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

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

Chairman's Message *By Jim Kane, Chair, PWSA (USA) Board of Directors*

Engagement Drives Progress

Your engagement can make a meaningful positive impact and your voice is important to the association.

Caring people just like you started PWSA (USA) over 40 years ago, and we continue to be at our core a grass-roots organization. We are made up of people with both passion and purpose. You and your ***ENGAGEMENT*** in our PWS family are our most powerful tool to ***Save and Transform Lives***.

Over the years, it was always involved members of the PWS community driving our organization forward. These engaged folks brought PWSA (USA) along from a very small entity to one that now provides programs and services addressing all of our Five Pillars of Support: Awareness, Family Support, Research, Education, and Advocacy.

Throughout our family's involvement in PWSA (USA) over the past 30 years, we have benefited many times from our contacts in the association. From the first diagnosis to early medical advice to support with school IEPs to assistance in navigating behavior issues and medication adjustment and finally to locating an appropriate residential care placement, the people of PWSA (USA) were there for us every step of the way. We met them, they befriended us and we became engaged in the family. Our ***ENGAGEMENT*** literally saved our daughter, Kate, and our family.

After being involved with our association for well over 30 years, I am honored and humbled to now serve as your chair of the board. With the other directors, legions of volunteers, and dedicated staff, we are working to improve the lives of those affected by PWS, but we can do more good with your ***ENGAGEMENT*** and help.

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From The Home Front

How did we get here?

"Difficult roads often lead to beautiful destinations."

By Andrea Warren

Honestly, I've struggled to write this because we are not a remarkable family; our journey just happens to be unusual. Sometimes, and especially this summer, I almost feel guilty that my children are doing okay. How crazy is that?

This is our family: Bob and I have been married 24 years and have four children. Our three biological sons are Robbie (23), Sam (18), Taylor (14, with PWS). Our daughter, Lizzie (9, with PWS) joined our family through adoption.

Our journey with PWS started as most do, with what we thought was a typical pregnancy. However, it was my eighth pregnancy (five had ended in miscarriage). The fact that I was able to carry our third son to term seemed like a miracle in itself. Shortly after Taylor's birth, the doctors knew something wasn't right. Three weeks later, we left the NICU with a g-tube and a diagnosis of Prader-Willi syndrome. We were devastated and envisioned some tiny creature who ran around stealing food from people's plates after reading information we found on the Internet. Fortunately, that hasn't exactly been the case.

We quickly got connected with our state chapter and I was assigned a mentor who is one of my dearest friends today. We found hope and support from PWSA (USA). And we got to know a sweet, loving, little boy who filled our lives with therapies, doctor appointments, new priorities, and lots of smiles and hugs.



The Warren family

This new life wasn't easy: Balancing the intense needs of this new baby with two energetic boys, navigating government agencies, finding new doctors and endless appointments. We survived the first year and life slowly got easier. Feeling like our family wasn't quite complete but suspecting we were working with a murky gene pool, we

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Chairman's Message, *continued from page 1*

Your ***ENGAGEMENT*** can take many different forms, and making a meaningful positive impact doesn't have to take a large amount of time. Each opportunity below generates progress for our cause and personal satisfaction that comes from contributing to our mission. Please consider:

✔ Being involved in your state or regional chapter – they're delivering support and bringing community members together near your home;

✔ Becoming a PWSA (USA) public policy advocate – it is easy, online at https://p2a.co/KglyyNs, takes only 1-2 minutes and allows you to help change laws and regulations critical to our families;

✔ Attending our webinars and purchasing educational and logo materials from our store – sharing educational materials and enhancing awareness are things we all can do;

✔ Participating in upcoming surveys – please take just a couple of minutes to tell us more about your needs, communications and information preferences, your ideas, and more, and participating clinical trials;

✔ Supporting or hosting a fundraiser – every one of these, whatever the size, greatly helps the cause, and Rikka Bos and other staff and volunteers will make it easy for you; and

✔ Joining a committee or a task force attacking key issues and events – volunteers are the lifeblood of our group, so just let me know if you're interested.

A broad base of involved volunteers is vital because we serve a diverse population, and because our staff, volunteers, board members, and families are separated by time zones and geography. Your voice in the PWSA (USA) community is important, as it serves as a megaphone for the stakeholder groups we represent.

Becoming engaged in the PWS family is a real opportunity to help your family maximize its benefits from PWSA (USA), to serve individuals with PWS and their families, and to further our mission to ***Save and Transform Lives***.

Please be assured that I personally will work for the entire PWS community to:

- Create optimal ***ENGAGEMENT*** opportunities
- Strengthen the network of relationships
- Maximize our stakeholders' experience
- Ensure positive impacts for all

We appreciate your ***ENGAGEMENT*** in the PWSA (USA) family and are grateful for your continued support ***Saving and Transforming Lives Together***. Jim Kane, Chair, **Jkane@pwsausa.com** ■

The Home Front, *continued from page 1*

decided if we were going to add a girl to our family, we would have to go find her. This was before Facebook groups, but through our Google support groups, we knew there were several babies with PWS who needed forever homes. It took nine long months to complete our home study and by that point all the available babies had been matched with families. We considered adopting a child with a different disability but decided it would be best to stick with what we knew. Almost a year after we started the process, Lizzie's information was shared within a support group. Four months later, we were matched with her. Seven months later we brought her home and, in Bob's words, "pink took over our home like Kudzu!" It would take another year before she was officially a Warren.

Before adopting, a friend told me the line between sainthood and crazy is a fine line. We are definitely not saints and most of our days are lived in the crazy: Double the doctor/therapy appointments, double the IEPs, double the anxiety and questions, double the battle for growth hormones and services. We felt as a family we were supposed to do this, mostly because of our faith. We felt we were at a place we could welcome with joy a child with PWS and know that it was not the end of the world.



Taylor is the world's biggest sports fan, loves unconditionally, has a great sense of humor, and is a real-life version of Buddy the Elf. He is our family cheerleader. Lizzie is as girly as they come, and loves everyone. She asks a lot of questions and is very expressive. Nobody said having a child with a disability would be easy, and having two, doubles the challenges at times. This was not a journey we would have initially chosen for our family, but one we chose to embrace and find the best in it. We love our family and wouldn't trade any of them for the world.

P.S. Our son Sam, who graduated from high school this year, writes for an online magazine, *Odyssey*. Read what he wrote about his brother, Taylor. http://bit.ly/2vPv8rSOdyssey_Sam_PWS ■

The Over-Looked Sibling:

Increasing Awareness and Support for Siblings of Individuals with PWS

By Stefanie Varga Ph.D. LP, Clinical Neuropsychologist

Part one of a two-part series



In the United States, we have been fortunate to benefit from a range of societal and legislative changes that make the lives of individuals with special needs or disabilities and their families more comfortable than several decades ago. Families of individuals with special needs continue to gain attention in the media and benefit from increased support through the schools and their communities. As parents of children with PWS, we can feel confident that our need for accommodations across a range of settings will be met with some degree of acceptance, and we are grateful to be living in a less restrictive and more accessible environment for individuals with special needs.

The siblings of individuals with PWS play integral roles in the lives of their families over the course of a lifetime, yet their experiences and challenges continue to be relatively neglected. To have a sibling with special needs is a reality many children never choose - they are simply born into it. In my practice as a child psychologist, I often witness the over-looked needs of siblings. While parents seem to have some appreciation that their non-identified child may be experiencing some degree of increased stress or difficulties with adjustment, their understanding as to how to address these issues is limited. The weight of parents, medical providers, and institutional concerns tend to focus on the child with special needs.

While the advantages to having a brother or sister with special needs or a disability are numerous, better understanding the common challenges seems critical if we are to offer support to families of children with special needs as a whole. I see that my children are more empathetic, more responsible and even resilient in comparison to their same-age peers, but I also often witness their quiet and private moments of confusion, disappointment, sadness and frustration in coping with a sibling with special needs. Some of the experiences my own children face, as do many siblings of individuals with PWS, are outlined listed below, followed by some family and parenting tips.

1. A different experience of family and togetherness. Most children understand "family" to mean spending time together; however, the quality of family time with a sibling with PWS can involve various challenges. Families may spend more time apart. One parent may be assigned to the sibling, while the other attends appointments the child with PWS. Both parents may not always be able to attend special events or go places for various reasons related to their special needs child. There are often more therapy and medical appointments for the child with PWS, and for some, physical barriers to access. For the family with a child with PWS, some of the most prominent issues tend to be around food and diet, leading to increased stress for other family members. Given that individuals with PWS have special diets and food related issues, siblings may face emotional stress around access to food, differing meal schedules and problems during family meals. Access to food in the house may be restricted, and siblings may not have access to certain dining experiences. Birthday parties and eating in restaurants may become highly stressful or over-controlled events. Traveling and vacations may become more stressful. Non-relative support persons (caregivers that are not related) such as in-home aides, therapists or other professionals may be present at family events, changing the family dynamic. Siblings may find themselves seeking refuge at school or friends' homes to escape the stress of "family."

2. Trouble sharing feelings. Some siblings may feel embarrassed about their siblings or may even feel sad, resentful or even angry watching the time that their parents dedicate to their brother or sister with PWS. Negative comments about their brother or sister are typically not tolerated. Acceptance and forgiveness for their siblings' behaviors tends to be heavily encouraged or emphasized in families. Siblings may feel that they are not allowed to openly share their feelings, particularly their negative emotions, let alone complain, for fear of looking selfish or insensitive.

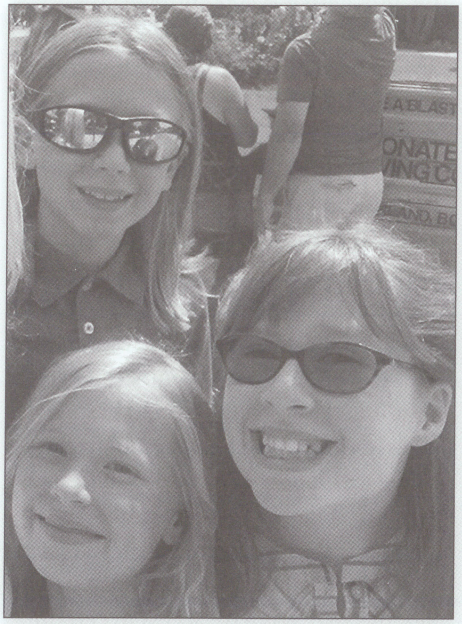
3. Pressure to be better, stronger, or perfect. Siblings of individuals with PWS continually witness their parent's struggles to meet the needs of the special needs child. Many also witness the parent's emotional suffering and can

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Sibling, *continued from page 3*

feel helpless or afraid about the impact to them personally, and the family. Many siblings feel like they can't bring their own struggles or stress to the table, for fear they will overwhelm the parent or family unit. Some children may feel like they need to be better than their sibling, or even perfect, to make up for the challenges of the sibling with PWS. At times, they may feel like no matter how great their achievements or behavior, it is never enough. What are the standards for behavior for the sibling of a child with special needs or disability? This typically differs for each family, but commonly siblings may feel that their achievements do not matter or that their achievements mean everything.

4. Feeling as though their problems are not important. Many siblings with PWS have serious medical issues that take up an inordinate amount of a parent's or family's time. There may be life-threatening problems. The issues of a typically developing sibling may seem minor or less important in comparison to the child with PWS. Parents may encourage siblings to be tough or remind them to be thankful that their issues are not as serious. Siblings may feel that their problems are being over-looked. In some cases, this may lead children to choose to simply take care of themselves or convince themselves that they do not need parent attention. Others (specifically younger children who do not have advanced verbal skills) may begin acting out or finding negative ways to get attention.



5. Feeling isolated. I have witnessed this one repeatedly in my youngest daughter, noting her complaints of feeling lonely and isolated given that her sister is not a typical playmate. Children with PWS, particular those with autism spectrum behaviors, tend to prefer solitary play, may have repetitive or obsessive interests, or do not share or cooperate with siblings in the same ways. Children with PWS tend to have developmental delays, so that the typical child (even though younger) has more advanced skills and different play interests. Siblings may fear scrutiny and judgment by their friends or peers, or experience fear or frustration when questioned about their brothers or sisters with PWS. Some may feel self-conscious and confused as to how to explain their sibling's issues to their friends. Understanding sibling concerns and helping them to know how to answer questions by their peers or even other adults is critical. Siblings may feel uncomfortable inviting friends over for fear of extreme reactions or behavioral problems in their sibling (and judgment by peers). If their sibling is not accepted, they may feel disappointment and rejection. My youngest daughter has expressed concern when her sister is not invited to a party, or gathering. This can be hurtful if the child desires to share certain experiences with their sibling. How is a sibling to appropriately deal with unkind comments and questions? This is something that siblings are never formally taught, but learn the hard way - through experience. Early understanding of societal intolerance, and even hate, can change the way children view the world, leading to feelings of cynicism or resentment.

6. Always needing to help. The burden of needing to care for a sibling with special needs is a common issue. Again, it is a skill that is never taught. Some typically developing children are expected to help care for their sibling with special needs even when that sibling is older. My youngest daughter often pays special attention to her sister's diet or other compulsive behaviors. She often worries and feels the need to inform her parent of possibly concerning behaviors. She worries about her sister at school and whether she is accepted. At other times, a child may fantasize that the sibling problem will disappear. Other children who cannot tolerate the stress may ignore their sibling with PWS or become rejecting. The emotional toll of a child to care for their sibling, especially one with special needs, can be heavy. My oldest and youngest have learned from experience how to calm their sister, and at times are more skilled than adults in handling behaviors. Some siblings may need, or become experienced in deescalating serious situations or will assist and even take over for a parent who becomes overwhelmed or frustrated. The pressures on the typical child in such situations often go unnoticed. Older siblings may experience "parentification" where they are expected to have many responsibilities for themselves and their sibling, having duties similar to those of a parent. Such children may grow up too quickly and miss out on being able to fully experience their own childhoods. The increased responsibility may be regarded by the parent as a positive, but is often silently contributing to emotional distress in the sibling.

Given that increased support and services for the sibling of a child with PWS are needed, a few recommended strategies for addressing some of the issues above will be outlined in the second part of this series in the next issue. ■

Puberty Hormones

By Kathy Clark, R.N., M.S.N., B.C.-C.S., Coordinator of Medical Affairs, PWSA (USA)

Puberty has such a bad reputation and hormones are blamed for the challenging behaviors we see in adolescence. Some typical teen issues, like poor impulse control and bad choices, are the product of prefrontal cortex (brain) development, and not because of hormones at all.

"Hormones" in puberty refers to testosterone (male) or estrogen (female). Both genders make both hormones, but in different proportions. Testosterone has many positive effects, such as a growth spurt, increased muscle size and strength, bone strength, a sense of well-being, genital growth, increased energy - but also acne, body hair, and perhaps aggression. Estrogen also prompts a growth spurt, breast development and is very important for bone quality, but also prompts some moodiness, and eventually menstrual periods.

Without puberty hormones, bone strength and bone quality will not be normal. Complete lack of estrogen will create bones that may fracture easily and vertebrae that may compress. For boys, testosterone is naturally converted to estrogen – leading to stronger bones. Estrogen is the strong bone sex hormone.

To produce sex hormones, the preteen pituitary gland begins sending signals to the gonad (ovaries or testes). Gonads have two jobs, both under the control of this system. The easier job is to make hormones. The harder job is to make sperm cells or to mature an egg – which helps explain why people with PWS are almost never fertile, and yet many of them will have some natural puberty. To make the situation a bit more confusing, the early underarm or pubic hair often seen in PWS isn't from true (pituitary-gonad) puberty. It comes from adrenal gland hormones. This is a different system, sometimes called "adrenarche" and it is not real puberty.

For boys with PWS, puberty and fertility are complicated. Undescended testes don't work optimally even if a great surgeon moves them into the right spot. There are no such issues for girls with PWS, so they are more likely to have ovaries that will make hormones. But for both boys and girls, the main problem isn't typically the gonad (testis or ovary). The hormones are low because of dysfunction of the hypothalamus, which in turn controls the function of the pituitary gland – and the pituitary gland controls the gonads.

...all parents want good health for their children, and sex hormones are part of the recipe of a balanced body, especially strong bones."

Few women will claim to enjoy the experience of menstrual periods, and many parents want to spare their daughters this burden. Estrogen causes growth of the uterus and the lining of the uterus, but in 2018, periods can be controlled or eliminated. When doctors prescribe estrogen supplements, it is often as a "birth control pill" or OCP (Oral Contraceptive Pills). OCPs today come in very low doses. There are also estradiol patches, but these could tempt picking behavior.

Estrogen or an OCP does not increase fertility or help an ovum mature – that is under the control of pituitary pulses. Having periods because of taking estrogen pills does not increase the possibility of pregnancy – remember, these are also called "birth control pills." Taking estrogen will not make the hypothalamus and pituitary work which is how eggs get developed.

For boys with communication or developmental challenges, the worry about puberty is related to fears of aggression and worse behavior in puberty. In the past, the only way to give testosterone supplements was by monthly intramuscular injections – which meant 28 days of worry and no opportunity to take away the medication if problems began. Now there are many options, with much lower doses and methods which shorten the action of the hormone. Testosterone shots can be given subcutaneously at home, once per week, in much lower doses. Patches can be worn on the skin, with some younger teens wearing these only overnight, reducing the amount of absorption and avoiding daytime picking at the patch. A topical gel could be applied but with great caution to avoid transferring the invisible gel to other family members. Gel comes in a pump or foil packets, with a range of strengths and doses available. These treatments do not treat infertility or allow the body to develop sperm. They can allow normal adult development and function.

Adding sex hormones is a complicated decision to discuss with your endocrinology provider. While few parents celebrate puberty – all parents want good health for their children, and sex hormones are part of the recipe of a balanced body, especially strong bones.

More great information about puberty and these hormones is at hormones.org. Look at our website under Medical A-Z – Puberty - for sex education materials for teens with developmental delays, in English and Spanish. ■

Approved by Susan Myers, M.D., Clinical Advisory Board

There is nothing better than the encouragement of a good friend.

- Katharine Butler Hathaway

Blood Drawing Tips and Tricks for Prader-Willi syndrome

Does anyone enjoy a blood test? Yes! Some individuals with PWS really enjoy anything to do with visiting the doctor, including being examined, getting shots and blood tests. It can be technically difficult to get blood from a person with PWS. Low muscle tone and increased fat under the skin (even in slender people) may make finding the vein more difficult for the phlebotomist. Growth hormone deficiency seems to affect vein growth, and some children will develop bigger veins after they begin growth hormone therapy.

Early experiences are vital to setting a positive tone. Remember that fear rather than pain is the issue with most needle situations. An adult helper with strong negative feelings about needles or blood tests may not be the best coach for this situation. Since persons with PWS do not enjoy surprises or changes to routines and can worry if given too much information in advance, parents need to consider the perfect balance of information and timing before a visit.

Distraction is a helpful technique, but don't be surprised by children who want to watch the needle; many children find this essential to coping. Toys, music, soothing voices all help tremendously. If your child benefits from rewards, plan something small, like a sticker, for after the poke is finished. If your phlebotomist does a terrific job, be sure to remember their name and ask for them the next time you come.

Many pediatric settings have "poke programs" in place, and parents should ask about the latest options. Health care professionals also want a positive experience for your loved one and may have creative ideas. ■

Tips for a better blood draw:

1. Arrive well hydrated. A long car ride and very little to drink means that the veins will be flatter than normal and hard to enter.
2. Dress in clothing that allows easy access to the blood drawing area.
3. In cold weather, bundle up and make sure the arms are warm before the blood draw. Some people benefit from using a warming pack.
4. Alert the staff if there have been previous bad blood drawing experiences to request their most skilled and patient technologist. Two attempts per person should be the maximum allowed.
5. Request that the tourniquet be placed over clothing, not directly on the skin, where it can pinch and cause more pain than the needle itself.
6. There are a variety of topical (rubbed on the skin) numbing creams. These must be placed in advance and require a prescription but may be available in the blood drawing lab. While these products numb the skin, they do not a prevent a person from being scared. They can take up to 30 minutes to be effective, so they are not for everyone.
7. Ask about Buzzy Bee, a vibration device that is a proven interceptor of needle pain. Buzzy is a distraction as well as pain disruptor.
8. There are a variety of "vein finders" which are placed on the skin. You are most likely to see these in the NICU or hospital setting.
9. While sugar is avoided in the PWS diet, neonatal research supports the effectiveness of a tiny drop of sugar water (sucrose) for pain control in new babies. This may be available in the blood drawing lab. There is no evidence that this helps children older than a few months.

Back to School...

See page 13 for publications for education professionals.

CFC® Combined Federal Campaign *Approved Charity*

Federal Employees! The Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all."

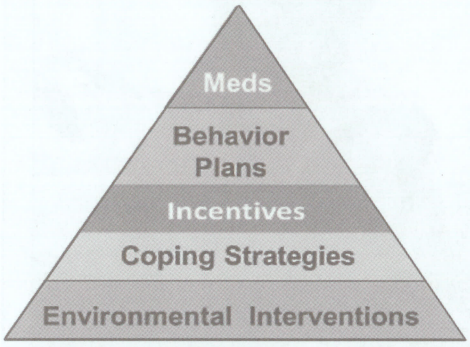
PWSA (USA) CFC ID # is 10088

Click or visit http://www.opm.gov/cfc/index.asp to learn more

Mental Health and Behavior Changes – When should parents seek help?

By Kathy Clark, R.N., M.S.N., B.C.-C.S., Coordinator of Medical Affairs, PWSA (USA)

The possibility of psychiatric illness increases as typical teens approach adulthood, and this is also true for individuals with PWS. Behavior patterns in PWS are quite unique to the syndrome. It may be hard for parents to sort out what is a mental health "problem" from what is "just PWS." Undiagnosed medical problems can also cause behavior changes. Not every new behavior signals a psychiatric diagnosis, but all new problematic behaviors should be evaluated by a physician.



PWS Intervention Pyramid

Making the environment solid is the first step when behaviors escalate. Extensive information on intervention pyramid has been developed by PWS experts Drs. Jan Forster and Linda Gourash and is available on our website or by speaking with the crisis counselors at PWSA (USA).

Even with structured behavior plans and a well-managed environment, some individuals may benefit from short-term or long-term medications. There is not a specific medication to treat problem behaviors or psychiatric illness for persons with PWS. Having a psychiatric diagnosis is important in choosing the right medication.

PWSA (USA) has resources for psychiatrists which includes the advice to start with the lowest dose and raise doses or add additional medications with caution. **Psychiatrists can call PWSA (USA) and request printed information or a consultation with an expert member of our Clinical Advisory Board.** ■

These symptoms should prompt an urgent (within days) psychiatric evaluation:

- Change in personal hygiene and self-care - not bathing or getting dressed
- Unable to sleep at night, or significant increase in sleeping during the day
- Weight loss or complaints about being unable to eat or swallow (medical evaluation first)
- Hearing voices, seeing things that are not there, or expressing odd beliefs
- Sitting quietly in a chair for hours or refusing to get out of bed
- **Concerns about possible abuse are urgent and should be given immediate attention. Traumatized people may act out and be unable to describe their experiences.**

PWS Awareness for NICU Advanced Practice Nurses at National Conference

By Kathy Clark, R.N., M.S.N., CS-BC, Coordinator of Medical Affairs, PWSA (USA)

With over 400 NICU nurses gathered, PWSA (USA) attended the Academy of Neonatal Nursing (ANN) Advanced Practice Neonatal Nurses national conference in Portland, Oregon, May 3-5, 2018.

The PWSA (USA) awareness booth at the conference stayed busy. Our NICU booklet, currently on-line, was created specifically for this meeting, as a half-size printed booklet, to demonstrate that resource. Nurses were urged to send and/or direct newly diagnosed parents to us, to obtain the *Package of Hope*, plus other resources we provide. I was able to share and describe the support, education, and research that is possible for babies born today.

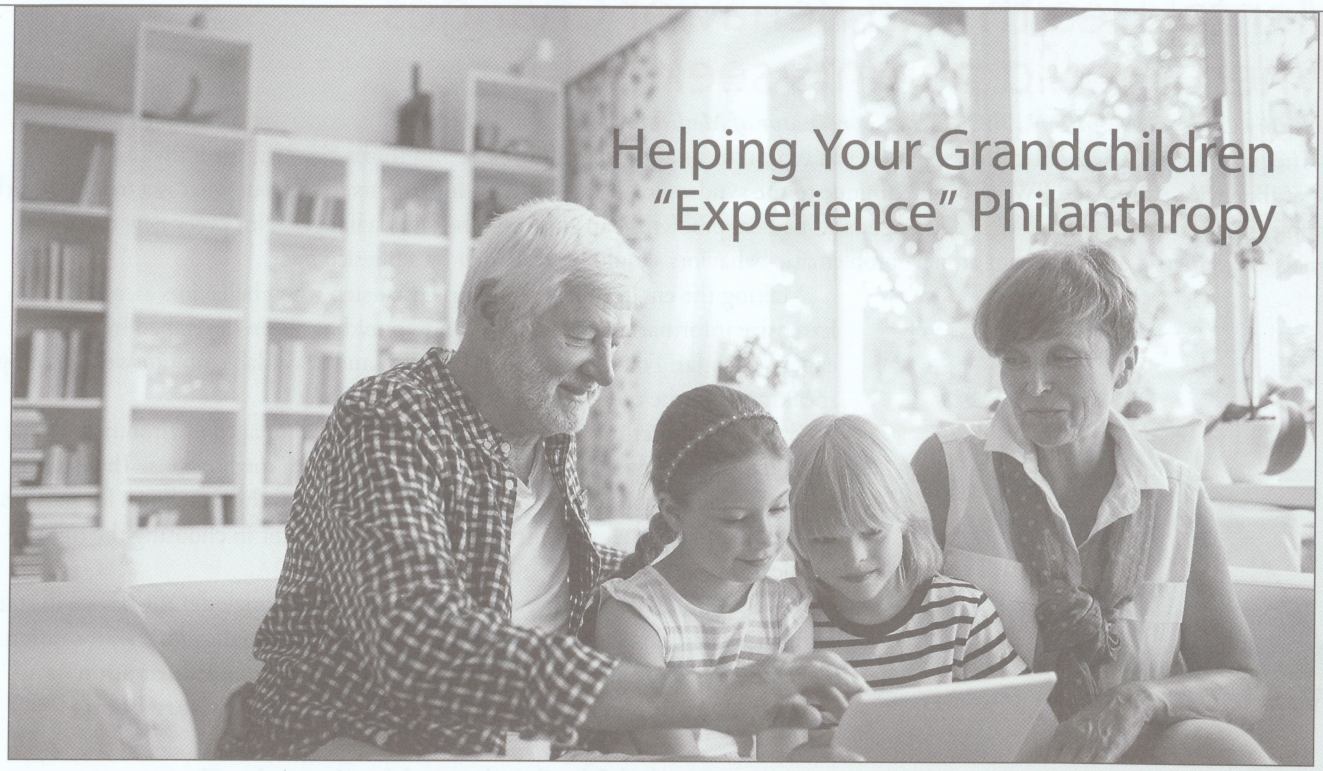
Not surprising, attendees also approached me to speak about older persons with PWS. I was happy to guide them to support resources specifically for adults with PWS and their caregivers.

Online materials for parents of newly diagnosed:
https://pwsausa.org/wp-content/uploads/2015/10/NICU-when-your-baby-is-in-the-hospital-12-2013.pdf

En español:
https://www.pwsausa.org/wp-content/uploads/2018/03/NICU-spanish.pdf

For grandparents:
https://www.pwsausa.org/prader-willi-diagnosis-grandparent/

Also, visit our online store for resources for adults with PWS. ■



Helping Your Grandchildren "Experience" Philanthropy

How often do you hear that today's generation of children are self-absorbed or one of entitlement? That's a pretty harsh statement to make, and one that I don't entirely agree with. I think kids today don't just want things – they want experiences too!

Children see the needs of the world everyday on the news – earthquakes, floods, fires. They see that we have resources to step in and assist those who are suffering. Children simply want to be involved bringing help to those in need: they want the experience of helping others.

Grandparents can have an important role in sharing the "experience of philanthropy" with their grandchildren. Grandparents: Teach your grandchildren by modeling charitable behavior. Your efforts will help drive home the idea that volunteering and "giving back" are invaluable ways to be part of a community. Take time to explain why the causes you are passionate about are meaningful to you (and encourage them to share causes and ideas they are passionate about too!). Don't forget to give examples of how your actions will help others not just today, but in the days, months, and years to come.

Your willingness to share the "experience of philanthropy" with your grandchildren is a gift of yourself that will last a lifetime. You'll also be empowering a generation of children with the knowledge that they too can help others in a profound way.

Here are a few suggestions to help you share the "experience of philanthropy" with your grandchildren:

■ Going on a vacation? Consider a "volunteer vacation," and travel with purpose! Google it for the endless list of options.

■ Did you know that volunteering lowers blood pressure? It's true! Studies have also shown doing good for others boosts self-esteem and makes **YOU** happy. Make it a family tradition to commit to one big family fundraiser a year. Involve your grandchildren in the event.

■ Take your grandchildren with you the next time you volunteer:

■ Read books with your grandchildren, such as:

- *Make a Stand: When life gives you lemons, change the world!* By Vivienne Harr
- *Boxes for Katje* by Candance Fleming
- *Sophie's Lovely Locks* by Erica Pelton Villnave

■ Adopt a family/Secret Santa for Christmas

■ Create a Facebook Fundraiser to "donate" your birthday or other special day to PWSA (USA)

■ The possibilities to share the experience of philanthropy with your grandchildren are endless. Ask your grandchildren for their great ideas. ■

Submitted by Diane Seely, PWSA (USA) Parent Support Coordinator. This article and other free resources are provided by donations to PWSA (USA) Family Support.

Chapter Spotlight - Alabama

By Brittnee Peterson, Prader-Willi Alabama Chapter

During the 2017 PWSA (USA) National Convention in mid-November, I received feelings of 'togetherness' and 'understanding'. Those feelings were desperately needed as we had recently received our daughter Paislee's diagnosis; life before had felt so overwhelming at that point. At the end of the conference, I knew I didn't want those feelings to end! Before leaving Orlando, I spoke with a few people that helped guide me in the direction of starting a chapter for Alabama.

Announcement! We officially became a chapter in January, 2018.

We have so many things we would like to accomplish for our chapter. Where to begin?

1. Once official, I received a list of PWSA (USA) members in Alabama from Rikka at the national office and I was SHOCKED! There were at least 200 people on the list. A Facebook page and group for our chapter was immediately created to expedite communication. Then, calling people from the list began, sharing our contact information with families so we could connect. We are starting to grow and want to grow wisely with support from the national office, as well as people on the ground here in Alabama.

2. Currently we're working on putting together a network of doctors in Alabama specific to PWS, or at least knowledgeable, about Prader-Willi syndrome. In recent experience, I've personally experienced there are still so many medical professionals not yet familiar with this rare syndrome, also referred to as "PWS". Once the network is compiled, our goal is to publicize and promote it, and send to new patients in Alabama.

3. I am starting a fundraiser for someone very dear. Some of you may remember Kera Unfried, who recently passed away. She was the mother to sweet Delilah, age nine, with PWS. The goal is to raise enough funds for her family to have a getaway time of respite and healing. The goal is to be able to do something special for them during this difficult time. Contact me directly at the email below and/or watch for announcements about the event on the Alabama chapter page.

4. An ***On The Move*** event is being planned for this fall (Alabama summers are hot). Stay tuned for details!

5. We need volunteers of ALL kinds! If you are in or near Alabama, and can support getting our chapter up and running, I can guarantee we will have fun, make friends, and become a part of something great for the Prader-Willi Alabama Chapter, and Alabama families with persons with PWS.

6. Important: Please contact me via Facebook: **pwsausaalabamachapter** or email brittneepeterson8009@gmail.com. Thank you. I am grateful for your consideration and appreciate your help more than you could know. ■

Pennsylvania Mini-Conference November 9-11

PWSA of PA proudly announces their upcoming mini-conference November 9 – 11, 2018 held at DoubleTree by Hilton Hotel Pittsburgh-Cranberry in Mars, PA. Friday evening begins with a meet & greet of old friends and new. Enjoy veggies, fruit, open bar, & entertainment provided. Registration and the reception is open from 7:00-9:00 p.m.

Saturday morning starts with a hot buffet breakfast from 7:30 a.m. to 8:45 a.m. to prepare for a full day! At 9:00 a.m. sharp, the conference opens with welcoming remarks. Presenting speakers include Janice L. Forster, M.D., on mental health issues in PWS, Amy McTighe from The Children's Institute on *Supporting Students with PWS in the School Setting*, and Luigi Garibaldi, M.D., UPMC Children's Hospital, will share information about their PWS clinic. Also Nora Chatha, Esq., will focus on *Guardianship versus Power of Attorney.*

Childcare is also provided at NO CHARGE; you will not want to miss this event.

During lunch, a chapter business meeting will be held with an emphasis on fundraising and the need for officers and board members.

The conference isn't complete without a special dinner and dance. The buffet dinner is included, as well as a DJ and photo booth. This fun celebration closes the conference with smiles, memories, and new connections for families.

There is **NO** conference fee for Pennsylvania residents (or their children with PWS) to attend. Conference funding was raised by PWSA of PA annual fundraising golf outings. Hotel accommodations are $112.00 per night, plus taxes and service fees. **Hotel scholarships are available from our chapter and space is limited.** Don't wait; register early for both the conference and hotel rooms. We want to see you there!

To register or more info, please contact Deb Fabio at debpwsapa@yahoo.com 724-779-4415 or Bonnie Azzara at bonniepwsapa@yahoo.com 412-527-2097. **Financial assistance requests, requires ALL completed forms MUST be received no later than October 14. Please contact us and we can email the form.**

DEADLINE TO REGISTER FOR THE CONFERENCE & THE HOTEL IS OCTOBER 14, 2018. No Exceptions! ■

Chapter View

Volleyball Tournament and Family Fun Day

In memory of George Hunt, IV, to benefit the Prader-Willi Florida Association

WHEN: Saturday, October 6, 2018. Sign-in begins: 8 a.m. First game begins: 9 a.m.

WHERE: Volleyball Courts at Woodlawn Park in St. Petersburg

WHAT: Volleyball Tournament and Family Fun Day. Come out and play! Or come to watch, explore/bid on our auction items, fun games, inflatables. First, second and third place prizes will be awarded. A cornhole tournament is open to all interested! Join us for this fun event - all are welcome!

FEES: Teams of four may enter with $100 registration fee. For additional information or to register yourself, or your team please visit our website at https://clobberfestvb.wixsite.com/clobberfestvb or email Terrann Mayo at clobberfestvb@gmail.com.

*If you or anyone you know is interested in sponsoring the tournament or donating an item to the silent auction/raffle, please contact Terrann Mayo for more information at email shown above.

PWFA is a 501(c)(3) and all donations are tax deductible to the extent allowed by law. All the proceeds go to PWFA.



Front row left to right: Lynn, Kathleen, Keaten. Back row left to right: Terrann, George, Emmary.

George Hunt, IV, father to Keaten Hunt, age nine, with PWS., was a professional beach volleyball player and won several tournaments. When he passed away, friends and family organized the first Clobberfest tournament as a fundraiser to aid Keaten. Those funds covered a pool heater; this helped Keaten be able to continue swimming when the water became too cold. Two years later, Terrann Mayo (George's stepdaughter) was determined to organize the tournament again, this time to help others like Keaten. The Florida chapter has been very supportive to George's family since he passed. We don't know what our lives would have looked like without their wonderful support and friendship. ■

Chapter Events and Happenings

What is going on in your area?

Autumn brings cooler temps and a great time to get out and spread awareness with others. Read about what is happening in other chapters. Make time to join or plan an event for your state and share with others our PWS CommUNITY

September

- **15th**: San Francisco Bay Area PWS Support Group Meeting
- **15th**: PWSA-AZ's OTM Swimming and Waterslide Event
- **22nd**: PWSA of Ohio 2018 Mini-Conference and Fun Day in Columbus
  Learn from great speakers, meet other families and join the fun at this day-long event. For more info http://pwsaohio.org/events/2018-mini-conference-and-festival 330-723-0004 • E-Mail: pwsaohio@aol.com
- **22nd**: PWSA-WI, Inc. Strike Out PWS
  PWSA-WI, Inc. is hosting their annual **Strike Out PWS** event on Saturday, September 22, from 1-3:30pm at AMF Bowlero in Wauwatosa, Wisconsin. This event provides a safe social experience offering an afternoon of FUN for all.
- **23rd**: PWSA-PA Family Day with the Pittsburgh Pirates at PNC Park

October

- **6th**: 2018 Aquarium of the Pacific 5K Run/Walk (California)
- **7th**: 2018 JetBlue Long Beach Marathon and Half Marathon (California)
- **27th**: PWCF Annual Conference
- **27th**: 2018 Michigan Prader-Willi Syndrome Conference (Free)
  All associated with someone with PWS are welcome. International and national speakers, Q&A available with all speakers, newly revised *Medical Alerts* booklet given to all in attendance. **No child care available. NO children over age four nor adults with PWS due to food accessibility and liability. Registration required; submit online form (for **each** registrant) https://pwsami.org/blog/2018/08/21/2018-mi-conference/ no later than October 12 for this full-day event. Visit above link for more info.

November

- **4th**: Los Angeles County Support Group Meeting
- **4th**: Sacramento Area PWS Support Group Meeting

Chapters: Send your info on upcoming events and announcements; *The Gathered View* can help you announce your news. Next deadline: October 1 for the November/December issue. Email: *editor@pwsausa.org*

We hope you find this publication and our materials helpful and that you consider a tax-deductible donation to PWSA (USA) to assist in developing more good work(s) like this. Please visit our website, or use this envelope provided, to submit your donation. www.pwsausa.org

Need for Communication with Individuals with PWS



By Conor Heybach, Member, PWSA (USA) Adults with PWS Advisory Board

Society these days has several problems when it comes to communication with disabled people, including those with PWS. A colleague told me her favorite quote is "nothing about me, without me". It inspired me to write an article for the need for communication - with individuals with Prader-Willi syndrome. There are way too many situations in society where disabled individuals are ignored through the channels of communication. Let's take Prader-Willi syndrome as an example. PWS is a genetic disorder that's not well-recognized, and this is where society needs and should make efforts to take the time to communicate, ensuring the voices of disabled individuals are not being ignored and taken seriously.

People with disabilities are sensitive individuals who have their own voice. Society needs to take the time to listen to us.

Many individuals with PWS struggle with this issue every day, including myself and my fellow colleagues on the Adults with Prader-Willi Syndrome Advisory Board. I will share a perfect example of how this is a recurring problem for me. Maintaining good oral hygiene in individuals with PWS is challenging and often compromised. Due to the fact that we are mouth breathers, we tend to have very dry mouths. That, along with a lack of saliva, results in poor hygiene.

Whenever I go for my usual six-month family check-up with the dentist, communication has been a struggle for me. This seems to be a general problem in the medical profession. Doctors tend to give you a generalized answer, not the answer and feedback you are expecting and want. They tend to give me a vague answer, like "Your gums are a bit irritated; you should make them your main focus next time you brush your teeth". So, I'm thinking- "oh that's not that bad, considering the fact that I have Prader-Willi syndrome". After the dentist leaves, the hygienist cleans my teeth, and they tell me to stay on top of the brushing, and keep up the good work. So I'm feeling positive about that feedback I received, or so I thought. Then they end up giving my mother or father the full results in the report and they are always different from what I was told. The results that my mother received is: "it seems that he doesn't brush his teeth often or it seems like he never does". This makes me very upset because this is MY oral hygiene and I should know what is really going on with my teeth. Like most medical professionals, they believe they will hurt your feelings if they tell you the whole truth especially if you have a disability. But, it has the opposite effect; by not telling me directly, it hurts my feelings and is disrespecting me, especially as an adult, even if it is unintentional. People with disabilities are sensitive individuals who have their own voice. Society needs to take the time to listen to us.

In closing, I hope this article inspires families who have family members with PWS, or any other disabilities. Make requests, and have good, open communication and expectations with both family members and health care professionals alike. ■

Managing Behaviors



This video provides tips and strategies to help prevent and reduce challenging behaviors in children with Prader-Willi syndrome.
https://youtu.be/EjwT3mSKaJk

In 20 power-packed minutes, you will learn:

- The meaning of behavior and positive behavior support
- How to engage in supportive communication with your child
- The importance of implementing structure
- The need for clear expectations and the value of planning
- Practical tips for creating positive behavior reinforcements and outcomes
- How to positively respond to a "meltdown"
- How to start a positive behavior support plan

Australia is Reaching Out

Changes are afoot for families and individuals living with PWS in Australia. In the last several years, the country has commenced rollout of a new National Disability Insurance Scheme. Just under 2% of Australians with a 'significant and permanent' disability look set to receive substantially improved support funding to purchase 'reasonable and necessary' supports to achieve their goals and live an 'ordinary life'.

These NFIS funds (not means tested) are on top of free National public health (also not means tested) and the disability support pension (means tested). The other beauty of the new NDIS is that the payments are transportable. Under their old system the payments were made to the provider which meant individuals were reluctant to give up their spot in that service, known as 'postcode lottery'. Now the payments will be directed through the individual enabling transportability. They can chose to move postcodes and purchase the services elsewhere.

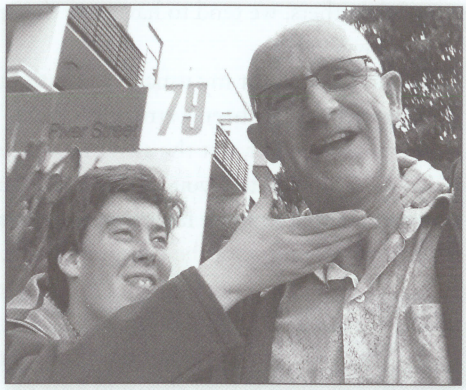
With opportunity comes risk. One of the existing challenges Australia already faces is how to train support providers and community in how to support and interact with people with PWS. With the new funding, the training challenge may double in size as additional individuals finally receive support funding and go shopping for their support services. Australia is similar in land size to USA or Canada, however, they have only one tenth the USA population, so the individuals with PWS are very spread out and invariably extremely isolated.

PWS Australia is taking on the challenge by launching a new project called ***Reaching Across Australia*** – a project about equity. The concept is to research process and content for delivering family support services into regional, rural and remote communities. As part of this process, they have also taken steps to amalgamate their small State Association into one stronger National organisation. The dream is for PWS Australia to eventually deliver a fairer, more equitable service to families right across Australia, regardless of their postcode.

'I have been astounded and encouraged by the generosity in sharing ideas and resources', says James O'Brien, parent of a 24-year-old son with PWS. 'Organisations such as PWCF, PWSA (USA), FPWR, colleges including the Vanderbilt Kennedy Center and University of Florida, and service providers, such as the Arc of Alachua County, have all rallied behind this project'.

James has been traversing the United States by car, with a string of appointments booked from Florida to Boston, to Chicago and then, on to Canada. Europe and India are also on the list as he reaches out to the PWS community worldwide. His daughter, Gina (playing college basketball at Weber State in Ogden, Utah), is joining him for some of this adventure.

The research has in part been funded by the Churchill Foundation, an organisation that provides grants to Australians (and Canadians) to enable overseas study. Once completed, James will be providing the Churchill Foundation with a report that will be available publicly.



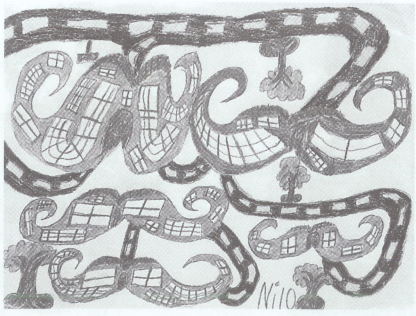
~ Submitted by James O'Brien, President, PWS Australia and Director with IPWSO (shown above with his son, Ashley)

PASSION CORNER

My son Nilo is 13 years old, and one of his passions is art. He was born with PWS, but doesn't let that get in the way of expressing his amazing creativity. He loves working with acrylic paint, crayon, pencil, water color, chalk, and anything else he can get his hands on. He won the "Royal Masterpiece Award" from his school for his "Bird's-Eye View of the Mustache City". See more of Nilo's art at: www.artofnilo.wordpress.com "The Ocean Scene" is one Nilo worked on for months.

~ Submitted by Paula Anderson, mom to the amazing Nilo Mohadjer :-)





Introducing Mary Burr, PWSA (USA)'s New Medical Coordinator

Mary S. Burr, DNP, CPNP, became Medical Coordinator on August 1, 2018. A key resource person in PWSA (USA)'s Family Support program, Mary is excited to join the organization's Family Support team, which provides information and mentoring to new parents and more. Offering medical alerts, written and video resources and counseling supports, crisis intervention in many areas, this team is designed to meet the needs of those in the PWS community.

A Certified Pediatric Nurse Practitioner, Mary earned a Bachelor of Science in Nursing degree at the Catholic University of America, and then both Masters and Doctor of Nursing Practice degrees from the University of Maryland. Her career includes having been a pediatric nurse practitioner specializing in endocrine diseases, a nursing program faculty member and clinical instructor, and as medical provider at the Kennedy Kreiger Institute in the Division of Physical Medicine and Rehabilitation.



Mary Burr



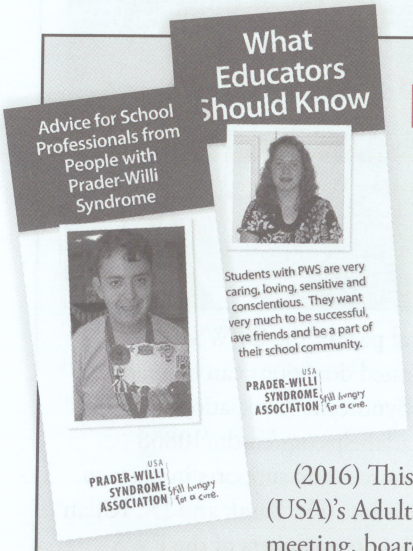
Mary embraces the importance and challenges of directly integrating multiple medical, educational and social services into the care that is provided to families and children with complex medical needs. Her extensive experience managing the care of children with endocrine disorders is a tremendous asset to our team.

As a president of the Pediatric Endocrinology Nursing Society, plus making educational and research presentations and authoring published articles, Mary demonstrates how she has given back to her profession, the patients, and the families she has served.

Mary will be working four days a week, taking over from Kathy Clark as Kathy retires this month.

She and her husband, Philip, reside in Baltimore, Maryland, have 2 married adult children and 2 grandchildren. She volunteers for her church and in her community at large. Mary enjoys spending time gardening, doing floral designs, cooking, boating, and golf.

Please welcome Mary to the PWSA (USA) family. ■



Heading to School?

See these and other materials on our website and in our "Shop" online page

What Educators Should Know

(2012) Offers guidelines and strategies for helping the student with Prader-Willi syndrome stay focused, develop skills and knowledge, and minimize problems associated with the syndrome in the school setting. ■

Advice for School Professionals

(2016) This publication was created by members of PWSA (USA)'s Adults with PWS Advisory Board. At their annual meeting, board members were asked what they would like school professionals to know in order to effectively and appropriately serve students with Prader-Willi syndrome (PWS) based on their school experiences. Contributions by: Shawn Cooper, Brooke Fuller, Conor Heybach, Kate Kane, Lauren Lange, and Abbott Philson. To order or see other fine publications, please visit our online shop: https://www.pwsausa.org/shop/ ■

CHUCKLE CORNER

Our daughter Lizzie, age 9, asks endless questions. Any answer I give is immediately followed up with "why"? This can be very distracting when I'm driving in Atlanta traffic so I sometimes ask her to stop talking for a bit. Once I asked her to let me focus on driving and I heard her mumbling in the backseat. When I asked what she was doing, she said, "I'm talking to myself and you interrupted me!"

~ Andrea Warren
Johns Creek, GA

Meet the New Board Members

Please extend best wishes and support to your newly elected 2018-2021 PWSA (USA) Board of Directors: Crystal Boser, Daniel J. Driscoll, M.D., Ph.D., Christine Geraci, Kristi Rickenbach, Paige Rivard, Marguerite Rupnow. Congratulations!

Thank you

PWSA (USA) wishes to extend their gratitude to the officers and directors who have recently served the association, our families, and professionals who have made a difference.

- Leon D. Caldwell, Ph.D., Washington, D.C.
- Tom Conway, Albany, NY
- Jim Koerber, Corydon, IN
- Michelle Torbert, Homestead, FL
- Rob Seely, Dublin, OH
- Stephen Leightman, Cherry Hill, NJ

Farewell to Kathy Clark

Coordinator of Medical Affairs, PWSA (USA)

After two years in the role of Coordinator of Medical Affairs, Kathy Clark, R.N., M.S.N., has officially retired. Through her end of career service to PWSA (USA) we have collectively benefited from her thirst for knowledge and her ability to disseminate information. As a certified Pediatric Nurse Practitioner, Kathy was capable of translating into plain English the complicated and technical aspects of PWS research for our membership. She had a special interest in clinical trials which was how she initially became aware of PWS, being involved in the initial clinical trials for synthetic growth hormone.

In addition to serving PWSA (USA), Kathy is a past-president of the Pediatric Endocrinology Nursing Society. She and her husband, Spaulding Clark, have two adult daughters, and a grandson. They are planning to spend more time with family and enjoy some traveling.

Please join us in our overall thanks for Kathy's hard work and dedication to our organization.

App for PWSA (USA)

http://bit.ly/2CsjHsnPWSAmobileapp



Thanks to the Settles family, browse information on our website via a free app (link above) on all mobile devices via iTunes or Google Play.

In Remembrance

We are deeply saddened to inform you that Jacob Yashinsky Zavitz, an extraordinary young man and valued, active member of our PWS community, died Tuesday, July 10th after a tragic car accident.

We are all sending love and prayers to Jacob's father Dan Yashinsky (longtime member and former co-chair of the OPWSA Board), mother Carol Zavitz, brother Natty Zavitz, and the Yashinsky and Zavitz families.

Since birth, Jacob was a wise soul and fighter who challenged every notion of limitations for people with PWS, and a creative and expressive spirit. A leader in every community he participated, Jacob enjoyed his work as a crossing guard and bringing his custom made jewelry to OPWSA events. The consummate salesman, Jacob talked with every person. Rarely did someone walk away from that table without a purchase.

Jacob was honest in acknowledging and articulating the challenges of life with PWS, which helped us understand. Reading his poetry to groups gave others insight and perspective, always with humour, and a gentle jab at parental controls. Listen to "Me Without You". http://bit.ly/2OOgklYMeWithoutYouJacob. Jacob and his father spent hours fishing and storytelling.



His family is an integral part of the OPWSA community and has requested donations can be made to the Ontario Prader-Willi Syndrome Association in Jacob's honour. https://www.canadahelps.org/en/dn/10868

OPWSA is putting resources and supports in place to help families cope with this loss. Dr. Basak and Dr. Kilian have opened the PWS Clinic to members of the PWS community who need to talk or grieve; e-mail Kindercare Pediatrics to book an appointment. Please feel free to contact usontariopws@gmail.com

To share memories or send a message to Jacob's family, go to: https://www.surveymonkey.com/r/rememberingjacob

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

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

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

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

The Gathered View (ISSN 10 77-9965)
Sara Dwyer, Editor
Lota Mitchell, Andrea Glass, Denise Servais, Kathryn Lucero

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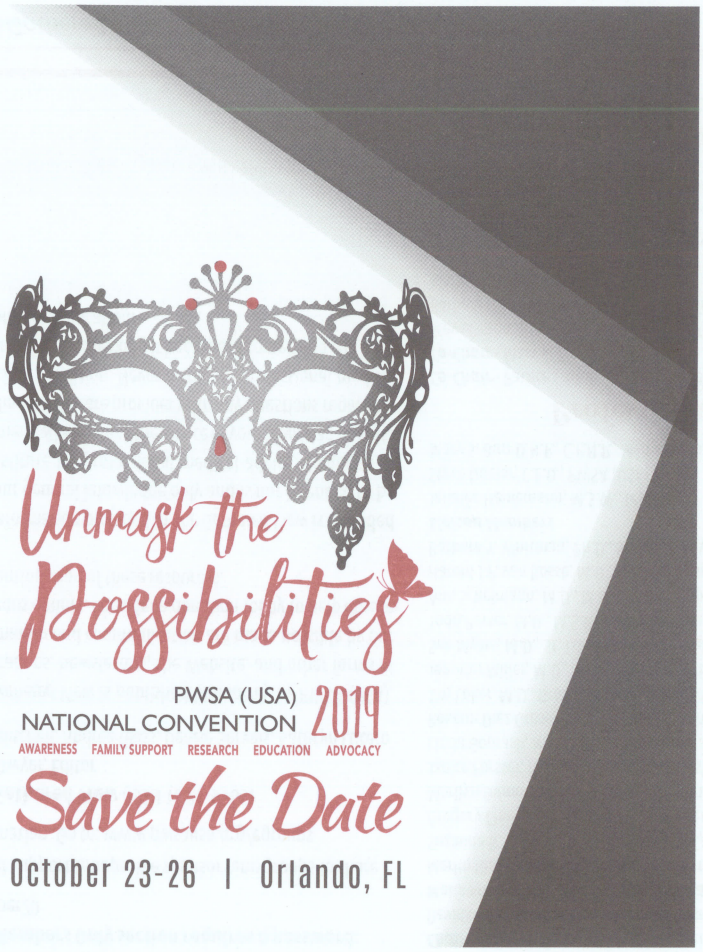
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