related thefts, there are differing levels of complexity.

One-Step: Megan

Acquire Food

The simplest form of food-related theft is one-step food acquisition. Such individuals are at risk of stealing food - from other's

lunches, from the school or work cafeteria, or even shoplifting from the gas station down the street. Megan's story is a good example of simple, one-step food acquisition to gain access to food: just taking it.

Two-Step: Kirk

Acquire Money, Buy Food

Two-step food acquisition – stealing money to purchase food – can occur as well. Kirk's story (where he took money out of his father's wallet in order to buy food) is a classic example. When an individual is known to steal money to acquire food, it becomes necessary to lock away purses, wallets, and bedrooms to keep the individual safe.

But money isn't the only thing that gets food.

Two-step: Walter

Barter Possessions for Food

Another form of two-step food acquisition is bartering – trading an object for food. Walter knew that the boys on the school bus were interested in comics, so he took one out of his brother's collection to barter for food. There can be a delay in the discovery of this kind of behavior, and restitution is difficult because it involves both the brother and another child.

Three-Step: Eloise

Acquire Object, Exchange Object for Money, Buy Food

Next we move on to three-step food acquisition: stealing an item which can be exchanged for cash which then is used to buy food. Eloise's story highlights the potential emotional repercussions that such thefts can cause; her mother could be deeply hurt by theft of her jewelry. Unfortunately, potential emotional repercussions may not enter into Eloise's thinking. She doesn't intend to hurt her mother; she simply intends to obtain food.

Each of these examples is food-related theft, no matter how many steps we add. Each also involves a breach of boundaries to acquire food.

Managing Food-Related Theft

When managing food-related theft it is important to remember that the underlying *drive* of the theft is outside the control of the person with PWS. The individual with PWS wants to be "good" in your eyes and do the "right" thing, but the drive to obtain

food is too strong. It is up to the family, care providers, and the community around them to provide the compassionate supports they need.

Restrict one-step food theft by preventing access to all food sources with a lock (i.e., refrigerator, food pantry, etc). Human supervision alone is inherently fallible. Lock down sources of money to prevent "two-step theft." Reinforce personal boundaries by locking bedrooms, especially older siblings. For "three-step" acquirers, lock jewelry boxes or keep valuables behind locked doors. In addition to locking access to food wherever possible, provide continuous supervision. When the hope or chance to acquire food is not possible, the person's mind is free to think about other important things.

Sometimes people, especially extended family members, are resistant to the idea of locking up food or keeping food in a restricted area. In this case, it may be helpful to describe PWS's hyperphagia food drive like this: think of having a good friend who was just diagnosed with diabetes. Would you have rich desserts or candy bars out on your counter tops or on the table, even though you know they are trying not to eat such foods? Of course not. It wouldn't be the compassionate thing to do. It would just increase your friend's anxiety, suffering, and daily struggle. More than most of us, when someone with PWS sees food, he wants it, and he can't get the thought of it out of his mind.

When working through food-related theft (whether one-, two-, or three-step) it is best to respond by matter-of-factly acknowledging the taking of the food and quietly reducing calories from the remainder of the day or week to compensate. Take responsibility for your lack of providing adequate food security and secure the food source so that it is no longer accessible. Never punish or shame the individual for stealing food; this is simply a symptom of PWS.

Some may suggest punishment (such as taking away a preferred activity) in response to a food-related theft. Such a person might say, "Megan knows that she can't go out to recess because she stole chips from another student's lunch. How could we reward her with recess after she stole food from another student?" They may even be proud

of the individual with PWS for verbalizing their understanding that they have lost recess because they stole food. But the question is not “*does the person understand why they are being punished*” but rather “*will the experience of punishment or threat of punishment prevent the individual with PWS from stealing food in the future?*” In almost all cases the answer is “No, neither punishment nor threat of punishment prevents food stealing behavior.” The critical piece to understand is that even if the individual with PWS understands and accepts such punishment *it will not shape future behavior*, which is the intended goal of punishment.

The most effective way to manage food-related theft is to eliminate all opportunities for the individual with PWS to do it!



Non-Food Related Theft

There is a different kind of theft that occurs in some people with PWS, that of stealing non-food items. This behavior can range from the “innocent” taking of items to compulsive stealing. Underlying all non-food stealing are likely higher degrees of egocentricity (“It’s all about me”) and impulsivity (“I want what I want and I want it right now”).

Not understanding social boundaries (“what’s yours is yours and what’s mine is mine”) may make stealing non-food items more likely. In the case of Isabelle, this would be the case if she took the star eraser from her teacher’s desk without understanding that she should ask before taking something that is in or on someone else’s property.

Having low impulse control may increase the potential for non-food stealing behavior. An example of this might be the individual who walks through a store, sees an item they really like, and impulsively pockets it. In our case of Isabelle, the fact that she knows the eraser does not belong to her, or that to take it constitutes theft,

or even that she’s already been in trouble for stealing something in the past does not enter into her impulsively-made decision-making process.

There are also people with PWS who appear to have extremely “sticky fingers” and indiscriminately steal objects. These individuals may experience more of a compulsive “need” to steal or “collect.”

Managing Non-Food Related Theft

The management of non-food theft is similar to that of food-related theft. First, teach and reinforce the understanding of boundaries. Make sure that stolen objects are returned to their owners with a written letter of apology whenever possible. Writing the owner’s name on all objects to the extent possible is helpful. Mutually and cooperatively creating rules regarding non-theft behavior is helpful. Writing down or using pictures to symbolize the rules helps make it easier to enforce them. Here’s an example scenario of how to create those rules together.

Aide: “Isabelle, I heard that you *love* erasers! Which eraser is your favorite?”

Isabelle: “*I don’t have a favorite. I like all of them.*”

Aide: “Me too! Hey, I was thinking of our class rules the other day. Do you think it would be a good rule to say that other students shouldn’t take your erasers, even if they like them?”

Isabelle: “*Yeah!*”

Aide: “What should a student do if they take an eraser?”

Isabelle: “*Give it back and say sorry.*”

Aide: “Brilliant idea! I’ll write that down on the bottom of our Class Rules List! Students should not take erasers from other students. If they break that rule, they should give the eraser back and say sorry.”

You’ll notice that throughout this dialogue the aide is phrasing things in the positive and turning the discussion towards how Isabelle would feel if someone took *her* erasers. This is done to get Isabelle’s buy-in to increase her compliance, not necessarily to reduce her degree of egocentricity or to teach empathy, although these are excellent skills to teach.

It should be remembered that Isabelle’s egocentric desire to have that eraser may still overpower her affection or empathy for her teacher. There is, however, an appropriate recourse built into the rule-making process:

Isabelle told the aide what a student should do if they take an eraser and it’s written down in black and white. Isabelle may initially deny and/or persevere, but if the aide is patient and calmly brings Isabelle’s attention to their written agreement, this will help Isabelle return the eraser. As soon as Isabelle returns the eraser the aide will praise *praise* her.

What if our hypothetical Isabelle brings home an object from school that does not belong to her, and when questioned she says a friend gave it to her? The circumstances of this scenario should be investigated for accuracy. Or what if another parent calls Isabelle’s parents because they believe Isabelle took their child’s CD? While Isabelle is adamant that the CD is hers, a search of her collection reveals an identical CD. It could be that Isabelle didn’t *intend* to steal anything but actually believed her friend’s CD was indeed her own. This example underscores the importance of labeling all of the individual’s items to allow parents and care providers the ability to quickly resolve such situations.

What we’re looking for isn’t exactly a “cure” for impulsive theft but rather management of the environment to eliminate the expression of the symptom. It is possible that the individual with PWS may struggle with impulsive theft throughout their lifetime, so the knowledge and understanding of this symptom by those around them will make a big difference.

Continuous supervision is highly advisable when someone is known to have a history of stealing, and especially in situations where theft could have serious repercussions. It is also advisable to introduce your individual with PWS to your local police department, and provide officers with written information about the syndrome, available from the PWCF office and our website.

Theft can be tricky to manage in persons with PWS. The fundamental keys to reducing both food and non-food theft are environmental management, supervision, and continuous caring support of the individual with PWS.

For more information about Prader-Willi syndrome, please contact the Prader-Willi California Foundation at info@pwcf.org or 310.372.5053. ■

Our Roots: Where PWSA (USA) Began

By Denise Servais

Here's a trivia question - What state was home to the first headquarters of PWSA (USA)? If you answered Minnesota, you would be correct! It was in the mid 1970s when PWSA was born, and the Twin Cities would be home to the association for the next 14 years. It was also around this time when the Minnesota state chapter came into being. Gene and Fausta Deterling, from Minnesota, were some of the founding members, along with the late Marge Wett, who became the association's first executive director.

Since that time, the Minnesota state chapter and its members have been influential in making positive changes for children and adults with PWS. Some of these early parent members, including the Deterling and Vernig families, opened up the state's first PWS group home, called Oakwood, with limited funding. Eventually the group home was sold and all the interest generated from the Oakwood sale was donated to the Minnesota (MN) chapter. The "Oakwood Fund" as it is now called, generates up to \$5,000 a year and is used to help fund everything from medical and dental expenses to camp experiences for children and adults with PWS.

Other parent members, such as Jim and Joan Gardner, were pioneers in advocating tirelessly for changes in the state's laws to recognize PWS as a disability by Health and Human Services.



left to right: Lynn Garrick, Matt Lumen, Marty McGraw, Fausto Iglesias and his son Aggie Iglesias.



Erin Bale (left) and Jill Mulcahy (right).

Minnesota has hosted two national conferences. The largest PWSA conference was hosted here in 2001 and included both national and international speakers and members.

The MN chapter continues to be active in its participation. There are currently 125 members, including families and service providers. Kristi Rickenbach is the current president. The MN chapter association hosts a fall and spring conference every year. Past topics have included a variety of interests from wills and trusts to technology and speech therapy. Past speakers have included Dr. Gourash, Dr. Jennifer Miller, and Dr. Forster.

The chapter is now in its 3rd year of hosting an annual golf fundraiser. Last year's fundraiser raised \$30,000 to fund both the national and local chapter.

The MN chapter and its members look forward to continuing to support and serve our children and adults with PWS. ■

CHUCKLE CORNER

Yesterday Miranda, age 21, and I took some books to a used book store. We had quite a few so it took both of us to push/pull three buggies full from the car. Miranda had lost 133 lbs over the last 18 months. While we were heading in, Miranda suddenly stopped and said, "I can't go, Mom." I, thinking she might be feeling unsteady going up the slight incline, say "Come on, Miranda!" She replies, "I CAN'T!!" I go around to where she was and see her pants down around her ankles! She was standing in the front entrance of this huge bookstore with her flowery underwear shining! They had fallen off because they were too big! I hurried to try to help her pull them back up but can't because she was standing on them! All the two of us could do was stand there in fits of laughter. We finally got them pulled up and made it inside.

-Laura Calfee, Tennessee

iHOLA!

By Nina Roberto, E.D. of the New York Association and on the State Chapter Leaders Team as representative to Spanish-speaking families with PWS.

iHola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi. Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que necesitan informacion y ayuda. Les quiero dirigir a www.pwsausa.org donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, ninaroberto@verizon.net. ¡Hablamos pronto! ■

Eating Well: Making Family Meal Choices Easier

Reprinted with permission from a post on June 27, 2014 by Beth D'Addono For the Daily News in Philadelphia, PA

Children with special needs take their parents on a very particular and personal journey. For Deb Lutz, the latest leg of that journey is today's opening, in Marlton, N.J., of **b.good**, a fast-casual eatery celebrating healthful cuisine that is locally sourced and seasonally inspired.

Lutz is just the fourth franchisee of this New England-based restaurant started by two boyhood buddies in Boston. She plans to open five **b.good** locations, including one in Philly and another near her Bryn Mawr home.

The restaurant menu includes healthy options like house-ground burgers, homemade vegetable burgers and hand-cut baked "fries," plus salads and smoothies made with greens and fruit. There's a philanthropic component in the business plan, too: Part of the restaurant's proceeds will benefit Sunday Suppers, a Philly nonprofit that strives to strengthen the health and well-being of families through the transformative power of family meals.

Lutz and her husband, Rob, have seen the power of family meals in their own home. Their 14-year-old daughter, Isabel, has Prader-Willi syndrome. The impact that Isabel's condition has had on the family cannot be overstated. The Lutzes also have an 11-year-old daughter, Natalie.

When the family does go to a restaurant or to a party, there's a game plan in advance.

"We talk about making lower-calorie choices, sharing items to keep within her limit," Lutz said. "Maybe it's putting five things on her plate of her choosing, then that's it. Once she gets a plate of food in front of her, you can't take it away."

The good thing

One of the reasons Lutz was drawn to **b.good** was the dearth of healthy restaurant options for her family. And after 20 years marketing consumer products at Johnson & Johnson, she was ready for a career change, ready to do something more personal.

When she met one of **b.good's**

When the family does go to a restaurant or to a party, there's a game plan in advance.

founders at an international franchise convention, she was immediately attracted to the concept. "I thought he was on point with where people are going with food now. They want to know where it comes from, they want to connect to their community and eat well. And the food has to be delicious."

Deb's first restaurant, at the Promenade at Sagemore Shopping



Rob and Deb Lutz with Natalie, 11 and Isabel, 14

Center on Route 73, has seating for 100, including an outside patio.

Local food sources will include Black Angus beef from Roseda Farm, in Monkton, Md.; sweet potatoes from D. Spina & Sons, in Salem, N.J.; milk and ice cream from Chambersburg's Tricking Springs Creamery; and burger buns from Wild Flour Bakery, in Northeast Philly.

As she feverishly gets ready for today's opening, Lutz said that she feels nothing but optimism for the future.

"I am so thankful to Isabel in so many ways," she said. "Her PWS has brought us together and made us stronger as a family. My husband and I were united from day one in making all this work. Our daughter Natalie is very sensitive and understanding, not just about her sister's issues, but about other people's issues as well. We've all had to learn a lot of patience." The biggest challenge is knowing that Isabel will never be able to live independently.

Whatever Lutz may say, the constant policing and vigilance made necessary by PWS must get exhausting. "It does sometimes," she admitted. "Those are the days when, after the girls are in bed, Rob goes out for a tube of cookie dough. We eat that, and we're good to go." ■

~ Andrea Glass



ATTENTION Federal Employees!

If you work for the Federal government, 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

For more information about the CFC program and how it works, go to their Web site at <http://www.opm.gov/cfc/index.asp>, or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee. ■

Africa realities for PWS – Zimbabwe

The following are excerpts from my communication with Denise Seely, a volunteer at our PWSA (USA) office. Denise was a nurse in Africa for over 25 years and worked with AIDS orphans in southern Africa. She and her husband, Bob, father of our board member, Rob Seely, now live in Bradenton, Florida and have a small nonprofit to support AIDS orphans in Zimbabwe. I asked her to review some of our literature and put it in perspective of some of the realities in Africa. With her assistance and that of some of the wonderful professional delegates we have in Africa who are part of our international organization, IPWSO, we hope to create some information that is appropriate for their realities. It is also a sobering reminder that although we struggle to get our children's needs met in the USA, we should also be grateful for what we do have – and thank IPWSO for their wonderful support to so many countries in desperate need – Janalee Heinemann, M.S.W., PWSA (USA) Director of Research & Medical Affairs

- Diagnostic Testing – Genetic Testing (Would have to be done through IPWSO because it is unavailable and unaffordable to most of the population) Note: IPWSO has supported genetic testing in 38 countries.
- Decreased fetal movement and subsequent lethargy in newborn; Poor weight gain in infancy w/feeding problems; (Need follow-up with a physician if born at home or in the rural clinics, as midwives deliver most babies in Zimbabwe. Pre and post natal care available for all pregnant women, and infant weights are closely monitored. Breastfeeding is not only encouraged, but infant formula must be prescribed by a physician, and very difficult to find in stores in Zimbabwe.)
- Hyperphagia; Food foraging; Obsession with food – (Food shortage is a way of life in Zimbabwe. Food is expensive to someone who does not have a job, and in most sub-Sahara countries the diet is limited as they eat the same things over and over.)
- Constant food restriction and behavior management is stressful for family members. (Generally speaking, Africans do not have 'pantries' or refrigeration; the only staple they keep on hand is the maize meal, salt, sugar and sunflower oil that they prepare their 'sadza' with 3 times per day (Breakfast is a porridge). The rest of the food is bought fresh daily (vegetables, fruits and occasional chicken). The children do not drink 'milk' after they are weaned off the breast as it is unaffordable...rickets are seen often.)
- Short stature if untreated; Needs growth hormone treatment (If growth hormone is available, it would have to be imported and would be unaffordable to most families.)



Denise Seely and missionary Mark Moody from Indiana, with young patient from Zimbabwe

- High pain threshold (Fires cause burns and deformities. The African's lifestyle is very hard, and fire is a part of everyday life of the African... they cook by fire, heat water by fire, stay warm by fire. Fires are built in the kitchen hut, right in the center of the hut, and people sleep there on the floor in the winter. It is common for babies to roll over into the fire when they are sleeping. Many people incur injury to their feet as they do not have shoes.)
- Respiratory concerns – Weak muscles, Hypotonia, Sleep Apnea (TB is an ever present threat in the developing countries...I am wondering how this would affect a child with PWS?)
- Lack of vomiting – The presence of vomiting may signal life-threatening illness (There are a lot of gastrointestinal 'bugs' and also because of impoverishment and poor sanitation, there are complications of water-borne diseases and food poisoning. Diarrhea and vomiting is ever present in children in many African countries.)
- Severe gastric illness...CAT scan may be necessary to determine degree of problem. (Cat scans very expensive...only for patients with medical insurance...about 5% of the entire population of Zimbabwe.)
- Dental problems – (Dental care generally is too expensive for the population unless they can get an appt. with a dental clinic in the government sector.)
- Speech articulation defects (There are few, if any, speech therapists left in Zimbabwe now.)
- Skin lesions and bruises – (The last I heard there was one Dermatologist in all of Zimbabwe, a lady from Germany.)
- Obesity related problems, including hypertension, hypoventilation, right-sided heart failure, etc. (There is one cardiologist in Zimbabwe who works within the private sector...he is unaffordable to most of the population there. Blood pressure (BP) can be monitored at local gov't. clinics but if there is a cost, whether \$5 or \$50, it is difficult for an unemployed African to come up with a payment, so they avoid going to clinic to have their BP monitored.)

continued on page 13



WE REMEMBER

Shirley Neason, 1930 – 2014

*By Ruth Peterson, her daughter
with additional information provided by Lota Mitchell*

My little brother had Prader-Willi syndrome. He passed away 34 years ago [suddenly, at age 14], but being Daniel's mother gave Mom a mission that provided hope and support to families who have had loved ones dealing with the syndrome.

When Daniel was born in Tennessee [in 1966], Mom and Dad were not given much hope that he would ever grow and thrive. Nothing was really known about PWS; however, Mom was not one to give up. I [was seven years older than Daniel and can] remember her developing ways to engage him as a baby, and as he grew, she would devise ways to help him learn.

When we moved to Washington State, Mom found many answers at the University of WA [at the first Prader-Willi clinic in the world, headed by Dr. Vanja Holm]. They were able to provide a diagnosis, but there was so much that was unknown. Mom worked with the university to find answers to those questions. She spent time encouraging parents who had just had their child diagnosed, and she became an expert.

Mom weighed the food that Daniel ate down to the last gram. She kept meticulous records and studied nutrition so she could give my brother the most nutritious and satisfying diet without resulting in the weight problems that are so prevalent in people with the syndrome. Mom had books filled with nutrition and calorie data and would calculate his daily intake, making necessary adjustments according to his needs.

Mom was also the information and support source for families who were dealing with the syndrome. She and another



family [Gene and Fausta Deterling] founded the Prader-Willi Association [now the Prader-Willi Syndrome Association (USA)], and she created a newsletter called *The Gathered View* to provide a regular source of information for families. [Shirley was Vice President of the new organization and served as a board member for many of the early years. She was the first editor of *The Gathered View*, and she wrote PWSA's first publication, a *Handbook for Parents*, published in 1978.]

My Mom was small and quiet, but she was a pit bull when it came to determination. My little brother was a great kid - happy, loving, and well-educated. Mom's influence has touched hundreds of people. She is one of my biggest heroes. ■

Africa, continued from page 12

- Mild to Moderate Cognitive disabilities – Learning problems in school. *(This area may be a problem as schools are in turmoil and many teachers are not doing their job properly because they are not receiving decent salaries...to expect a teacher to give extra or special time to special students is not realistic.)*
- Behaviour Problems – OCD, Tantrums, Rigid but Sweet and Loving; Need consistent use of positive behavior management. *(Generally maShona do not discipline their children...they are very tolerant of their children, but the children are usually quite well behaved...they would need to be trained in positive behavior management.)*

NOTE:

I realize so many of my comments sound negative but it is just the way it is living in Zimbabwe. While I am less familiar with other African countries, my guess is it would be much

the same in Kenya, Tanzania, Burundi, Rwanda, Malawi, Mozambique, Zambia, Swaziland, Democratic Republic of the Congo and other such sub-Sahara countries. South Africa (RSA) is the exception. In spite of their hardships, the people in Zimbabwe are the most wonderful people in the world to meet. It has been my joy and blessing to work with them throughout the years.

*“My life is pretty simple.
It's all about taking the next step...
just take the next step.”*

- John Creel

contributed by Clint Hurdle

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Thank you for Contributions in June-July, 2014. We try to be accurate in recognizing contributions above \$25, and apologize for any errors or omissions. If you notice an error, please tell us.

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We Want to See Your Smiling Faces!

We need photos (digital preferred) of individuals of all ages, both genders, and all ethnic backgrounds. The picture must be

PWSA (USA) is accepting pictures of your child/adult with PWS for use in our publications, on our website, and in various other formats.

a MINIMUM of 1200 pixels high OR wide, in a JPG format. The 1200 pixel requirement is only for height or width; it is NOT necessary to be that size in both directions.

From the PWSA (USA) website, please complete a Photo Release form, <http://www.pwsausa.org/photo%20release%20fieldform%20PWSA2010-08.pdf> (or from the office) and return the completed form and photo to news@pwsausa.org. ■

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

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The Members Only section requires a password. Please enter PWS for the code.

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

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e-News...

Reminder – stay informed and stay current with PWSA (USA)’s free e-News every two weeks.

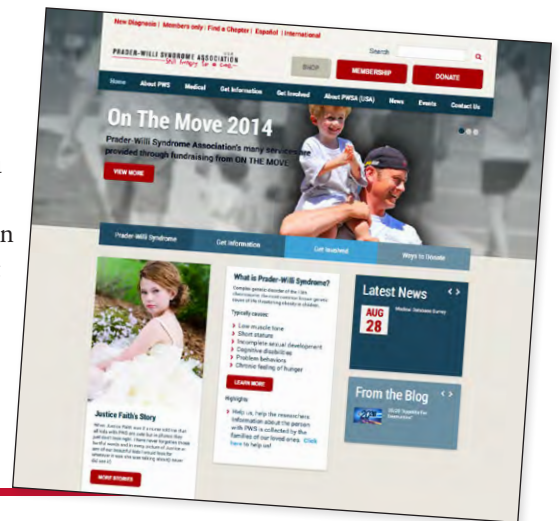
Sign up today at www.pwsausa.org!

Welcome to our new Website!

By Denise Servais

PWSA (USA) is pleased to announce the release of our new website. The new website is designed with a fresh look and user-friendly navigation. Everything you need is in one place and updated with the latest information about our products and services. You will be able to review and purchase PWSA (USA) items. You can also connect easily to our social media sites and donation links (and even find out where donations go!). The site is still being updated with the newest information.

We hope you will enjoy browsing our new site and find the information you may be looking for. We strive to provide our members with the most current information they need quickly and easily. We would be pleased to receive your comments at news@pwsausa.org or ksmith@pwsausa.org. ■



On October 18, 2014, the Sarasota tennis community will swing their tennis racquets at The Meadows CC to help promote awareness and raise funds for the PWSA (USA). For details, contact Pam Ferrara at the PWSA (USA) office.

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