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

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

Ask Your State about the Workforce Innovation and Opportunity Act (WIOA)

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

In recent years there has been a national push for increased independence, community integration and inclusion and decreased restrictions and segregation for people with intellectual/developmental disabilities by individuals with ID/DD, families, professional providers and federal and state policy makers.

In 2014, the Workforce Innovation and Opportunity Act (WIOA) was signed into law by President Obama. The WIOA places emphasis on vocational rehabilitation services and transition services for youth transitioning from high school to a post-secondary program, higher education setting or into the employment force. The WIOA requires each state to dedicate 15% of their federal grant funds to pre-employment transition services for individuals with disabilities. Additionally, half of each state's supported employment grants must be spent on services for those with the most significant disabilities (defined in WIOA section 511). The intention of this increased focus on support and training is to increase job related skills allowing for more competitive employment opportunities for individuals with disabilities.

The WIOA limits placements in sheltered workshops and other employment environments where individuals earn less than minimum wage. The WIOA does NOT require states to close their sheltered workshops; rather, it limits the use of sub-minimum wage as outlined in section 511. Individuals already employed in a sheltered workshop are grandfathered in in terms of placement; however, the agencies are now required to provide them job skills training and offer opportunities for employment in a less segregated setting.

This change took effect on July 1, 2016 and many of you have been affected by your states' implementation. Each state has the flexibility to respond to and implement the WIOA as they choose, as long as they meet the federal requirements. It's important that you do your own research, and ask your providers and local disability services office how the WIOA is being implemented in your state. ■

Each state has the flexibility to respond to and implement the WIOA as they choose, as long as they meet the federal requirements.

Resources

http://bit.ly/2mKAthuCongressHR803

http://bit.ly/2muZVXCguidanceWIOA

http://bit.ly/2mRvyvDwagelimitsWIOA

PWSA (USA) Advocacy Alert Network Seeks Members

The PWSA (USA) Advocacy Committee is seeking interested persons to participate in the newly created Advocacy Alert Network. Persons who join the Network will be notified by Committee members of pending legislative issues affecting PWS and be provided with a model email or letter that can be used to contact legislators regarding the issue. In this way, we hope to increase our voice on significant legislative matters affecting the PWS community. The time commitment required for this important endeavor is not great and anyone who is interested in becoming part of the Network is urged to join. If you are able to participate, or if you have any questions about this project, please contact Tom Conway (TConway@pwsausa.org). ■

Volume 42, Number 2 ~ March-April 2017 ~ Our 42nd Year of Publication

Executive Director View

The time has come that many of us didn't want to think of happening – and that is that Janalee Heinemann is retiring after 37 years of dedicated service to PWSA (USA). For the past few years she has been partially retired, but still working as hard as ever. This time she is really retiring. Countless lives have been touched by her compassion, knowledge and guidance during those 37 years. She will be greatly missed, and all in the family of Prader-Willi syndrome wish her well in the coming years. Be sure to read her farewell letter on the next page.

At the same time that I am regretfully anticipating Janalee's full retirement as of May 1, I am also pleased to announce that Evan Farrar will be her replacement as Research Coordinator. Evan is uniquely equipped to be taking on this work, which he describes as primarily facilitating: grant funding and the research process; communication between the SAB, CAB, and staff; between PWSA (USA) and other national and international organizations; and the knowledge of day-to-day issues for families to researchers.

With a master's degree in Mental Health Counseling, he will serve half time wearing his Research Coordinator hat and the other half doing Family Support Counseling.

"Things usually turn out the best for people who make the best out of the way things turn out."

~ John Wooden

Evan joined PWSA (USA) in 2007. He has served the organization in several capacities including as Executive Director. He is happy now to be staying part of the time in the family support program, where he has had the benefit of mentoring by David Wyatt, who began the program, and then by Janalee, both greatly increasing his understanding of PWS.

Evan feels honored to follow Janalee in this important work and says he is "excited at this great opportunity to be involved in a different aspect of PWSA (USA)'s work. Our experience with families and family support is important in the research process."

On a troubling note, please read Stacy Ward's front page article on what is happening across the whole country in regard to sheltered workshops and day programs. This is important and difficult information and the first of several articles. Many workshops and day programs are closing or trying to find a way to continue to exist. If your state has not yet demonstrated the effects of the Workplace Innovations and Opportunities Act (WIOA) which took effect in July 2014, it is highly likely that it is going to happen in order for the state to be in compliance, and this may impact your adult child. ■

~ Ken Smith, Executive Director, PWSA (USA)

If you want to truly inspire others to be more productive and collaborative use more positive communication...
Have a vision and the conviction to see that vision realized...
Strong relationships drive real motivation and change. Communicate and show people you care about them...
~ Dave Gordon

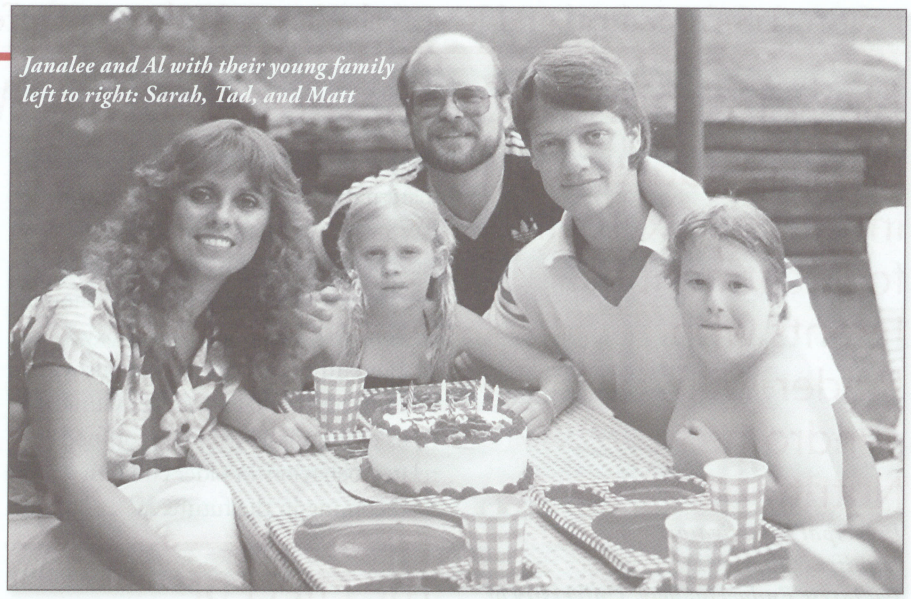
Introducing

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

We are very excited about unveiling our new official PWSA (USA) logo and tagline. The tagline *Saving and Transforming Lives*, represents what PWSA (USA) is all about: us and our wide community of any person touched by PWS. Whether it's helping a family with a crisis problem, helping with a school issue, broadening our awareness and education, or providing people with the medical knowledge they need for their loved one, we save lives today so we can transform those lives tomorrow.

The entire process took over six months and the logo you see here was chosen to best represent a feeling of warmth and hope, as well as representing the new tagline. The butterfly in the logo tied into our vision of representing PWS and PWSA (USA): a butterfly is a beautiful creature that has gone through a long, enduring journey to transform into something beautiful. The butterfly icon shows that there may be challenging times; yet beyond those times, beauty, hope and love can happen. ■

Completing Our Pilgrimage Together



Janalee and Al with their young family left to right: Sarah, Tad, and Matt

By Janalee Heinemann, M.S.W., Coordinator of Research and International Affairs, PWSA (USA)

When I began with PWSA (USA) in 1980, we were in uncharted territories. No one had a map to give us of how to get where we needed to go, so we had to create our own.

At that time, I was planning to marry Al; he had full custody of his two children, Sarah, age 6 and Matt, 7. Matt was extremely obese and had this mysterious disorder I had never heard of called Prader-Willi syndrome. All I could find on the syndrome was a couple of paragraphs in a medical journal in the library. After much searching, I was excited to find out that there was a fairly new organization that had been formed: the Prader-Willi Syndrome Association (the USA was added later to distinguish it from the state chapters that were beginning to form). That association had its first conference in 1979. Being that I was in school getting my Master's degree and with five children between Al and I, we did not have much money. So we drove from St. Louis, MO, and pitched a tent in Boca Raton, FL to attend the 1981 conference. We were desperate for information, advice and support!

Al cried at that first conference, but we came home with a lot of knowledge and the understanding that we were helping our son by locking up the food. Matt thanked us and said, "My hand go into the refrigerator and I can't stop it!" We also came back with the realization (thanks to much encouragement from Lota Mitchell) that we HAD to get involved on both state and national levels.

From there, we went on to found the state chapter in Missouri, I became a national board member… then president… and eventually, Executive Director in 1997. After 10 years in that position, I chose to step down and work more specifically with the medical and research, and eventually became the international vice president for the global organization, IPWSO.

Why did I get so involved? We realized that there was no "other" out there: to map our course and create a path, to forge ahead into the uncharted territories. It was up to us. So with pen, phone, and typewriter/computer, we marched on.



Matt, with Janalee and Al.

When I say "we" I hope you realize that whatever I did, I did with the help of a whole army of parents, relatives and professionals that continued to revolve and evolve over the years. Lisa Peters called it, "a sorority of soldiers." As Lisa wrote, "It is you, all of you, my sorority of soldiers, that inspire me." Over the years, I have been inspired 1,000 times over by loving and devoted parents of children with PWS, a legion of passionate professionals working with the syndrome, and our dedicated staff and volunteers at PWSA (USA).

When I took over as Executive Director, we were a staff of two people. There was virtually no literature on the syndrome except for a couple of brochures and a few medical articles. The reality of our growth has far exceeded my expectations, hopes and dreams. Unless you were part of this journey with me over the last 37 years, you probably cannot appreciate how far we have come. You may be more focused on how far we have yet to go. That is okay – we need and want your energy – just remember that we are all responsible for the course of this syndrome.

I have decided that, at age 72, it is time for me to fully retire. May 1 will be my final day. I feel good about the progress we've made over the years, and the people that will continue to further the cause as I hand over my "compass and hiking boots". For all of you energetic, younger "soldiers," try to see this journey not as a war, but as a pilgrimage, a voyage of hope with our sisters and brothers. Each and every one of you is essential to continue to create this pathway towards freedom for ourselves and our children. Thank you for your donations over the years, your volunteer time, and your inspiration. This was not a path I had planned to take with my life, but could I have really done anything more important? ■

New Research Grants Funded by PWSA (USA)

Phase 2 Study: Intranasal Oxytocin for Treatment of Infants with Prader-Willi Syndrome in Nutritional Phase 1a

Principal Investigator:
Jennifer Miller, MD
Pediatric Endocrinology, University of Florida

Abstract

Individuals with Prader-Willi syndrome (PWS) experience several nutritional phases through their lifespan. Initially, there is severe neonatal hypotonia with decreased appetite and impaired suck necessitating assisted feeding (nutritional phase 1a) (Miller et al, 2011). Nutritional phase 1a is characterized by the need for assisted feeding. The feeding can typically be accomplished using a special nipple/bottle, placement of a nasogastric tube, or placement of a gastrostomy tube. However, this is a dangerous time for infants with PWS, and has a high rate of morbidity and mortality due to aspiration and respiratory failure (Nagai et al, 2005). Feeding and swallowing skill development parallels psychosocial milestones of homeostasis, attachment, and separation/individuation. Mothers of infants with PWS often describe a feeling of lack of attachment or lack of bonding with their child due to the lack of suckling and responsiveness of the children.

In an open-label study, oxytocin nasal spray has been shown to be well-tolerated in infants with PWS and to improve feeding and social skills (Tauber et al, 2017). In this study we want to test whether daily oxytocin nasal spray will perform superiorly to placebo in improving suck, swallow, feeding, and maternal bonding in individuals with PWS who are in nutritional phase 1a. The results of this study will help determine if a larger, future trial should be done to consider intranasal oxytocin as standard of care for individuals with PWS in nutritional phase 1a. Clinical trials of intranasal oxytocin for food-related behaviors in older children will be forthcoming in the future. ■

The Effect of Growth Hormone Substitution on Sleep Disordered Breathing in Young Children with Prader-Willi Syndrome

Principal Investigator:
Catherine Choong, MBBS, MD, FRACP
School of Pediatrics and Child Health, University of Western Australia

Abstract

Children with Prader-Willi syndrome often have a disturbed breathing pattern in sleep, which can lead to symptoms of tiredness and behavioral issues during the day. Growth hormone is a very useful medicine for children with Prader-Willi syndrome, but it may worsen obstructive breathing during sleep. In very rare cases, this may be dangerous, as it could lead to suffocation in sleep. Therefore, doctors generally perform a sleep study before and 6 months after start of treatment with growth hormone. However, previous smaller studies have suggested that growth hormone may be safe and in fact even improve symptoms of disturbed breathing in sleep. In this study we want to use the data collected in a large group of Prader-Willi syndrome patients in Australia to analyze the effects of growth hormone on breathing in sleep. The results of this study can help us to understand better what the causes of specific breathing abnormalities in sleep are in children with Prader-Willi syndrome. Secondly, if growth hormone is associated with improved breathing in sleep, this can have a direct impact on the age at which growth hormone treatment should be started in infants and young children. Also, it will have implications on the usefulness of routine follow-up with repeated time-consuming and labor-some sleep studies. Importantly, the framework established by undertaking this study with scientific excellence in endocrinology, respiration & sleep, and consumer reference group input, will enable future more detailed analysis of sleep quality and behavior in this special group of children. ■

Profiling of the Gut Microbiome in Children with Prader-Willi Syndrome

Principal Investigator:
Andrea M. Haqq, MD, MHS, FRCP
University of Alberta, Canada

Abstract

Individuals with a genetic condition called Prader-Willi syndrome (PWS) are at risk for development of obesity at a young age. Children with PWS often have a very high food intake because they experience a constant feeling of hunger. However, even children with PWS who limit their food intake can still gain excessive amounts of weight. Attempts to control weight in PWS through dietary interventions have had limited success. The human gut contains bacteria that play an important role in food digestion. When the stomach and small intestine are unable to digest certain foods, gut microbes ensure nutrients are digested. Changes in gut microbes may lead to

continued on page 5

Research Grants, *continued from page 4*

obesity, but the specific role of gut microbes in weight control in PWS and childhood obesity is not yet fully understood.

In this study, they will compare the gut microbial composition of infants and children with PWS to individuals of similar age, sex and body weight who do not have PWS. Infants and children with PWS and controls (ages 0-17 years) will be recruited. A stool sample will be collected during one study visit at the University of Alberta. They will assess the microbiome at different stages of development to assess whether temporal changes in the microbiome are associated with temporal change in food seeking behavior and hyperphagia.

Hypotheses:

The gut microbial composition will be significantly different between PWS and matched controls.

Relevance:

This proposal uses state-of-the-art technology to address a critical clinical question. It will provide novel information to design therapies aimed at reversing gut dysbiosis (a microbial imbalance or maladaptation on or inside the body), and thereby improving metabolism and lowering inflammation in children with PWS with obesity. ■

Studies Continue on Prader-Willi Syndrome at Case Western

The PRETEND/Telehealth team at Case Western Reserve University recently had another enrollment trip for ongoing studies on Prader-Willi syndrome, this time in San Antonio, TX, March 8 through March 11. There, they recruited families with children with PWS 3-11 years of age for assessment of emotional, cognitive, and social abilities, and the opportunity to enroll in a 6-week play-based remote intervention program to improve skills in these areas.

If you are interested in learning more, contact Research Associate, Ellen Doernberg, at 216-368-0112, or via email a neurodevelopmentresearchlab@gmail.com. ■

(PWSA (USA) is providing sponsorship for both grants.).

Caregiver Stress Survey Update

Hello everyone,

The data collection for the PWS caregiver stress survey has ended successfully, easily surpassing projected goals of responses! Once the data is published, this will have much greater impact for PWSA (USA). We could not have come close to getting this great of a response without your diligent help!

The eight $25 Amazon gift card winners will be notified by PWSA (USA) staff. Thank you for all your help.

Michael A. Vice, Doctoral Candidate, Health Behavior and Promotion, Department of Health, Exercise Science and Recreation Management, The University of Mississippi ■



Want to be a part of the world's largest PWS advocacy community?

Become a member today! Go to: www.pwsausa.org and click on Membership

PWSA (USA) Member Benefits include:

- 20% discount on merchandise
- *Gathered View* newsletter
- Members only online access
- Free Webinar registration

CHUCKLE CORNER

Our daughter, Jennifer and her boyfriend, Marcus, live at Prader-Willi Homes Oconomowoc (WI). He also has PWS. On a visit, we took the two of them out for supper. As we were walking into the restaurant, Marcus says: "I have to warn you, I eat a lot of food when I go out to a restaurant!" I chuckled a little and said: "Nice try." He ordered the same thing our daughter ordered without incident! You got to love 'em!

~ Dewey W. Graves Jr., Michigan Center, Michigan

Pneumonia Vaccinations and Prader-Willi Syndrome

By Kathy Clark, MSN, PNP, PWSA(USA) Coordinator of Medical Affairs, and Richard G. Wunderink, MD, Professor of Pulmonary and Critical Care Medicine, Northwestern University Feinberg School of Medicine

Persons with Prader-Willi syndrome (PWS) have a higher than average death rate due to "respiratory events." This can mean many things – choking on food, aspiration of liquids with swallowing, obstructive apnea, and pneumonia. Pneumonia is an infection of the lungs that can lead to lung failure and the need for mechanical ventilation ("breathing machine"), as the tiny air sacs in the lungs fill up with fluid. Pneumonia can be the result of a virus or bacteria. Inflammation of the lung (pneumonitis) is often confused with pneumonia. Pneumonitis occurs with aspiration of chemicals, typically acid, food or other secretions from the stomach. We don't know how often pneumonia or pneumonitis occurs in persons with PWS, or what type of pneumonias are most common.

Healthy breathing requires brain control (knowing when to breathe deeply) as well as muscle strength – muscles of the mouth, throat, diaphragm and ribs. Muscle strength and brain control to synchronize the various muscles are very important in coughing, one of the most important protections against pneumonia and pneumonitis. Both brain control and muscle strength are weaker in persons with PWS. Because of the emerging evidence of aspiration (liquid going to the lungs, not to the stomach) with abnormal swallowing, we know that lung health can be easily compromised in individuals with PWS. If your loved one has experienced frequent "lung infections," abnormalities of swallowing are important to consider as the cause – with liquids entering the lungs rather than being swallowed.

While most pneumonias are caused by viruses, there are immunizations available to decrease the risk of certain bacterial pneumonias. Prevnar13 is very effective in preventing pneumococcal pneumonias, one of the most common causes of bacterial pneumonia. Most children born after 2001 have already been immunized with Prevnar13 and Hemophilus influenzae type B (HiB conjugate vaccine), which works against another common cause of bacterial pneumonia, as a routine part of childhood care.

Prevnar13 is also recommended for people with certain underlying health conditions including chronic lung disease, diabetes and heart disease, as well as diseases that decrease immunity to infection. Whether the health challenges in PWS are sufficient to warrant giving this vaccine to all individuals with PWS who may have missed these childhood vaccinations is unclear.

A second vaccine, Pneumovax, protects against additional strains of the pneumococcus. This second vaccine is currently recommended in the elderly and for children and adults with the same underlying health conditions listed above (lung disease, diabetes, heart disease, immune compromised diseases). Check with your doctor to see if these immunizations have been given, and if not, whether these would be recommended now.

Here is the CDC guideline to discuss with your provider: https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6140a4.htm

Here is more information about pneumonia:
http://bit.ly/2nkM9VcPWSAUSA

Reviewed by Marilyn Dumont-Driscoll, MD, PhD, PWSA (USA) Clinical Advisory Board Member ■

Jumper. Cracker. Squint.

We may speak the same language as our British friends, but some words have a different meaning across the ocean. In the USA, we would use these terms instead: **Sweater. Cookie. Lazy eye.**

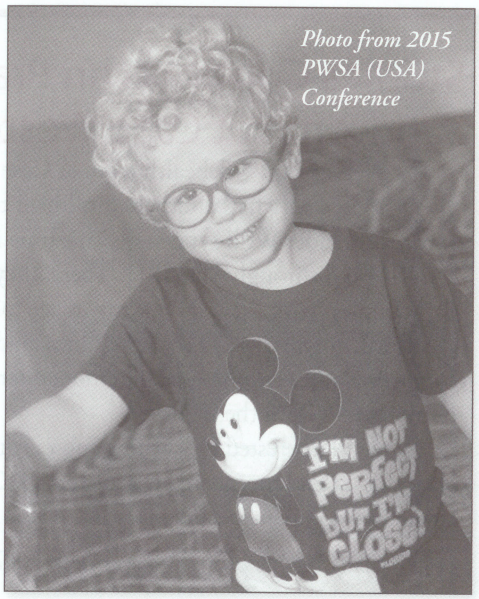


Photo from 2015 PWSA (USA) Conference

Eye muscle control is a common problem for children with PWS. Early in life, parents may notice one eye seems to drift away or take its time getting in line with the other eye. This may be more noticeable when the child is tired. The medical term for this is "strabismus" and it is commonly called "lazy eye" in the US. If it is not outgrown, the child's brain can become confused about which eye is giving the "best" information.

The PWS organization in the UK has a website filled with information, including a detailed series about eye problems in PWS. It explains issues and treatments; the only difference from our care in the U.S. was the reason for the vocabulary lesson – we don't use the word squint.

Here is the link: http://bit.ly/2m5ZqQ9LazyEye ■



Welcome Steve Queior Development Director PWSA (USA)

We are pleased to announce and introduce Steve Queior as our Development Director the beginning of March. Steve (last name pronounced "Kwee-or") brings a breadth and depth of valuable experience to our organization. Steve shares: "It will be an honor to be Saving and Transforming Lives through the strategic and caring work of the Prader-Willi Syndrome Association (USA).

"PWSA's mission of bringing key people and groups together to raise awareness, provide support, enhance education and advocacy, and accelerate research improving the lives of those impacted by Prader-Willi syndrome is a noble one. Helping to fulfill this mission will be stimulating, challenging, and rewarding for me."

Steve's career has included fund development work ranging from organizing and executing annual fund-raising efforts and membership campaigns, planning and implementing multi-year pledge initiatives and obtaining grants, and increasing sponsorships and net event revenues. Steve was president of the Chamber of Commerce in greater Sarasota and lives with his wife Katie, an R.N. Their daughter Jordan works in San Francisco, and they have two great dogs, Bobby and Chuey.

Join our board, volunteers, all our members, Ken Smith and all the staff, in welcoming Steve, who will take PWSA (USA) to the next level of positive impact and success. ■

Call for Nominations for PWSA (USA) Board of Directors and Volunteers for Committee Service

The source of PWSA (USA)'s strength lies in its membership - parents, extended family members, professionals, and others committed to promoting research, education, and support for families affected by Prader-Willi syndrome.

We are currently seeking candidates for the 2017-2020 Board of Directors and volunteers for Committee service. We have specific needs for talented individuals in the areas of:

- Finance - Fundraising - Public relations/marketing

Board and committee membership is open to family members and interested professionals.

Please contact us if you or someone you know possesses the qualities necessary to be an effective Board of Director:

- Ability to listen, analyze, think clearly and creatively, work well with people individually and in a group
- Membership in PWSA (USA)
- Commitment to serve a 3-year term (unless nominated to fill a shorter term)
- Willingness to attend Board and committee meetings and other special events; ask questions; take responsibility for a given assignment; support the Association as generously as your financial resources allow and assume shared responsibility for generating resources to meet Association goals; open doors in the community
- Possess willingness to learn skills such as understanding financial statements; cultivating and soliciting funds; cultivating Board members and other volunteers
- Possess honesty, sensitivity to and tolerance of different views; a friendly, responsive, and patient approach; community-building skills; personal integrity; a sense of values; concern for the Association's development; a sense of humor

What will you gain in return for your service?

- A sense of pride as you work to better the lives of all persons affected by PWS
- Input into decisions and policy-making that affects persons with PWS
- Increasing your knowledge about PWS and its treatment and management strategies
- Increasing your exposure to professionals who work with individuals with PWS

To nominate yourself or someone else, please contact Leadership Development Committee Co-Chairs Lisa Graziano or Tammie Penta via the PWSA (USA) office at 800-926-4797 or 941-312-0400 or info@pwsausa.org or by fax to 941-312-0142. *The deadline for nominations is May 12, 2017.*

To continue to grow as a vibrant, effective organization, PWSA (USA) also needs volunteers for fundraising, advocacy, and family and research support, among other areas. If you are able to free up time to help, please email us at info@pwsausa.org There is no deadline, as volunteers are always welcome. ■

Upcoming Awareness and Fundraising Events

right: Hunter Lens



The Hunter Lens Golf Tournament is Saturday, May 13, with a shotgun start at 1:00pm, at The Back 9 Gold Club, 17 Heritage Way, Lakeville, MA

We are off to a great start this year! You can help by hosting a fundraiser in your area. We will be here to assist you in putting together a successful event. To get started, please contact Leanne Gilliland at lgilliland@pwsausa.org or 941-487-6743.

Below is a partial list of events. Visit **https://www.facebook.com/PWSAUSA/** to look for events in your area.

4/29 Kissimmee, FL Florida ***"On The Move"*** Walk
Hosted by the FL Chapter http://www.firstgiving.com/pwsausa/florida

5/6 Jackson, MI Michigan ***"On The Move"*** Walk
Hosted by the MI Chapter http://www.firstgiving.com/pwsausa/MichiganOTM

5/13 Oconomowoc, WI Wisconsin ***"On The Move"*** Walk
Hosted by the WI Chapter https://www.firstgiving.com/pwsaofwi/7th-annual-on-the-move-walk-a-thon

5/13 Lakeville, MA Eighth Annual Hunter Lens Golf Tournament
Hosted by the Lens Family http://www.firstgiving.com/pwsausa/8th-annual-hunter-lens-golf-tournament

5/15 Spring, TX Seventh Annual Molly's Pub Golf Tournament
Hosted by Texas Prader-Willi Association
http://txpwa.org/register-golf-tournament-2017.html



Spring, Texas is the site of Molly's Pub Golf Tournament

5/20 Florida City, FL Ninth Annual "Casting for a Cause" Fishing Tournament, Michelle Torbert, Tournament Director
http://www.castingforacause.com/

5/19 Stillwater, MN Minnesota Golf Scramble:
Hosted by the MN Chapter https://pwsaofmgolf.eventbrite.com

6/3 Paducah, KY Paducah ***"On The Move"*** Walk
Hosted by the Thweatt Family
http://www.firstgiving.com/pwsausa/kentucky-on-the-move

6/17 Tucson, AZ Tucson ***"On The Move"*** Walk
Hosted by The Garcia Family
http://www.firstgiving.com/pwsausa/tucson ■

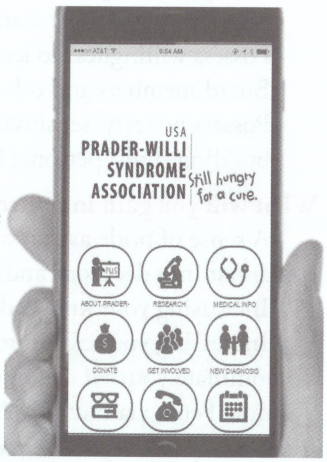
on the MOVE
PRADER-WILLI SYNDROME ASSOCIATION (USA)

Carry PWSA (USA) Wherever You Go!

By Evan Farrar, MA, Crisis Counselor, PWSA (USA)

Are you carrying PWSA (USA) in your pocket? If not, why not? Because now you can by downloading the **FREE** PWSA (USA) app for your smart phone. With this app, you will have immediate access to all the important information you need on the PWSA (USA) Web site with a touch of your phone screen. Forget a handout you wanted to share with a teacher or doctor? No problem. It's all on your phone! Through this app you can:

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



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

So what are you waiting for? Start carrying PWSA (USA) wherever you go by downloading today the PWSA (USA) app available for Android and iPhones. ■



L to R: Evan Farrar and David Wyatt

Now Online!

Our Wyatt Special Education Advocacy Training (WSEAT) is here!

By Evan Farrar, M.A.,
Crisis Intervention and Family Support Counselor, PWSA (USA)

In February, PWSA (USA) launched its new online version of the Wyatt Special Education Advocacy Training (WSEAT) for parents of school-aged students with PWS. The training is named in memory of David Wyatt, who was PWSA (USA)'s first Crisis Intervention and Family Support Counselor. The WSEAT includes:

- **Six modules** covering a range of special advocacy topics – including how to address PWS specific school challenges.
- **Designed** so you can view one or all the modules. You choose what you need!
- **Pre-reading** and **relevant downloadable resources** for each module.
- **An opportunity,** if you don't have one, to get a **FREE** copy of: *From Emotions to Advocacy: The Special Education Survival Guide.*
- **Recommended resources** for additional learning.

Training information, particularly the modules that address PWS specific school challenges, will be useful to school professionals as well.

All of this is **FREE** of charge because we want **EVERY PARENT** in the PWS community to have easy access to this crucial information. So, visit the WSEAT today at **http://www.pwsausa.org/wseat-webinar-series/** and help us spread the word!

To stay updated on the WSEAT, subscribe to *School Times* by e-mailing me at efarrar@pwsausa.org ■

PWSA-WI, Inc. Sixth Annual Snowflake Ball

By Crystal Boser

On Saturday, January 28, PWSA-WI, Inc. had the pleasure of hosting our Sixth Annual Snowflake Ball at the Watertown County Club in Watertown, Wisconsin. The venue was festive with beautiful blue and silver decorations, many created personally by individuals with Prader-Willi syndrome. 230+ people dressed up (some in ball gowns and tuxedos) wearing corsages or boutonnieres, and had their photo taken by our professional photographer, Tom Davenport. Thirteen amazing volunteers helped serve a delicious sit-down meal and a special toast was given by the organization's vice-president. Once the meal was finished, the real fun began! DANCING! Crowd favorites, such as the *Cha Cha Slide, Uptown Funk* and *YMCA* had EVERYONE on their feet with smiles on all the faces! It was a magical evening and, once again, we're looking forward to this next year! ■

Molly, Nolan and Amanda





Kate Kane (in center) with her family

Photos on left: Tom Davenport-RDI

PWSA USA WISCONSIN

Maverick



SAVE THE DATE

PWSA (USA) 34th National Convention
Tuesday-Saturday November 14-18, 2017
Caribe Royale Hotel, Orlando, Florida

PWSA (USA) Medical & Scientific Conference*
Thursday, November 16, 2017

AM Topic
Prader-Willi Syndrome Medical Overview-Advancements & Treatments
Jennifer Miller, M.D., Keynote Speaker
Endocrinologist
Associate Professor
University of Florida

PM Topic
Pharmacogenetics
Timothy Dallenbaugh, M.D., Keynote Speaker
Residency Program Director
Associate Professor of Psychiatry
University of Missouri–Kansas City
School of Medicine

SESSIONS

Abstracts for presentations or posters must be submitted for review by September 1, 2017. See details at:
http://www.pwsausa.org/wp-content/uploads/2017/03/Call-for-Scientific-Abstract-PWSA-USA-2017-revised-3.13.17.pdf

For more convention information visit www.pwsausa.org

Capture this unique opportunity to receive your AMA CME credits and also make a difference in the lives of those we support and others with similar presenting issues and concerns.

Additional Convention Events include:

The Professional Providers Conference – Thursday, November 16
The PWSA (USA) General Conference – Friday and Saturday, November 17 and 18







**Application has been submitted to receive AMA CME credits for physicians attending the conference.*

Photos from 2015 PWSA (USA) Scientific Conference

PWS Presentation at Scientific Conference in Cuba

By: Daniela A. Rubin, Ph.D.

In October I traveled to Cuba to participate in the XII International Scientific Conference UNICA 2016 hosted by the Universidad de Ciego del Avila (Ciego del Avila University). The conference had a session on Sports and Physical Culture which included a symposium in *The Behavioral Management of Prader-Willi Syndrome*. I was invited to do a keynote presentation on aspects of exercise and physical activity in Prader-Willi syndrome. All attendees were hosted in the same hotel and we shared rides from La Havana to Cayo Coco, a beautiful beach resort area about six hours from La Havana. The shared ride to the resort and all attendees staying in one place fostered professional exchanges with colleagues working in other disciplines such as education and pedagogy, technology and the area of performance enhancement for sport participation. I seized these opportunities to spread the word about PWS and all the efforts that regional, national PWSA (USA) and our international organization, IPWSO, do to improve the quality of life in those affected by the syndrome.

During my stay, excellent professional and personal opportunities occurred to interact with the wonderful Cuban family, Dr. Loisel Bello Ulloa and Marlem Román Garcia, who participated in the behavioral management of PWS symposium. I learned about their child who has PWS and all their unmeasurable efforts to bring education and awareness to Cuban families who have a child with PWS. Much of their initial efforts were thanks to the support of IPWSO. The efforts of Dr. Bello and his wife Marlem have spirited include education and training not just for families but also for professionals working with persons who have PWS. These seminars and educational sessions in turn fostered professionals in physical education (Dairen Falo Pages and Enio Rodriguez Alonso) to complete their Master theses' studies evaluating the role of supervised exercise programs in young adults with PWS.



Left to right: Sady Rodriguez Pérez, M.S.; Daniela A. Rubin, Ph.D.; Marcia Julia Salt Gómez, Ph.D.

I also interacted with Cuban and other Latin American colleagues working in the area of physical activity and sports performance. Because there were delegations from Mexico and Ecuador plus other national organizations, I shared brochures with them about PWS so they could bring back to their organizations information about PWS.

During my one-hour presentation, I covered as vastly as I could all aspects we had investigated with my group and the collaborations with Dr. Clark, Dr. Dumont-Driscoll and Dr. Andrea Haqq. My talk began with presenting the typical phenotype characterized by excess body fat and low muscle mass which results in a basal metabolic rate 30-40% lower than normal. I discussed that children with PWS present a motor developmental delay; and that we, and others, have shown impairments in balance, bilateral coordination, agility, speed and muscle strength (Lam et al. 2016). I presented how levels of spontaneous physical activity tend to be lower than in people without the syndrome (Castner et al. 2014) and that we, and others (Butler et al.), have speculated that the low levels of moderate-vigorous physical activity in PWS are related to poor muscle tone as well as poor motor proficiency.

I showed our data in which we have demonstrated that aerobic exercise triggers relatively normal hormonal responses in children with PWS: a decrease in insulin and increase in epinephrine and norepinephrine immediately post-exercise (Rubin et al. 2016). Notably, the increase in stress hormones is lower in PWS than in those without and there is an absence of growth hormone response. Metabolically, there is acute breakdown of glucose (sugar) and fat with an increase in fatty acid use during recovery from exercise (Rubin et al. 2014, 2017). I shared other exercise interventions from other groups that evaluated exercise routines of different complexity in youth with PWS at home, showing improvement in health parameters.

My presentation concluded with sharing our game-based physical activity intervention (Active Play at Home) conducted in California and Florida for parents and children with and without PWS. Examples were presented of our materials as well as some of the improvements we have seen in motor skills (Rubin et al. 2015). Finally, I emphasized how this type of physical activity routine presents the possibility to develop the motor abilities as well as a ludic (showing spontaneous and undirected playfulness) aspect in children with PWS at the home setting.

My participation in UNICA 2016 was an extremely rewarding and enriching experience. I would like to thank the organizers of the event, (especially Sadye Rodriguez Pérez) for their invitation and IPWSO for sponsoring my presentation. I can be contacted at drubin@fullerton.edu if you have questions or comments; if you are interested in our studies, please visit: http://pws.fullerton.edu. ■

PWSA Tennessee



Hello! My name is Terry Davis, and I'm the current President of the Tennessee chapter. My husband and I live in Knoxville and have two biological children (ages 24 and 21). In 2005, we adopted my niece (now age 17) who was diagnosed with PWS just a few months before she turned five years of age.

Our chapter was formed in November 2009 by a few PWS families and Steve Asbury (our current Treasurer and godparent of someone with PWS). I have been a board member and/or officer since October 2011. Other officers are Sonja Jack (VP), Missy Tomes (Secretary), and Deb Bryant (Asst. Treasurer), and board members are Carrie Daughtrey, Misti Love, and Mallori Swinford. We also have a PWS Ambassador on our board (Joe Bolander), who always has great ideas and calls our families to personally invite them to our events! Our mission is to improve the lives of everyone affected by PWS through support, education, advocacy, and research.

According to PSWA (USA) records, there are about 350 known families in TN who have children with PWS ranging in age from newborn to age 44. Because of HIPPA regulations denying us access to those in TN with PWS, we have had PSWA (USA) mail a package about our chapter to the families they have in their database every other year. This has been very beneficial in reaching out to them and letting them know about our chapter! We also have a Facebook page that is accessible to our families.

Visit our website **www.pws-tn.org** that has a lot of valuable information and resources for families. After hearing from a grandmother about the horrifying experience they had when her grandchild was born and diagnosed with PWS, we felt that we needed to distribute a brochure about PWS and our chapter to all the NICUs, endocrinologists, geneticists, pediatricians, and Ronald McDonald Houses throughout Tennessee. These will be printed and mailed out soon. The brochure is available on our website as well. Watch for our new t-shirt to promote more awareness of PWS too!

Our chapter has always had small attendance at our events but we have a fundraiser and a Family Day each year usually in the Nashville area, to help our chapter grow! We have had Family Day at the Nashville Zoo, the Adventure Science Center, and Fannie Mae Dees Park. Our fundraising walk has always been at the Vanderbilt Kennedy Center with an educational session afterwards. We've had many great speakers such as Elizabeth Roof (who we are very fortunate to have as an advisor on our Board of Directors), Jim and Joan Gardner, Janet Agarwal, and reps from one provider who just began working with our state's new "Employment and Communities First" program through the Department of Intellectual and Developmental Disabilities. We hope to have a 5k walk/run to raise more awareness in our state and funds for our chapter events, PSWA (USA) and a community home for PWS adults (there are no PWS-specific homes in our state).

Our first PWS moms' night out is Saturday, June 10, 2017 in Nashville. We are planning a cheese and wine tasting event as well as dinner. All of our board members have a child with PWS, and recognize how stressful life can be, and want to offer our moms a night out to be pampered. Future plans are to have a fashion show, makeup application, manicures, and neck massages. All of this will be totally free!

Our chapter is a member of the TN Disability Coalition and every February we attend Disability Day to speak with our state reps and legislators. We encourage board members and families to attend Disability Day, TN ARC seminars and conferences, as well as the PWSA (USA) national conferences. Elizabeth Roof, a Senior Research Specialist at the Vanderbilt Kennedy Center, is also a valuable resource for school related and other issues. See her short YouTube video at http://bit.ly/2ndBVGWTeacherTips that provides very helpful information and practical strategies for teachers who have students with PWS in their classroom.

We are excited to announce that we have a new geneticist, Dr. Jessica Duis, who just began working at Vanderbilt Hospital recently. She wants to team up with our chapter to start a Family Advisory Committee. She's planning a multi-disciplinary clinic at Vanderbilt so those with PWS can come to that clinic in Nashville and see all specialists in one day (an endocrinologist, pulmonologist, nutritionist and other specialists as well as Dr. Duis and Elizabeth Roof)! Dr. Duis wants to bring the best possible care to those patients whith PWS who may not have access to doctors and specialists in their area. She also is teaming up with our chapter to have a Family Conference each year with speakers who are knowledgeable about PWS. We're planning our first conference, to be held sometime in October, in coordination with our 2017 Family Day and pumpkin patch trip in the Nashville area.

Our chapter is very fortunate to have great officers and board members (all of whom have a child/grandchild with PWS or hyperphagia) as well as great advisors. We encourage more families to attend our events and become more involved in our chapter. We are here for you! YOUR help and input will make our chapter the best it can be! ■

A Vision for the Future

By Andrea Glass, mom to Ian, with PWS

As a parent of a child who is about to turn 22, I furtively look toward the future. I do not find it currently exists with bright opportunity. In the past, most opportunities for our children have been sponsored by a combination of federal and state monies. Not only are there more children who now qualify for this pool of money, but those funds aren't keeping up with demand. There's been a sea of change in how the government believes supportive funds to the disability community should be spent. Self-determination and supportive or shared living are the new buzzwords. Sheltered workshops and group homes are being phased out for what is considered a more community-based approach to meeting the needs of a disabled individual.

This new direction by the disability community that does not fit the needs of the PWS population concerns me. As parents of children with PWS, we witness maladaptive behaviors of varying degrees from our children; some are aggressive food seekers, others have meltdowns in public places, some can be aggressive toward caregivers but most of all, people with PWS are **not safe in unsupervised settings.** My life is lived always waiting for a phone call with bad news. It could be that a meltdown occurred and someone is hurt or there's significant property damage. Also, I'm constantly on guard 24/7 for a stomachache- a warning sign that my son has eaten more than his share. **THIS** is the PWS that I know.

As a group, we need to discover alternatives that will work for our loved ones, so they may live happy, healthy lives as independently as possible.

Simply stated: when I try to plan for the future, I'm uncertain where and how my son fits in with this new outlook of independent living and self-determination.

For day services, we're looking at either an agency-run program that may combine work and rehabilitation services or… we can *attempt* to manage these activities ourselves with self-determination funds. One fact is certain; for my son's safety, he cannot be in a setting without supervision by a professional who understands PWS. He can't take public transportation or speak well enough for the untrained ear to understand him. And all other typical PWS concerns are there too.

My son has taken community college courses (through high school vocational training) on self-advocacy. His favorite statement now is MYSELF. He absolutely has his own ideas.

First, he sees a life independent from his parents and PWS. He wants to live in a group home. However, the wait list for group home funding can be more than ten years away as funding goes first to the children turning 22 that are in residential school settings. Additionally, many states are "interpreting" the newest federal guidelines as a mandate to dismantle group homes. The "one size fits all" mentality has become the norm.

The 2014 changes in Medicaid regulations have led to a re-evaluation on service delivery and funding to agencies that provide group home living options for people with PWS. The Centers for Medicare and Medicaid Services (CMS) reimburses states in a range between 50% and 98% of these housing costs. States are left to interpret the rules and regulations regarding these services while following a framework set out in a 1,400-page document. Currently, states are performing surveys of each provider that receives this reimbursement to ensure compliance with the new set of regulations. These surveys have led to confusion and some devastating results. In some cases, the interpretation is that group homes are not desirable and all disabled individuals should live in supportive/shared living situations. Knowledgeable providers of group homes for PWS are certain PWS does not fit into this new model. The supervision requirements of PWS are much more intense than the supportive/shared living model can economically provide.

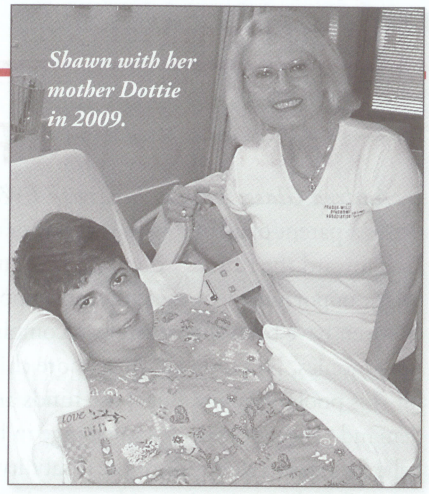
For example, in my state of Massachusetts, the costs of housing a person with PWS are between $150,000 and $200,000. High costs of rent, heat, food, and staff have led to a lack of funding for new group homes. There are many more individuals seeking placement than current availability. The current providers have been told there is no funding for new group homes. Homes that do exist are being downsized to no more than four individuals, and the surveyors are asking for justification regarding the secure environments in these homes.

In Wisconsin however, the costs of housing a person with PWS are significantly lower; between $80,000 and $100,000 depending on behaviors of individuals in the home. Lower costs of housing, food and staff and a fine-tuned formula for service delivery have created the ability for the Wisconsin agency to receive new funding for an eight-person home to open soon. In Ohio, the costs are about $100,000 per person, in addition to the cost of county subsidized costs of housing and food.

New York, Georgia and Florida also report long wait lists for group home living. For some states, there simply are no group homes for PWS. With these new regulations in place and funding becoming even tighter, the housing options of the past

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The PWS Monster


Shawn with her mother Dottie in 2009.

By Shawn Cooper, member, PWSA (USA) Adults with PWS Advisory Board

Editor's note: I learned Shawn's weight reached 189 pounds in 2009 from her parents who then were in a panic. I wrote to Shawn because I wanted to read - *in her words* - about her success with losing and maintaining her weight loss.

Hello Sara.

I am a 43-year old adult female living with Prader-Willi syndrome. At my parents. I can control it (eating) around Thanksgiving and Christmas. I use a salad plate as my dinner plate and what ever the tip of the serving size spoon touches of each dish that is made then that is all I take and a sliver of each pie's and a taste of the other dessert's, and that way I am satisfied and because also (I WANT TO LIVE AND DO NOT WANT TO DIE!) Because in this way I can have everything that everyone else is having and on birthdays when we go out to the all-you-can-eat buffet resturant I get everything at once: my salad and my dinner and I don't overflow my plate and I don't go back up for seconds. At my apartment and the enAble day service of Roswell, GA, I fix and cook my foods but with my one on one support staff with me when I am in the kitchen and when I am around the food. I am on the PWS adult advisory board too.

Before Thanksgiving my weight was 127.5 on 11/23/2016 and after Thanksgiving my weight was 125.1 on 11/28/2016.

Yes, having Prader-Willi syndrome is hard and some times I have slips but I always write it down on my log book and highlight it in yellow.

I go to the Enable day services and meet my one on one with staff Vonda Bloomer. And then we go to the planet fitness to work out and I workout with a personal trainer Allen Patrick. I work out for 2 hours then we go to the Atlanta Humane Socity at the Mansell Campuse where I volunteer! I am a dog walker and their dog whisperer. I work with the ones who are scared and frightened and get them ready to be adopted.

To My Brothers and Sisters and My Little Buddies out there who have Prader-Willi Syndrome: "Box That PWS Monster And Fight it."
I Believe in each and everyone of you and I know you can do it and
I also want you all to know that you are never alone.
I am here for you whenever you need me.
I Love you all so much. So please be strong and be safe.
From Shawn Cooper

From Shawn's parents Dottie and Dale Cooper-

"Shawn weighed in at 125 pounds, her target weight established after extensive testing. As her parents, we are so very proud of Shawn and her efforts to get and keep her weight under control. In addition, we are so appreciative of all the support and guidance in this endeavor. Shawn is so proud of herself. We can't thank everyone enough for the guidance and support for Shawn and our family over these many years. The **PWS Demon (Monster)** *she mentioned is a term the PWS Adult Advisory Board came up with years ago to attempt to communicate the drive for food. It is a way to describe what happens when the craving for food takes over their personality and they overeat. This board meets every January in Sarasota and, with assistance of their sponsors from National, come up with ideas that will assist adults with PWS."* ■

Vision, continued from page 13

are uncertain for the next generation of young adults with PWS.

As a group, we need to discover alternatives that will work for our loved ones, so they may live happy, healthy lives as independently as possible. We need to share our collective visions to find successful solutions to this growing issue. Do you have a vision to share? Please feel free to email it to me at: andreaglass33@gmail.com and let's work together for all children and persons with PWS.

Thank you to all PWSA board members, staff members and provider agencies for your candid input to this article. ■

~Andrea

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Our Mission: Prader-Willi Syndrome Association (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

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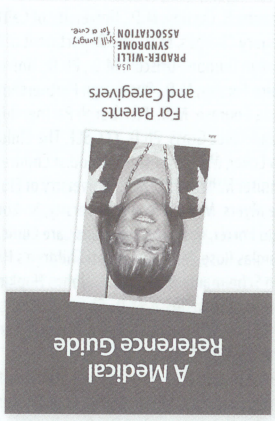
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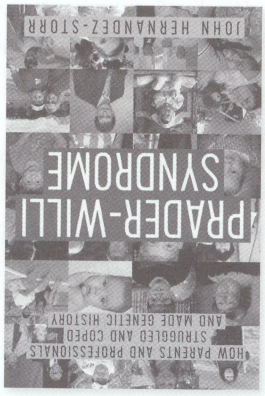
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A Medical Reference Guide: A Diagnosis and Reference Guide for Parents & Caregivers. Summary in chart form for parents and caregivers who need a quick introduction to Prader-Willi syndrome. $5.50 (2015)



Prader-Willi Syndrome: How Parents and Professionals Struggled and Coped and Made Genetic History Author John Hernandez-Storr's 256-page book shares info on the evolution of the medical world working to understand Prader-Willi syndrome (PWS), with personal stories of the original PWSA (USA) pioneers. Author John Hernandez-Storr is a father to a daughter with PWS. $15.00 (2016)

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