

The Gathered View

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

Baby, it's COLD outside!

By Kathy Clark, RN, MSN, CS-BC, Coordinator of Medical Affairs, PWSA (USA)

My husband and I differ on where the thermostat should be set. I even have an app that lets me adjust the house temperature from my phone. Ideal temperature is a favorite discussion year-round at our home. How can one person be bundled up yet so cold, while the other one is barefoot and drinking ice water?

People experience their own unique comfort zones, established by regions in the hypothalamus (brain) and regulated by muscle mass, fat distribution, hormones, and metabolism. For these reasons and more, individuals with Prader-Willi syndrome need extra consideration and protection in cold and hot climates. World-wide, cold temperatures are a far greater risk than hot weather.

Think three layers – even for a car ride. Keep a fleece blanket in the car to wrap up your passenger until the car heats up.

- Inner layer that wicks sweat away from the skin - lightweight wool, polyester, or polypropylene (polypro). Never wear cotton in cold weather as it absorbs moisture and keeps it next to your skin.

- Middle layers that insulate and keep heat in - polyester fleece, wool, microfiber insulation, or down.

- Outer layer that repels wind, snow, and rain.



Maddie Hurdle with her family enjoying the outdoors.

Hands and feet get too cold quickly, so check fingers and toes frequently when outside. Feet should have at least two layers. Many hands are warmer in mittens than in gloves, and should have three layers. Make sure children keep their mittens on, and keep moving when they are outside – make a game of wiggling fingers and toes.

Cover the neck and head – The large blood vessels in the neck should be completely covered as they are a source of heat loss when left exposed. A turtleneck shirt, a high collared warm coat, and a muffler or turtle fleece will give the three layers needed. Hats should be chosen for ear protection and should be double layered.

Warm internally – a warm drink upon coming indoors will heat from the inside out. Take off the outer layer, and adjust to the indoors before stripping off the other layers. Use fingers and toes as an indicator of good core temperature.

Heat packets (HotHands) can help preheat boots or be kept in a coat pocket to warm cold fingers. Keep some of these in your car for safety and comfort.



A young Alex Agarwal

For more information, be sure to review our handout on Hypothermia and Prader-Willi Syndrome – An Overview by Barb Dorn. Click here: <http://pwsausa.org/wp-content/uploads/2015/10/Hypothermia-an-overview.pdf>
<https://medlineplus.gov/ency/patientinstructions/000866.htm> ■

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Hidden Swallowing Problems in PWS Subclinical Dysphagia in Persons with Prader-Willi Syndrome

Gross R. RD, Gisser R., Cherpes G., Hartman K., Maheshwary, R. 2016. Subclinical dysphagia in persons with Prader-Willi syndrome. Am J Med Genet Part A 9999A:1-11.

PWSA (USA) fully funded this recently published research, which identified significant swallowing problems (dysphagia) in persons who have PWS. Our thanks to the authors for this important research, and we look forward to further studies to help us understand how to protect the health of persons with PWS.

The term “subclinical” means “without symptoms”. This means that problems can exist without anyone noticing unusual swallowing and without the individual being aware of any problems. While we have long been aware of the high risk of choking and the increased incidence of pneumonia in our population, the reasons have been unclear – and this has prevented us from knowing what actions to take for prevention.

Breathing and swallowing are complicated and connected actions, coordinated by numerous areas in the brain. Muscle strength and sensory skills are needed for effective swallowing. Most healthy people exhale (breathe out) after a swallow is completed, which helps protect the lungs. Try it yourself – it just happens naturally. But this may not be the case for everyone with PWS.

In this study, thirty individuals between ages 4-55 years underwent a radiology procedure called videofluoroscopy. They were tested while swallowing a thin watery liquid, and then a small cookie.

- **66% of subjects still had liquid in their throat after they were finished swallowing. Normally there should not be any left after a swallow.**
- **In eating the cookie, almost every subject had some bits of the cookie left in their throat after their first swallow. These people were unaware of this leftover food.**
- **All subjects had slow passage of the cookie into the stomach; it did not make its way down at a normal speed or in a normal pattern.**
- **30-40% of the swallows recorded were followed by inhaling, not exhaling, which increases the risk of food or liquid getting into the lungs.**

PWSA (USA) recommends that parents mention this research to their healthcare provider, and that you observe the swallowing behavior of your loved one with PWS. If you are working with a feeding specialist, they need to read this research as well. While we have yet to prove that swallowing studies are needed in every individual with the syndrome, such studies are essential if there are symptoms such as choking and coughing episodes, reflux and regurgitation, and lung infections. If in doubt, ask your medical provider for a referral to see a swallowing specialist or gastroenterologist.

Based on this initial research we recommend that persons with PWS:

- **Pace and chase – slow down speed of taking bites, and take a sip of liquid between bites**
- **Eat with other people rather than dining alone**
- **ALWAYS eat at a table, sitting in a chair**
- **Have smaller meal size with planned snacks rather than big meals**
- **Cut food into small pieces; select easy to chew foods, lower in fiber**
- **Try toothpaste like Biotene which may improve saliva flow**
- **Stay hydrated between meals**
- **At the end of the meal, stay upright at the table. Have a drink to “flush” the esophagus. Be active for a while after every meal. Do not eat and then lie down; have the last meal well before bedtime to let gravity do its job.**

By Kathy Clark, RN, MSN, CS-BC, Coordinator of Medical Affairs, PWSA (USA)

Edited by James Loker, MD, PWSA (USA) Clinical Advisory Board Member and Carolyn Loker, Medical Liaison, PWSA (USA) ■

Spreading PWS Awareness at Obesity Week Conference in New Orleans

This is always a very busy and dynamic meeting the first week of November, bringing together thousands of doctors, nurses, dieticians, behavior experts, exercise scientists, and public health researchers. We would like to thank the **Ohio Chapter** for their financial support which helped make this possible. We are also grateful to **Dottie and Dale Cooper** who provided assistance on our last day.

*For 14 years,
what better way
is there to educate
an ENTIRE medical
specialty population
about PWS?*

Our PWSA (USA) booth was well attended and we were able to educate many who were unfamiliar with the syndrome, and discuss what we know about weight control for persons with Prader-Willi syndrome. Bariatric surgeons and weight loss clinic providers attend this meeting and we appreciated the opportunity to discuss the unique aspects of

hunger – which has not been proven to be “cured” with bariatric surgery. We also had many professionals stop by to talk about individual patients they had met and needed more information. Several people came who had personal connections with someone who has Prader-Willi syndrome. **The Medical Alert booklet** continues to be a favorite item, as was our new **GI brochure**. Our **Window of Opportunity folder** was given to many young professionals. This is a more detailed packet especially helpful to researchers. We brought flash drives loaded with most of our important handouts and articles, including the Medical Alert in 17 languages.

Our time in the exhibit area allowed us to make contacts with pharmaceutical companies, to encourage more research in our population. Although most of our time was spent educating and greeting attendees, we took time to attend an excellent talk on PWS by Dr. Theresa Strong; Janalee stayed in the genetics lecture area where there were many questions about PWS, and Kathy listened to a research talk on oxytocin. There was a poster presentation showcasing a multidisciplinary PWS clinic in Mexico and we were pleased that the authors stopped by our booth for our **Spanish language brochures**.

PWSA (USA) has been doing awareness booths at national and international medical conferences for 14 years. What better way is there to educate an entire medical specialty population? Although finding funding for hosting the booths is always a challenge, we feel it is an important part of our mission – saving and transforming lives. ■

By Kathy Clark, RN, MSN, CS-BC, Coordinator of Medical Affairs, PWSA (USA) and Janalee Heinemann, MSW, PWSA (USA) Coordinator of Research & International Affairs



Kathy Clark, left and Janalee Heinemann, right shared information, made great connections and worked tirelessly at Obesity Week Conference.



What's happening...

Our association and chapters are busy! Are you curious about nearby events to attend? Looking for a workshop or golf tournament? Want to increase awareness and fundraise by having an **On The Move** event in your town?

Click here: <http://bit.ly/2jA0J9wPWSA-USA2017Events> to visit our Facebook page to learn more about events in your area, or inquire about starting your own! We are here to help you. ■

A New Year

Ken Smith, Executive Director, PWSA (USA)

As we move into the new year with its opportunities and challenges, I hope that everyone in our PWS community had a blessed, happy and – best of all – drama-free holiday.

The mission of the Prader-Willi Syndrome Association (USA) is to “...enhance the quality of life of those affected by Prader-Willi syndrome.” But it requires more than the national office to accomplish all that is needed. It takes individuals holding grassroots fundraisers in their front yards, it takes groups walking or golfing to raise money to provide services. And it takes chapters working in their own states to bring about change.

I'd like to share with you an excerpt from the newsletter of one such chapter, the Prader-Willi Alliance of New York (PWANY).

“The PWANY is dedicated to working with our state leaders to have PWS legally recognized as an automatically eligible disability for OPWDD (Office for People with Developmental Delays) services. This would end the senseless denial and appeal process. This would end the unnecessary distress that the appeal process puts on our families. Most importantly, this would end the fear that parents face of having a child that is too high functioning cognitively to receive services but still battling a disorder that requires 24/7 vigilance to remain safe from food. Our children deserve to be cared for and protected no matter their IQ.”

You can read more about PWANY in the **Chapter Spotlight** on page 9. And you can also read in the **International View**, page 10, about how the people in Australia are coming together to obtain services for their children with PWS. Always, the operative word is “together”.

What a terrific project for chapters both large and small to take on in 2017 – getting their own state to legally recognize PWS as an automatically eligible disability for services! Granted, this is a huge challenge, but one with so many benefits and one that could make a huge difference in so many lives. ■

And now for exciting **Breaking News!**

Rachel Johnson, Administrative Coordinator of PWANY, reported on January 10 to us that “Senator Rob Ortt (R-Niagara Falls), who currently chairs the Mental Health Committee in the Senate, introduced the Prader-Willi definition language we presented to him back in November: The Senate bill S.1219.”

She adds that there is “more work to be done, but the first hurdle has been overcome.” As their newsletter concluded, “*Together we can make changes for a better tomorrow.*”

“We have created momentum towards this goal and we are being heard in Albany... Together we can make changes today for a better tomorrow!”

Every day can be a fresh start if you commit to letting it be by letting go of what happened yesterday. So long as you continue to carry yesterday's defeat (or the previous moment's defeat) into the present it will quickly turn into your future.

Today, realize that you can have a clean slate any time you would like simply by letting go of what has just happened and focusing on what you are doing right at this moment.

*~ Steve Gilbert
Submitted by Clint Hurdle*

Be Prepared! Life Planning for Post-High School Education

By Kate Beaver, MSW, CSW, Crisis Intervention and Family Support Counselor, PWSA (USA)

Before your child graduates from high school, there should be a transition plan in place no later than their 16th birthday. This preparation will help this young adult to find a vocational or day program following their graduation. Some high schools may be better at this than others and parents need to know where to turn for help if the school doesn't seem to be providing sufficient feedback and information to them. Also, see our **Transition Resource Guide** for lots of information on this topic. <http://bit.ly/2j5tMktPWSAUSATransition>

Highlights to assist you-

- Contact your local office of a vocational rehab program. Each state has its own laws and regulations, so it's best to contact your local office to find out what is involved in registering with them. Services are free. Some of the services that might be available are: vocational testing, and funding for skills training (tuition, books, transportation, supplies, tools, testing & fees). There may also be help with counseling, guidance and job coaching. Ask questions!
- If you need to locate your local department of vocation rehab, call 211 and ask for that local office phone number; 211 is a "hotline" service that offers information about social services in your community. The call is free and they are open 24/7.

- Below is a list of Web sites that will help you locate main vocational rehab centers. It is wise to view the Web site before making contact with your state Vocational Department. Find out what services they can provide, and what **documentation you must provide** for these services. If your child is over 18 and you are not their legal guardian, your child must sign a permission slip for the counselor, and other rehab representatives, to help you.

<http://bit.ly/2kaQcWFPWSAUSApdf>

<http://askjan.org/cgi-win/TypeQuery.exe?902>

<https://www2.ed.gov/about/contacts/state/index.html>

- When working with a counselor, have a few goals (and priorities) identified, discuss various options with the counselor that **do not include (or access to) food**. Call PWSA (USA) 800-926-4797 for handouts on job environments, educating counselors about PWS, and what works best for people who have PWS in a job or vocational environment.
- Make friends and collaborate with your vocational counselor; they can help in many ways. ■



Adapted from: "Where to go if your child needs a job"
<https://parentingspecialneeds.org> Jan/
Feb 2016

Special Education Support for the Military



November is designated Military Family Month; for service members, the burden of being away from your family is EVERY month if you are in the U.S. Armed Forces.

When we think about members of the armed services who help protect the United States, we often forget the extra burden their service puts on military families who have a child with a disability. This is especially true because of significant differences between civilian and military special education systems. Our partners at Wrightslaw have been at the forefront of advocating for students with disabilities in the military's special education system. In honor of military families, they recently dedicated their e-letter (the *Special Education Advocate*) entirely to this important issue. If you are a military parent, this will be a tremendous resource for you. If not, please share this message so other military families will know about this valuable resource. This is one crucial way we can say thanks to military families for their service to the nation. ■

- Evan Farrar, MA, Family Support Counselor, PWSA (USA)

Click this Wrightslaw Web site link below to read more information to help your family:

<http://campaign.r20.constantcontact.com/render?m=1101518003158&ca=cf3fa04c-3c48-423c-bcad-1d0ec3c1fb27>

Organization News

PWSA (USA) Parent Mentor Workshop

The first Parent Mentor Workshop, was hosted by PWSA (USA) staff Lori Moline and Diane Seely November 18-20, 2017 in Pewaukee, Wisconsin. It was a great success!

Eighteen parent mentors attended, along with guests Carolyn Loker, PWSA (USA) Medical Liaison, Rob Seely (PWSA (USA) Board Member, Volunteer) and Estelle Graves (Michigan Chapter). PWSA (USA) employees included Jackie Mallow (Conference Coordinator), Lori Moline (New Parent Support Specialist), and Diane Seely, (New Parent Support Coordinator). Guest speakers were Dr. Jennifer Miller and Ms. Hannah Stahmer, from the University of Florida.

A welcome reception Friday kicked off the weekend and workshop binders, donated by WD Partners, were distributed – filled with guidelines, handouts, etc.

Saturday was a full day, beginning with introductions, followed by learning sessions. Ms. Stahmer, MS, RD, LD at University of Florida, began with a presentation on dietary management, sharing an approach to maintaining a long-term, healthy diet in PWS, teaching behaviors where food is concerned. Next, Dr. Miller's first presentation was thorough and covered many informative topics including Integrative Listening Therapy, and ended with questions and answers.

PWSA (USA) Executive Director Ken Smith's keynote on the state of the Association following lunch included how we can continue to offer our services to the PWS community.

Ms. Stahmer and Dr. Miller both gave several sessions on various topics and the mentors attending enjoyed the opportunity to ask questions and received answers and helpful feedback. We ended the day with parent mentor Kathryn Lucero. A Certified Integrative Nutrition Health Coach, Kathryn taught us some simple ways to help reduce stress.



Front row L to R: Jackie Mallow, Julie Casey, Tanya Kaminski, Dee Dee Lewis, Diane Seely, Amy Stuckey, Crystal Boser and Tammie Penta. Back Row L to R: Carolyn Loker, Estelle Graves, Katie Bey, Kristi Cole Rickenbach, Jenny Wolkenstorfer. Catt Pudney, Paige Rivard, Kathryn Lucero, Jenny Gibbons, Kenna Grigorov, Bobbi Pogrart, Michelle Torbert, Lori Moline, and Valerie Cirino.

Sunday we watched a video of many newly diagnosed infants and young ones. Diane Seely and Lori Moline followed with presentations on mentor guidelines, duties, parameters, responsibilities and resources available to us all. It was important they understand that they have ALL of the resources at PWSA (USA) to guide the family and help in their specific area of need. And we stressed that they do NOT need to know all of the answers!

A video from Leanne Gilliland at PWSA (USA) on fundraising included how and when to encourage / engage newly diagnosed families to become involved.

Several new parents inquired about becoming more involved in our Parent Mentoring Program, and some agreed to start chapters. Watch for Ms. Stahmer's contributions on our new PWSA (USA) Blog.

After the final question/answer session, the workshop closed with thanks from co-hosts Moline and Seely, to the hardworking committee and volunteers. Many attendees shared positive feedback of this first workshop. *We put our hearts and souls into this program and appreciate hearing from you.* Please continue to share with us. ■

~ **Diane Seely, New Parent Support Coordinator, PWSA (USA)**

Our Parent Mentoring Program

Parent Mentoring at PWSA (USA) has expanded recently with the increasing numbers of families we are helping. As a new parent, or the parent of a child newly diagnosed with PWS, you are eligible for our Parent Mentoring program. Your Parent Mentor is someone who will walk this journey with you, giving information and support needed as your child grows. Parent Mentors are an essential part of our team at PWSA (USA), which includes experienced

professional family support advocates, medical counselors, a residential placement advocate, and a school advocacy expert. The Parent Mentoring Program is led by Lori Moline and Diane Seely. They provide frequent training and updated materials to the Parent Mentor volunteers; there are regional training meetings for our team of 28 mentors. When parents hear the words "Prader-Willi syndrome", it can be devastating. Few parents ever forget the moment their child was first diagnosed.

In the beginning, there is often a period of grieving for the perfect child that was eagerly anticipated, and then perhaps relief knowing that a diagnosis provides a pathway for treatment and health.

Knowing the diagnosis provides a plan for caring for your child. It also means that there is – HOPE – and a strong community that is there for you – to empower, inform, guide and support you. The PWSA (USA) Parent

continued on page 7

Organization News

Parent Mentors, *continued*

Mentoring Program is about making connections with other “veteran” parents. One of the most difficult parts of this journey is reaching out, talking and meeting other families. Each of our Parent Mentors has shared similar experiences; we too have been comforted and nourished by our Parent Mentors.

It begins with a phone call. Once the connection has been made, we prepare a customized *Package of Hope* for you, containing current research material, educational literature, counseling, nutrition, and medical information. Contents are hand-selected by parent mentors focusing on each family’s specific needs, to guide and support them. These compassionate, caring and confidential connections can be a lifeline of HOPE.

PWSA (USA) Parent Mentor staff moderate and supervise three Facebook groups for parents of children by age: birth to three, three to five, and six to twelve. These facilitate communication and a sense of community among newly diagnosed parents, parent mentors and PWSA (USA) Parent Mentoring Program staff. One of the greatest gifts you will receive is the sense of community- the knowledge that you are not alone. The Program includes mentoring to grandparents via a social media connection for them, where they can learn more about PWS and receive support from other grandparents.

Mentors educate and advocate on behalf of PWSA (USA) through the home community, provide up-to-date materials, shared via social media, national conferences and the PWSA (USA) Web site. A subscription to the PWSA (USA) newsletter, *The Gathered View* will be sent to you via email or mail. You will be provided educational webinars, including speakers such as Dr. Jennifer Miller.

We provide parents lines of communication with experts in Prader-Willi syndrome.

The Prader-Willi Syndrome Association (USA), Parent Mentors and the Prader-Willi syndrome community stand together to celebrate every victory, applaud even the smallest of successes and be present when times become challenging. A Prader-Willi syndrome diagnosis will not define your child, nor destroy your family, nor defeat us. It can only STRENGTHEN us! Learn more by clicking on the links at the PWSA (USA) Web site. ■

<http://www.pwsausa.org/family-concerns/>

<http://www.pwsausa.org/parent-mentoring-program/>

To enroll visit our Web site www.pwsausa.org or call: 1-800-926-4797

Lori Moline, New Parent Support Specialist

lmoline@pwsausa.org

Diane Seely, New Parent Support Coordinator

dseely@pwsausa.org



L to R: Lori Moline, Carolyn Loker



L to R: Kenna Grigorov, Kathryn Lucero, Jennifer Miller, MD, Diane Seely

A New Parent Mentor

By Kathryn Lucero

Tears, lots and lots of tears. Grief, anger and sadness. These are just a few emotions a newly diagnosed parent may go through. Once these emotions hit you and you can see past the tears, you go into overdrive, or at least I did. I researched and found resources for my son, I wanted to save him, take it all away and make his life how I had imagined, PERFECT. Looking back on those feelings, although more recent than some, I’ve already taken strides to make Ronan’s life better with the love and support from our Prader-Willi community. Since Ronan’s diagnosis, I became more involved with PWSA (USA). In the past two years I also became an advocate for the Association, and was given an opportunity to become a mentor for other parents going through a similar journey.

This Parent Mentor Program trained us to help parents of a child who is newly diagnosed, or maybe who have recently reached out to PWSA (USA), with someone to walk through their journey. Parent mentors are a shoulder to cry on, a cheerleader, a resource and a friend. We want new parents to know that they have this great community supporting them in their journey.

This workshop was an amazing opportunity for us parent mentors to brainstorm, learn from one another, and bring information back to parents that we’re helping. Questions seen daily on forums were answered and this knowledge shared will arm us, as our children and the children of the parents we mentor, grow. Becoming a parent mentor has been one of the most rewarding things I have done since Ronan was born. I am looking forward to the next parent mentor meeting and watching the program grow. ■

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



On Saturday, October 1st, PWSA (USA) held an *On the Move* walk in Sarasota at JD Hamel Park. Local members of our community walked over the Ringling Bridge to raise awareness and funds. Many thanks to all of those who came out to support the event! Special thanks to *Casting for A Cause* who sponsored the event. ■



Above: Janalee Heinemann PWSA (USA), enjoyed having her grandchildren Noelle and Rocco Tenaglia participating with her at this fun *On the Move* event. Way to go!



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.



PWANY - Prader-Willi Alliance of New York

By Rachel Johnson, Administrative Coordinator, PWANY

Thank you for reading about PWANY. A little about me first; in 2010, I began working with the Prader-Willi Alliance of New York after my daughter Ellie, was diagnosed with PWS. I became active early, serving as board member, then elected vice-president, and president. In a new capacity, I now support PWANY on staff, as their Administrative Coordinator.

The New York chapter was formed in 1990 with the following original board members:

James Bartlett, Volena Rowe, Christina Caudill, Beth Lynch, Lonia Cillo, Harry Persanis, Carol Flick, Henry Singer, Gloria Hanna, Sheldon L. Tarakan, Dr. J. Henry Horbeck and Carolyn Whitlock.

Henry Singer continues to serve on the board.

PWANY works closely with PWSA (USA) and is a chapter in good standing of the national association.

Our chapter vision focuses on wanting all people with Prader-Willi Syndrome living in New York state *to have the hope and support they require through the advocacy of the Prader-Willi Alliance of New York, Inc. (PWANY).*

Our membership and newsletter mailing is approximately 1,000 parents, professionals, and members of the medical community. We also reach out to our community via our Facebook page and a newsletter mailing. We have 310 people with PWS in our database, ranging from infant to 62 years of age. The **Office for People with Developmental Delays (OPWDD)** claims to have 400 in their system, but we should have many more; some may be unidentified in both our systems.

PWANY is actively working with Statewide Public Affairs to create change in NYS legislation currently used to determine eligibility for services from the OPWDD. These services are vital to the well-being of people with Prader-Willi syndrome in NYS. Too many people are being denied services based on IQ and are forced to appeal, sometimes several times, in order

to become eligible. Our hope is to help protect the future generations of children with PWS by advocating for the current law to be re-written to include PWS as an automatically eligible diagnosis. We are making considerable strides in accomplishing this goal and are hopeful that we will see this change happen sooner rather than later. We need the participation of our PWS families in order to ensure success. We need to know if your child was ever denied services, the basis of the denial, did you appeal, were services later granted? **It is of the utmost importance that your story is heard!**

Please share with us by sending an email to: alliance@prader-willi.org or telephone Rachel Johnson at 607-351-3098.

PWANY is working with Statewide Public Affairs to create change in NYS legislation currently used to determine eligibility for services... Our hope is to help protect the future generations of children with PWS

PWANY participates in various social functions, increasing education, awareness, social and fundraising efforts. We host an annual Conference.

This year, our 27th Annual Conference will take place on Friday and Saturday, April 28-29 at the Desmond Hotel in Albany, NY. More information and registration can be found by clicking on our web site link: www.prader-willi.org.

PWANY is fortunate to have Dr. Morris Angulo from Winthrop Hospital serving as our Medical and Scientific Advisor. Dr. Angulo is the Director of Medical Genetics and

Assistant Director of Pediatric Endocrinology at Winthrop University Hospital, and is a nationally recognized specialist in Prader-Willi syndrome with one of the largest numbers of patients in the US.

2016 has been a record-setting year of fundraising, through the Elgarten's Inaugural Golf Tournament, a Guinness World Record Fundraiser, and many donations in memory of loved ones in our community.

There are PWS-specific group homes in New York. Many providers are a part of our organization and attend our conferences regularly.

We are fortunate to have Stacy Ward, PWSA (USA), serve as our Provider Advisor.

Learn more about us and our good works by clicking on the link to our Web site: www.prader-willi.org. ■

What's happening Downunder? PWS News from Australia

Contributed by Georgina Loughnan

(This is a success story on a large scale - being able to coordinate such a huge country and organise a fundamental change for those with PWS is nothing short of fantastic, and all done by those with a passion to make change a reality! Well done our Aussie friends!)

Australia has a population of just over 24 million people spread out over an area of 7.7 million square kilometres (4.8 million sq. miles). Based on the conservative PWS statistics of 1:20,000 live births, there could be 1208 people with PWS in Australia. We are greater in area than people and are geographically divided into 8 regions (states and territories). Australia has had a national PWS association and 3 state associations, but recently met to work towards the amalgamation of all state bodies into the one national association. Together we hope to speak with one stronger united voice, while maintaining regional branches to manage networking and local events!

We have only four paediatric and three adult PWS publicly funded medical clinics throughout Australia, to provide a service for our people with PWS. Over the past 25 years, individuals with a passion to improve the care of people with PWS have come to the fore and developed training programmes for families, educators, employers and caregivers of people with PWS.

About six years ago, Anne Sakaris, a mother of an adult son with PWS, developed a personalised training programme for small groups of support staff, in the state of Tasmania (population of 520,000) where there is no paediatric or adult clinic. She has also encouraged a local Specialist Physician specialising in Internal Medicine, Robyn Wallace, in establishing a Specialist Healthcare for Adults with Intellectual Disability, to provide a holistic service for adults with PWS. Anne's work has greatly improved the awareness and care of people with PWS in Tasmania.

Victoria, another state of Australia

(population 5.9 million), has a highly active PWS community. For the past five years Kate De Josselin, a mother of an adult son with PWS, who has a background in education, training and policy writing, has been the Training Coordinator for PWS Victoria. She has developed seven training workshop modules, edited the Australian (PWS) Medical Alert Booklet (taken from the PWSA (USA) original booklet) and (PWS) Wallet Alert Card. Her training extends to schools, residential and day programme caregivers, government agencies, medical and allied health staff and advocacy groups, in the form of onsite or video conferencing, throughout Victoria.

In September 2013 The Prader-Willi Syndrome Better Living Foundation (PWSBLF), a not-for-profit organization, was established. Their vision is to enable young people and adults living with Prader-Willi syndrome to lead quality and rich lives through supported accommodation, maximised independence and meaningful community engagement. With a commitment to best practice, research, innovation, local and global expert collaborations, the PWSBLF is best positioned to address the existing inadequacies related to housing for adults with PWS. The PWSBLF and the Prader-Willi Syndrome Association of Victoria Inc. are partnering to provide support and solutions to PWS families in accessing housing and support. PWSBLF and PWS Australia (PWSA) recently commissioned Melbourne University to survey the Australian PWS population, analyzing their current needs to determine how these needs will be best serviced by the new Australian National Disability Insurance Scheme (NDIS).

In January 2016 PWSA secured a Capacity Building Grant from NDIS to develop the Web site (pws.org.au) and resource materials for all people involved in the lives of those with PWS.

PWSA has recently teamed up with Fragile X, 15Q Duplication Syndrome and Angelman Syndrome in research conducted by Murdoch Children's Research Institute (Melbourne, Victoria) to develop a newborn bloodspot test for diagnostic purposes. Hopefully, this will lead to earlier and cheaper diagnosis, plus improved targeted interventions.

A Memorandum of Understanding has been finalised between PWSA and

the Foundation for Prader-Willi Research (FPWR) in the USA to enable Australian families to join the FPWR World PWS Registry.

Kathlene Jones, the mother of a young child with PWS living in Victoria, has worked tirelessly over the past 18 months to establish Australia's own research foundation – Prader-Willi Research Foundation of Australia (PWRFA). She has brought together national and international PWS experts to source best-fit practices for Australian research. Negotiation has commenced with PWSA to establish a Memorandum of Understanding outlining responsibilities and collaborative opportunities.

A Health Care forum, coordinated by Kathlene, was held on November 28th in Sydney, New South Wales (NSW) to initiate a review of current Australian PWS services with the view of addressing the needs of all people with PWS and reducing the existing gaps in PWS care and services throughout Australia.

In NSW (population 7,638,200) PWS care is currently provided by two paediatric and one adolescent/adult PWS clinic. PWS training is provided for families, schools, employers, service providers and professionals throughout NSW, by the coordinator of the Royal Prince Alfred Hospital PWS Clinic, Georgina Loughnan.

PWSA has recently been supported by Interaction, a well-established PWS service provider in NSW, in bringing Dr. Janice Forster to Australia for a highly successful lecture tour. This was in conjunction with her Down Under tour of New Zealand and Australia. Interaction is now working on a caregiver training programme to be conducted by Norbert Hoedebeck-Stuntebeck and Hubert Soyer from PPCB in 2017.

The PWS community in Australia is going through a period of increased awareness and boosted morale due to much change occurring within the disability support sector. The enthusiasm and involvement of parents (of both children and adults with PWS), caregivers and professionals is growing. This has been fuelled by good leadership of the PWSA (namely, James O'Brien), active members of PWSA and state associations and the encouragement that resulted from the IPWSO Conference held in Toronto this year.

Resource: <http://ipwso.blogspot.com>

Register to Win an Amazon Gift Card with your Participation– Research on PWS Caregiver Stress

We invite you to participate in a research study on the ‘**Relationship between caring for individuals diagnosed with Prader-Willi syndrome (PWS) and caregiver stress**’. These survey results will provide vital information to caregivers, service providers, and policy makers on strategies and supports needed in the care of individuals with PWS.

This survey will take approximately 30 minutes to complete. Because of your generous feedback and time commitment, all survey participants will, upon completion, have the opportunity to enter a drawing for a chance to receive one of eight \$25 Amazon gift cards. (If you leave the survey without completing it and decide to come back later, you will need to start from the beginning.)

NOTE: To assure anonymity of your responses, at the end of your completed survey, you will be directed to a separate survey form to enter the drawing; this ensures that there is no connection between your survey responses and your contact information.

Study Requirements: To participate, you must:

- be at least 18 years old,
- be a family member of an individual diagnosed with PWS (i.e. parent, step-parent, sibling, grandparent, etc.)
- the individual being cared for is at least four years of age,
- the individual is not living in a supported living environment (i.e. supervised group home or supervised apartment).

By right clicking on the link below and opening it, you are agreeing to participate in this research study.

http://survey.az1.qualtrics.com/SE/?SID=SV_eCEbma2boaBbYTb

This study has been reviewed by The University of Mississippi’s Institutional Review Board (IRB). If you have any questions, concerns, or reports regarding your rights as a participant of research, please contact the IRB at (662) 915-7482 or irb@olemiss.edu.

Thank you,
Michael A. Vice, Doctoral Candidate, Health Behavior and Promotion
Department of Health, Exercise Science and Recreation Management
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 **CHUCKLE CORNER**

Nolan, age 13, attends a special needs school and today was his first day in a new classroom with a new teacher and new kids, so reading through his daily sheet from school I wasn't surprised to hear that he had some challenging behaviors. But I couldn't help laughing when I read that he refused to come in from recess, stating that he "needed to work on his tan". Not sure where that came from, but considering that he is as pasty white as can be, I found that hilarious. That's my boy.

~ Jennifer Kryzak
Cedarburg, Wisconsin

Want to Share YOUR Story?

PWSA (USA) is accepting stories and pictures of your child/adult with PWS for use in the "From the Home Front". Individuals of all ages, both genders, and all ethnic backgrounds are welcomed.

We have professional writers available to assist you in crafting your story. For consideration or questions, please email us at pwsaeditor@pwsausa.org. We'd love to hear from you!

Photos should be a MINIMUM of 1000 pixels high OR wide, in a JPG format. Simply email your stories and photos to pwsaeditor@pwsausa.org. We can't wait to hear from you! ■



WE REMEMBER

Edward Scott Brady, 61, of Willow Street, Pennsylvania, died on August 23, 2016, at Lancaster General Hospital, Lancaster, PA after a brief illness.

Scott, known to his friends in the Lancaster area as “Scooter,” worked for Goodwill Industries before retiring several years ago. Prior to moving to Willow Street, he was employed at Human Resources Center, Honesdale. Scott’s love of animals inspired him to volunteer for many years at the Dessin Animal



Shelter, Honesdale.

Born December 29, 1954 in Staten Island, New York, Scott was diagnosed with PWS while in his early 20s. Working with the Prader-Willi Association of Pennsylvania, Scott’s parents, the late Edward Henry

and Regina Brady, were instrumental in starting the Byerland Church Residential Facility, Willow Street, which specializes in the care of adults with PWS. Operated by Community Services Group, Inc., this home provided Scott loving care and support specific to his unique needs for nearly 30 years. The family is forever grateful to the caring staff, both past and present, who became like family not only to Scott but to them as well.

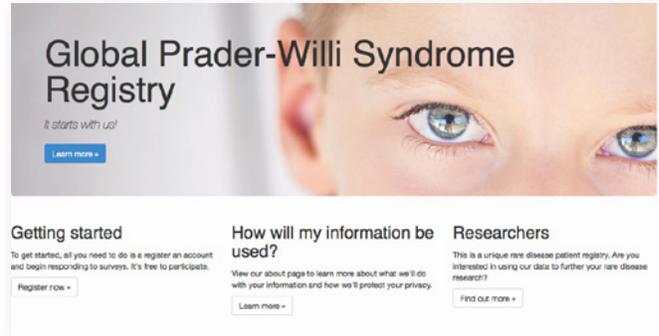
Scott had a very busy social calendar with many activities that he enjoyed. He was a Special Olympics bowler and regularly attended Happy Hearts Senior Center where he formed many friendships. He was a warm and affectionate person who was beloved by all who knew him.

Memorial remembrances in tribute to Scott can be mailed to Prader-Willi Syndrome Association (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238; or online at www.pwsausa.org. ■

Every Person Matters

Register Now

Global Prader-Willi Syndrome Registry



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

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

The Global PWS Registry is a secure database compliant with U.S. Health Information privacy laws and FDA regulations. To create the most robust PWS registry possible, every person with PWS should be included in the registry. Through a series of electronic surveys, the registry collects information on a wide range of topics including developmental history, medical complications, and quality of life issues.

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



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.” 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. The PWSA (USA) CFC ID # is 10088 ■

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



SAVE THE DATE
FRIDAY | MARCH 24 | 2017
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For more info, ordering tickets, please click the link below:
<http://bit.ly/2igKTUYClintHurdleHotStove4PWSAUSA>



THANK YOU to all of our “Angels” that made the 2016 Angel Drive an outstanding success! Nearly **870** donors contributed over **\$231,000** to our 19th annual Angel Drive. This is an increase of \$100,000 over the past three years. Your amazing support will ensure all families receive the research, family, crisis, medical, school and educational support they need in 2017. We are so grateful to be able to serve our community because of loyal and generous supporters like you. A special thank you goes to a small circle of major donors who provided funding to match donations to the Angel Drive. We look forward to another wonderful year ahead! ■

e-News...

Reminder – stay informed and current with PWSA (USA)’s free e-News. Sign up by clicking on our Web site: www.pwsausa.org and watch for the next update!



How often do you shop online? Register PWSA (USA) as your charity of choice when shopping on Amazon! Amazon will donate 0.5% of the price of your eligible **AmazonSmile** purchases to Prader-Willi Syndrome Association (USA) whenever you shop on AmazonSmile.

Go to <https://smile.amazon.com/ch/41-1306908> and get started. ■



My Story – on my rare condition called Prader- Willi Syndrome.

By *Shea Velestuk*

*Thanks to Bryce Schaufelberger,
President, Mission Self Advocacy Group,
Abbotsford, BC, Canada for sharing her
story.*

Hi! My name is **Shea Velestuk**. When I was a baby I was floppy and low muscle toned and then I got tested for this rare condition PWS – Prader-Willi syndrome, and it came back negative.

When I moved to Mission, British Columbia, I was overweight and we didn't know why, so we went to the doctor and asked to get my blood tested again to see if I have this condition; and at 17, I was diagnosed with PWS.

PWS is a genetic disorder that occurs in approximately one out of every 15,000 births. PWS affects males and females equally and affects all races and ethnicities. PWS is recognized as a common genetic cause of childhood obesity.

The common characteristics defined include small hands and feet, abnormal growth, small in height, very low lean body mass and early onset childhood obesity. Also muscle tension that makes it hard to stretch muscles and feeling hungry all the time, this creates extreme obesity and intellectual disability. Symptoms of Prader-Willi syndrome are believed to be caused by a region of the brain called the hypothalamus not working properly. The hypothalamus, small and at the base of the brain, plays a crucial role in many bodily functions, including hunger and feeling full, temperature and pain regulation, fluid balance, puberty, emotions, and fertility. Doctors are not really sure how the genetic problem with PWS causes the problems with the brain.

In addition to obesity, a variety of other symptoms can be associated with Prader-Willi syndrome. Individuals usually exhibit cognitive challenges with measured IQs ranging from low normal to moderate mental retardation. Those with normal IQs usually have learning disabilities. Other issues may include speech and speaking, short stature, small hands and feet, scoliosis (curved spine), sleep disturbances with excessive daytime sleepiness, undescended testicles in males, high pain threshold, and infertility. Behavioral difficulties may include Obsessive Compulsive Disorder, symptoms of skin picking, and difficulty controlling emotions. PWS is a spectrum disorder and symptoms vary in severity and occurrence among individuals.

Infants with PWS are hypotonic or “floppy”, with very low muscle tone. Weak cry and a poor suck reflex are typical. Babies with PWS usually are unable to breastfeed and frequently require tube feeding. These infants may suffer from “failure to thrive” if feeding difficulties are not carefully monitored and treated. As these children grow older, strength and muscle tone generally improve. Motor milestones are achieved, but are usually delayed. This is called Stage 1 of PWS.

Around age 2 and 6 years old, children with PWS are not able to control how much food they eat each day and their body does not process the food like normal people so they need to be monitored because if left untreated it will lead to morbid obesity and its many complications. This is called Stage 2 of PWS. In adolescence there is also delayed puberty.

For me and other adults and children it takes a long time for us to lose weight and all the time we sneak food because we're never full.

My childhood has been a battle with PWS and I will have this battle for the rest of my life. It's hard because the fridge and cupboards have to be locked at all times otherwise we can eat ourselves to death because our stomachs do not tell the brain that we are full.

I hope you have been able to learn something about PWS from me sharing my story! ■

<https://missionlocals.wordpress.com/>
<http://selfadvocatenet.com/>



SAVE THE DATE! November 15-18, 2017

As we plan for the upcoming convention, make your plans to be a part of this community of professionals, providers, families and colleagues who collaborate, learn, and build a strong corps of people known as the PWSA (USA) family.

Prader-Willi Syndrome Association (USA)

34th National Convention
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**Deadlines to
 submit items
 to The
 Gathered View:
 Dec. 1; Feb. 1;
 Apr. 1; June 1;
 Aug. 1; Oct. 1**

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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Access our Web site: www.pwsausa.org for **downloadable publications, current news, research, and more.**

The Members Only section requires a password: member20

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

The Gathered View (ISSN 10 77-9965)

- Sara Dwyer, Editor
- Lota Mitchell
- Andrea Glass
- Denise Servais
- Kathryn Lucero

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Medical information published in *The Gathered View* is not a substitute for individual care by a licensed medical professional.

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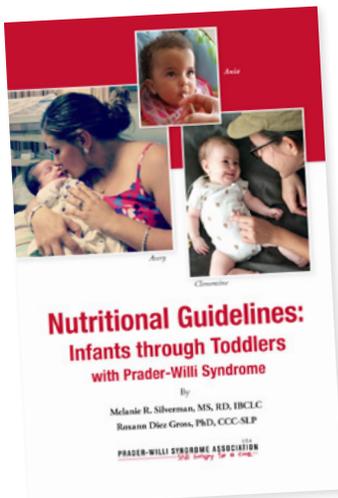
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Learn more about saving and transforming
 lives at <http://www.pwsausa.org/>



New Publication on Nutrition Care for Infants and Toddlers!

The newest publication published by PWSA (USA) will be a great reference for anyone with questions or desire to learn more about the nutritional care of our youngest children with PWS!

Written by Melanie R. Silverman, MS, RD, IBCLC and Roxann Diez Gross, PhD, CCC-SLP, this booklet is presented in chapters by age group. Read answers to many questions on growth and feeding, food security, meal planning, and includes guidelines, new data and growth standard charts. This fact-filled book, highlighted with photos of our young ones with PWS, is available for purchase (\$7.50) through the PWSA (USA) Web site. ■



Third Annual Hot Stove Banquet with Clint Hurdle

Don't miss this great event with all proceeds benefitting PWSA (USA). See page 13 for details.

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