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

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

Countdown: Excitement grows as we get closer to "Together In Paradise"

PWSA (USA), deeply committed to providing education about Prader-Willi syndrome, truly understands the value of meeting you in person.

More than just a meeting, our upcoming national "*Together in Paradise*" convention **November 14-18** in Orlando, Florida is an **experience**! We offer lots of quality interaction – including making and seeing good friends – throughout our days together. Attendees find that being a part of the **largest** attended conference in the world – for families and professionals who support someone diagnosed with Prader-Willi syndrome – **totally life-changing**.

Whether you attend professionally or have a family member you love and provide care for, the wide array of educational and networking opportunities provides something for everyone.

Medical & Scientific Conference: Thursday, November 16

Scientists, researchers, and medical professionals share ideas and report on progress. This helps to meet the ever-present goal to **support research** that will identify effective treatment, and improve the quality of life for individuals diagnosed with PWS.

Professional Providers Conference: Thursday, November 16

Educational, social services, and residential professional providers come together to discuss identified and supported **best practice** and standard of care.

General Conference: Open for All Attendees – Friday/Saturday, November 17-18

These two days attract parents, grandparents, caregivers, and professionals – plus offer programs for the kids! Attendees are guided through an **array of topics** that can be tailored to your individual preferences. This is your time to build relationships with other families, attend counseling sessions and support groups, meet with top specialists and authorities on PWS, and simply have fun. Experts in the field provide attendees with **up-to-date information** and resources for addressing the very complex needs of supporting and caring for an individual diagnosed with PWS.

Young Infant Program (YIP) 0 – 1yr: Friday/Saturday, November 17-18

While it's hard for our young families to feel comfortable with having their infant too far from their sight, this warm, **nurturing nursery** allows parents the opportunity to gain support and valuable education needed for raising their precious little one. Our onsite nursery is staffed with individuals who are caring in addressing their specific needs.

Youth & Infant Program (YIP) 2 – 6yrs: Friday/Saturday, November 17-18

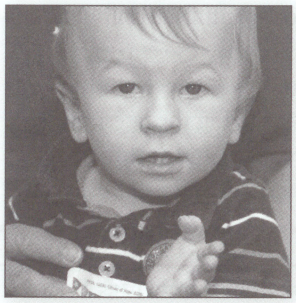
Your little ones with PWS, or young siblings of those with PWS, just want to have **fun, laugh and explore,** and this two-day program was developed with

continued on page 2

Lucca is My Why

Kenna's 2015 PWSA (USA) Conference Experience

After receiving the PWS diagnosis of our son Lucca, I began searching everywhere for information and resources that would best help our family and improve his quality of life.



Prior to Lucca's first birthday, we attended a PWSA (USA) national conference in Florida. We were so excited to be around other families who understood what we were going through and to learn as much as we possibly could. The conference was well organized, informative, and fun! The coordinators did a wonderful job structuring presentations that allowed families to easily plan and navigate their schedules! They also planned programs for all the children (those affected by PWS & siblings of PWS individuals) attending the conference alongside their parents. They too were well structured and fun!

Although we could not possibly learn everything all at once, our experience with PWSA (USA) left us feeling better equipped to provide the necessary resources for our son. Not only did I gain priceless knowledge, I met families from all over the US that have become some of my closest friends! ■

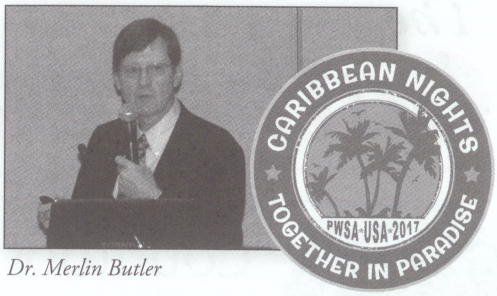
~ Kenna Grigorov (mother to Lucca, age 2 1/2), Overland Park, Kansas.

Volume 42, Number 5 ~ September-October 2017 ~ Our 42nd Year of Publication

Announcing

New Format for Medical and Scientific Conference in Orlando

By Merlin Butler, M.D., Ph.D.



Dr. Merlin Butler

The Medical and Scientific Conference at the 2017 National PWSA (USA) Convention will include a new format with an overall emphasis on the care and management of Prader-Willi syndrome and new scientific knowledge. This year's conference will encourage cross-discipline collaboration and information sharing. Newer researchers will have an opportunity to network with more experienced scientists, and all in attendance will benefit from presentations covering the latest on PWS advancements and treatments, pharmacogenetics, and future research trends and opportunities. Keynote speakers include Jennifer Miller, M.D., an endocrinologist and associate professor at the University of Florida, and Timothy Dallenbaugh, M.D., an associate professor of psychiatry at the University of Missouri-Kansas City. The Western Michigan University Homer Stryker School of Medicine designates this activity for 12 AMA PRA Category 1 Credits. Continuing Medical Education credits can be claimed as well as Continuing Education Unit credits for nurses, with dietitians and other health care providers welcomed.

This year's National Convention will be held November 14 – 18 at the Caribe Royale Hotel and Conference Center, 8101 World Center Drive, Orlando, Florida. The Medical and Scientific Conference will be held on Thursday, November 16 from 8 A.M. to 5 P.M.

Medical and scientific professionals interested in attending this year's conference can now register online at www.pwsausa.org. ■

Convention, continued from page 1

that particular goal in mind. Arts, crafts, story-telling, puppets, music, magic and more will **light up their faces** as they participate in structured play and staff-guided activities.

Youth and Adult Program (YAP) 7yrs and up:
Friday/Saturday, November 17-18

Children and adults diagnosed with PWS, ages 7+, are involved in an innovative, structured program, carefully designed to meet their unique medical, physical, and emotional needs. This is a **wonderful opportunity** for friendships to develop, fun to be had, and to be a part of a **peer group** that truly **understands** one another. The individuals are divided into eight groups based on age and are motivated, supported, and praised by trained, experienced staff members.

Sibling Program:
Friday/Saturday, November 17-18

While their brothers or sisters are busy in YIP or YAP, this program was developed to enhance siblings' individuality and reinforce their sense of importance. This program allows them to have fun, meet and **develop relationships** with others who are in **similar situations**, explore new possibilities and share experiences with one another. This unique opportunity provides attendees with a peer group that cannot be found in their own communities.

Gala:
Friday, November 17

Many families who support a loved one with PWS find it challenging to participate in social functions, as they need to be vigilant in monitoring unrestricted food access their child may encounter. While their 7-year-old and older child participates in their own highly-structured YAP GALA event, families will be able to socialize and make new connections, enjoy a date night with their significant other, or simply enjoy some well-deserved **down time.**

And Don't Miss...

While participating in this unique educational opportunity, make sure you stop at these two places! Check out our onsite **PWSA (USA) Bookstore**, where you'll find helpful resources such as informational pamphlets, educational materials, plus great branded merchandise with our new logo.

Don't miss visiting all the **Sponsor/Exhibitor tables**. See and learn even more about many products and services available to you and your family! ■



You like networking, improving your knowledge,
being with others who understand the journey,
so why wait? We'd love to meet you!
Join in the excitement, and be part of the experience!
The time to make your travel plans and register is NOW!
Visit *http://www.pwsausa.org/2017-pwsa-usa-national-convention-registration/*

Respiratory Complications in Children with PWS-

By Tan H-L, Urquhart DS. Respiratory Complications in Children with Prader-Willi Syndrome. Paediatr. Respir. Rev. (2016).

Summarized by Kathy Clark, Coordinator of Medical Affairs, PWSA (USA)

This article is a summary of 52 publications from around the world about the breathing problems seen in children with PWS. Included were many of our American publications. By combining the findings in multiple studies, the authors could describe the challenges and the effectiveness of various treatments with greater confidence; a single study may be exciting news, but the best information occurs when more than one researcher finds the same results.

Infants and oxygen

Why do so many babies need oxygen at night, and yet most do not need this when they get older? Parents struggle with the challenges of oxygen therapy, and may see no change in their baby with this therapy. However, breathing in infants with PWS is unique – along with their obvious muscle weakness, they have poor regulation of breathing from the hypothalamus.

In the hypothalamus, breathing is finely tuned to the body's need for oxygen through chemical receptors. A healthy hypothalamus prompts a deep breath and raised heart rate when there is too much carbon dioxide (CO2) in the blood. If CO2 is high, there is not enough oxygen for the body – and this balance is not well managed in babies with PWS. They also may be too weak to "blow off" the CO2 with a deep breath, and their chemical receptors may not do a good job of detecting this need. Adding oxygen stabilizes infants' sleep apnea; this is not a permanent problem.

Obstructive Sleep Apnea (OSA)

(OSA) is common in both adults (41%) and children (57%) with PWS. In the general population, people with this condition are often obese, and the obstruction is due to a heavy neck pressing on the windpipe. The authors explain that obstructive sleep apnea in PWS can be caused by the facial features that are so typical of the syndrome – small chin, small nose, and small mouth. Add weak muscles in the neck and mouth, and thick saliva, and there can be OSA without obesity – and without any symptoms, such as snoring. If the tonsils or adenoids are large, removing them often improves sleep quality, but these other PWS features may mean breathing during sleep is not completely normalized even after removing the tonsils; another sleep study may be needed.

Respiratory infections

We know this is a challenge at all ages. These authors remind us of the high risk of aspiration (fluids going into the lungs instead of down the throat) and recommend obtaining a videofluoroscopy (also recommended by research funded by PWSA (USA)) if a child has recurrent chest infections **or** these signs while feeding: noisy or "wet-sounding" breathing during or after feeds, eye reddening/watering, color changes, apnea or changes in heart rate related to feeding.

In the summary, the authors support the early use of growth hormone, as they noted the improvements in many areas of respiratory health for children who are on GH. This article may be helpful to share with your health care providers. ■

Reviewed by Todd Porter, M.D.

Important Development for PWS-Related Carbetocin Research:

Levo Therapeutics Announces Completion of Series A Financing

CHICAGO, IL, August 11, 2017 (Newswire.com) - Levo Therapeutics, Inc. announced today that it has completed a Series A financing, co-led by Samsara BioCapital and an undisclosed healthcare investment fund.

Levo also announced that it has executed a worldwide license agreement with Ferring Pharmaceuticals to develop intranasal carbetocin for Prader-Willi syndrome (PWS), building on Ferring's encouraging proof-of-concept data from a randomized, multi-center Phase 2 trial.

Proceeds from the financing will support a pivotal study of LV-101 (intranasal carbetocin) in PWS starting in 2018. In addition, Levo will continue to develop an earlier stage pipeline that builds on emerging science of metabolic hormone regulation in PWS.

"This is an important step towards addressing the serious unmet need that exists in Prader-Willi syndrome," said Sara Cotter, CEO of Levo Therapeutics. "With high-quality healthcare investors and a suite of novel programs, we are well positioned to develop impactful therapies for this challenging condition."

"Levo has assembled a unique pipeline that capitalizes on the improving understanding of Prader-Willi syndrome pathophysiology," stated Mike Dybbs, Ph.D., Partner at Samsara BioCapital. "We are excited to partner with Sara and the Levo team to help advance these important programs that have the

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Skin Picking

By Patrice Carroll, LCSW, Director of PWS Services at Latham Centers, Inc.

I have received more calls about picking than any other topic, and there is no issue that I have spent more time trying to solve.

Skin picking, in all its forms, is one of the most frustrating behaviors that providers and family members confront. The theories as to why it occurs and how to stop it are many, but none have been definitively proven so we do what we do best: try and try again to find something that decreases the compulsive drive to pick, tear and scratch at the skin. Although the severity and location vary greatly, I believe that the approach is the same - whether it is severe skin picking, that causes infections and tissue damage, rectal picking as well as superficial picking of cuticles and top layers of skin. I will leave the medication approach to the professionals and will look at this behavior from a strictly behavioral lens. In the years that I have been working with people diagnosed with PWS, I have seen the spectrum of intensity of skin picking and have witnessed the universal feeling from families when faced with this challenge - confusion, frustration, embarrassment and concern. I have received more calls about picking than any other topic, and there is no issue that I have spent more time trying to solve. What I have found is that there are two universal components to skin picking behavior - anxiety and opportunity.

Anxiety

Recent research has identified that it is a specific action of the gene deletion that creates anxiety in persons with PWS. People with PWS are anxious even if they do not display the typical signs and symptoms of anxiety. Make no mistake about it – they experience stress on a basic level and often cannot communicate their feelings in a helpful or healthy way. What causes symptoms of anxiety in the PWS population? Boredom, misunderstanding communication (verbal, facial, social), lack of appropriate peer interactions (feeling ostracized, being bullied), a desire for independence that often cannot be safely granted.

Children and adults with PWS generally have a great desire to get along with others, want to be leaders in the group, want to participate in age appropriate activities like their peers. At the same time, they know that they are different and require more support. Anxiety is deeply seeded and almost always comes out in unhealthy ways.

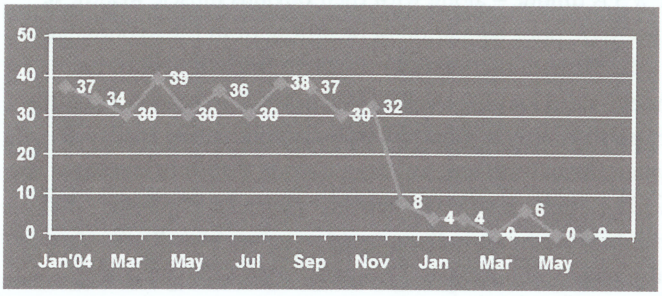
Opportunity

Existing wounds, bug bites, surgical sites and cuts are open invitations to pick. We have looked at whether endorphins play a role, are they generally itchier than their typical peers, or does picking create a pleasurable feeling? Maybe. What we do know is that covering the sites, using Vaseline or another lotion that makes it harder to tear at the edge of the skin, keeping fingernails short and providing sensory stimulation can decrease the severity and instances of picking.

Sensory stimulation: using any type of brush, vibration or rollers on the skin has shown to decrease skin picking behavior. What we don't know is why. It is possible that endorphins are released and these decrease the need to pick, or perhaps the process of sensory stimulation decreases anxiety – or perhaps both.

You may find tools for sensory stimulation in beauty supply stores, pharmacies, and on line – look for skin brushes; baby hair brushes; fascia rollers used by athletes; small rolling pins, or brayers from art supply stores; vibration devices including handheld devices, cushions and foot vibrators.

Below is an example of what sensory integration can do for even someone with a severe skin picking behavior. This chart shows the decrease in the number of episodes of skin picking after the institution of a sensory program for one individual:



Regardless of where your child falls on the spectrum of skin picking, it is important to address the behavior immediately when you first see it happening. It is far easier to stop or decrease this behavior in young children than in the adult population. Try everything! And keep trying! Look for ways to decrease anxiety, to improve communication and to look for a pattern and triggers to the behavior. I have seen picking behavior that has gone on for many years only to stumble upon a solution later in life. It is truly a "try it and watch" approach. **DO NOT GIVE UP HOPE.** There is an answer somewhere. We just need to find it, and until we do, keep the wounds clean and covered, distract instead of asking them to stop, and try to decrease stress and increase joy every single day.

pcarroll@lathamcenters.org

Latham Centers provides residential and educational supports to 86 children and adults living well with PWS. ■

The Ohio STABLE Account Experience

Pam Vogt, PWSA (USA) member and Ohio resident, has a daughter Kristi, age 45, with PWS. After some mental health issues earlier in her life, Kristi is doing very well now, lives at home, is relatively independent except for food being locked up, and has her own dog and horse. Like many other parents whose children grow into adulthood, Pam has concerns about saving money for Kristi's future, especially when she won't be around to provide funds.

As we are all well aware, more than $2000 accumulated in a savings account has meant the loss of government benefits like SSI and Medicaid. Parents told friends and family not to give their child money.

However, a federal law, "Achieving Better Life Experience" (ABLE) HR 647, passed in December 2014, has changed that dramatically. ABLE provides a way for families and individuals with disabilities to set aside funds for the person's needs, present and future, without penalty. "Disabilities" is a broad term, including physical, mental, medical, developmental disabilities and wounded veterans.

One of the provisions of ABLE is that states were permitted to develop their own versions. The very first state to do that was Ohio, with STABLE Accounts. The "ST" stands for State Treasurer, where the program is administered. In 2015, an amendment permitted nationwide enrollment between states, and STABLE has accounts created by residents of nearly every state.

A retired CPA, Pam has done all she could to assure her daughter's future, such as a special needs trust and her will leaving the house where they live to Kristi at her death. When she learned about STABLE Accounts through the Ohio Developmental Disabilities newsletter and a county information meeting, she thought it would be a good additional tool to make certain that Kristi will have the best life possible.

ABLE provides a way for families and individuals with disabilities to set aside funds for the person's needs, present and future, without penalty.

It sounded easy, and it was. Pam registered online, opened an account, and authorized her bank to transfer funds. She set up a "STABLE Account Card" (a loadable debit card) for Kristi which she (Pam) loads, which allows Kristi to use to buy what she wants, such as clothes. She felt that this empowered her daughter.

Up to $14,000 can be contributed to the account per year; the total allowed recently increased from $426K to a maximum of $445,000, although over $100,000 could affect SSI. If funds are invested, growth is not taxed.

Pam says that it helps her to feel good about Kristi's future, but she regrets that more people don't know about the program.

In July, STABLE Account was honored to receive the "Champions of Equal Opportunities Award" from the National Association of Councils on Developmental Disabilities (NACDD). To learn more details about STABLE Accounts, go to stableaccount.com. For information about your own state's status, go to the ABLE National Resource Center.

PWSA (USA) also has information about this important program on our website. And in the next issue of *The Gathered View*, read Stacy Ward's in-depth article about ABLE. ■

~ Ken Smith, Executive Director

Carbetocin, continued from page 3

potential to make a difference in the lives of PWS patients and their families."

[1]Burd L, Vesely B, Martsolf J, Kerbeshian J. Prevalence study of Prader-Willi syndrome in North Dakota. Am J Med Genet. 1990; 37:97-9.

Source: Levo Therapeutics, Inc.

Note: Levo Therapeutics, started by Sara Cotter (a parent of a child with PWS) is dedicated to advancing treatments for Prader-Willi syndrome and related disorders. To learn more about Levo, please visit www.levotherapeutics.com.

Failure to act is often the biggest failure of all. Initiate quickly but not carelessly or in a hurried manner that makes a miscue more likely. I applied this same advice to my own actions. Do not be afraid of mistakes, even of failure.

~By Coach Wooden
Contributed by Clint Hurdle

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

Counselors Corner

One of the most important resources for parents of children with PWS, and school professionals who serve them, is the PWSA (USA)'s Wyatt Special Education Advocacy Training, aka **WSEAT**. A free online training, the WSEAT offers 6 modules parents and school professionals can view. Each module includes recommended reading and downloadable resources.

Module 1 and 2: The Power of Inclusion and Responding to Behavioral Challenges: In these modules, parents will learn about the importance of inclusion and how schools should respond to behavioral challenges.

Module 3 and 4: Effective Advocacy: In these modules, parents will learn about school advocacy and practical advocacy tips and strategies.

Module 5 and 6: PWS Specific School Challenges and Solutions: In these modules, parents and school professionals will learn how to address common PWS-specific school issues, such as food security. These modules are also great resources for school professionals.

Through the WSEAT, parents may also order a **free copy** of the book *From Emotions to Advocacy* published by Wrightslaw.

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

How Positive Influences have Impacted our PWS Journey

By Dee Dee Lewis, Holmen, WI, mother to Jett, age 11

When I think back to when Jett was first born, I feel like it was all a blur except for some very vivid memories. Like most of your babies, my son Jett was born with a weak cry and was extremely floppy. He would spend three weeks in the NICU and was given the diagnosis of Prader-Willi syndrome. As devastating as it was, I am so thankful for the people who gave me encouragement (these are the vivid memories I speak of). I remember a nurse called 'Peggy' in the NICU. Peggy was firm but loving with me as she gathered as much information as possible on PWS. She handed me the info and said "PWS doesn't come with a one-size-fits-all manual, but it should come with parents who will never give up challenging their child to be the best they can be."

On the discharge day, the pediatric neurologist, who we had met with earlier during our stay, showed up in our room. He reminded me that much of Jett's future will be environmental and to give him every opportunity possible. In those first three weeks, those dear people will never really understand how their words would impact both my life and Jett's.

The first year brought multiple appointments and therapies. I was a full-time working Mom with a five-year-old daughter, a new baby and a husband who traveled weekly for work. As a software support person, I was thankfully able to work from home. Now looking back, I don't know HOW we did it; no doubt that is why that part of my life is mostly a blur.

PWS doesn't come with a one-size-fits-all manual, but it should come with parents who will never give up challenging their child to be the best they can be.

After Jett's first birthday, I looked at



Jett, age 10

continued on page 7

Jett, continued from page 6

what appointments and therapies were worthwhile and which ones were not. This freed up some time to just enjoy. It is around that time I started to live more in the present and simply take time to relax and enjoy this gift named Jett.

We have made so many beautiful memories with this boy. He has traveled all over the world with us. He is truly loved by all who meet him. His smile is contagious and keeps people coming back for more. We have challenged him to always try his best and he never disappoints. Accomplishments such as downhill skiing, swimming, baseball, riding without training wheels, completing 5Ks, and reading chapter books have been celebrated. Thank you to people who have believed he would succeed!

As a parent mentor for PWSA (USA), I can share snippets of our journey, and also be a part of yours. I understand at times it can feel frustrating when progress seems slower; but remember: that progress IS progress! Our children are their own individuals, with their own personalities, strengths and timeline for meeting their milestones.

If I could offer any piece of advice, it would be: stay in the moment; enjoy your baby and encourage and learn from each other. ■

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We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more good work(s) like this. Please see our web site, www.pwsausa.org

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MEN! Share your Input of your PWS Journey PWS Male Caregiver Survey

Are you a Prader-Willi dad or a male caregiver of someone with Prader-Willi syndrome? Have you often thought about how to share your journey with other dads and men? Do you feel there is enough attention given to how fathers handle the challenges of PWS? Have you ever wanted to learn more from a broader range of other dads and men who take care of children and adults with PWS? Have you ever wanted to get more involved in PWSA (USA), but did not know how? This is it!

The PWSA (USA) Board of Directors requests your participation and is very excited to ask your input and support in helping us collect information from an army of dads and caregivers for the **PWS Male Caregiver Survey.** This online survey will launch soon and we plan to present preliminary findings from all the surveys received at the PWSA (USA) 2017 Convention in Orlando, Nov. 17-18.

All completed survey participants will be entered into a raffle for one of four $25 gift cards.

Your survey response is confidential. Our report is from the collection of all data compiled, NOT INDIVIDUAL survey responses.

If a paper copy of the male caregiver survey is required, one can be mailed to you.

Watch for a link in an email. **Thank you for participating in this survey!** This important data from these surveys will be used to help us better serve all our families. ■

Peace and Progress,
Leon D. Caldwell, Ph.D.
PWSA (USA) Board of Directors

With Appreciation

Our best wishes to Dr. Dan Driscoll and Tom Noonan as they finish their terms on the Board of Directors. We are grateful for their services on the board and PWSA (USA) is deeply appreciative of their support. ■

Mitchell H. Cohen

Congratulations to Mitch with his recent election to the Board of Directors for 2017-2020. We are grateful for your service and support. Mitch and his wife Francine have a daughter Ali, who has Prader-Willi syndrome. ■

Family Support Campaign Update

The 2017 Family Support campaign kicked off a few weeks ago, and the response has been incredible! Thanks to our many generous supporters, PWSA (USA) can continue serving the PWS community, providing resources and support that truly save and transform the lives of individuals with PWS and their families. ■

Did you know?

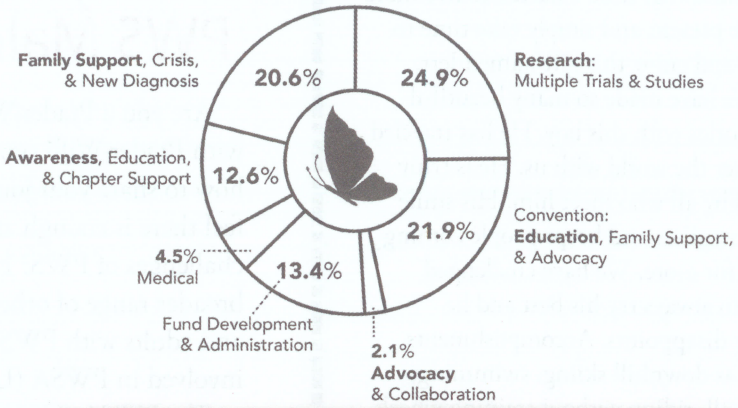
PWSA (USA)'s Family Support program is the only one of its kind. No other program is as comprehensive or life-changing and without it, many families would have nowhere to turn. In fact, PWSA (USA)'s Family Support professional staff recorded over 2,300 service activities in the past year.

What's more, PWSA (USA) does not charge for its services, nor do we receive any government funding. **We rely completely on the generosity of our donors to make our work *Saving and Transforming Lives* possible.** ■

SAVING AND TRANSFORMING LIVES

More than 6 of Every 7 Dollars Go to Programs & Services

2017 PWSA (USA) FUNDS



The total of the investments represented on the chart is $2,251,076, and the percentage allocations are based on the annual Prader-Willi Syndrome Association (USA) audit done by an outside CPA firm. PWSA (USA) board members and staff work very hard to make sure that the great majority of your organization's resource are used to help individuals, families, and our cause.

Still Time to Donate

Your gift to PWSA (USA) is an investment with a priceless return. If you haven't yet made a donation to the Family Support campaign, but would like to, please visit http://www.pwsausa.org/family-support-campaign/. Thank you! ■

on the MOVE Making a Difference!

PRADER-WILLI SYNDROME ASSOCIATION (USA)

There are so many FUN ways to fundraise for the PWS community! Whether you host an On the Move walk or run, create an online fundraising page, or "donate" your birthday or other special day, there's truly something for everyone! Here are a couple of great events coming up in September and October:

Idaho: "On the Move" Walk

Join the Idaho PWSA (USA) chapter for a walk in Julius Kleiner Memorial Park on Saturday, September 30th. The event begins at 10:00 a.m. with check in, and snacks will be provided. There's also a silent auction, so be ready to place your bids! There is no registration fee, however walkers are encouraged to raise funds and awareness by creating a personalized fundraising webpage (Note: you do not need to attend the walk to create a fundraising page). **For details, visit:** www.firstgiving.com/pwsausa/2017-IDAHO-OTM, **or contact Jim Wells at 208-344-6234 or** jimwells@hotmail.com.

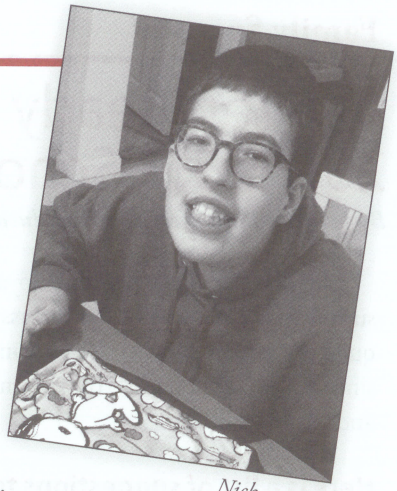
Florida: "Big George" Back in the Day Clobberfest

The "Big George" Back in the Day Clobberfest is a 4 on 4 beach volleyball tournament held on Saturday, October 28th, in memory of George Hunt, IV. "Big George" was an avid beach volleyball player whose love for the game was only exceeded by his love for his family. George's daughter, Keaten Hunt, was diagnosed with PWS at three months old. Held at Frenchy's Rockaway Grill in Clearwater, the event will also feature a silent auction. The entry fee is $100 per team and includes event t-shirts. Prizes will be awarded for first, second and third place teams. Proceeds from the event benefit the Florida chapter of PWSA (USA), and will be used to fund PWS research initiatives and to help individuals with PWS and their families. For more information, please visit the event website at https://clobberfestvb.wixsite.com/clobberfestvb, or contact Terrann Mayo at 727-420-8090 or clobberfestvb@gmail.com.

For more information about fundraising for PWSA (USA), or for assistance with your event, please contact Rikka Bos at 941-487-6729 or rbos@pwsausa.org.

Losing Heart

By Lisa Peters, mother to Nicholas, age 15



Nick, age 15

As a society, we value intelligence. We are brain heavy.

Folks with big brains are elevated in status and honored throughout our history.

Intellectual power has transitioned us as a human race, out of ignorance and into civility.

We hurl faster and faster forward into a high-tech world filled with wondrous devices designed to connect us as human beings.

We struggle to keep up with the latest versions of: iPads, smart phones, and interactive TV.

But with technology leaping forward faster and faster; I wonder just how connected we feel?

We tweet but do we talk?

We post but do we listen?

We "like" but do we know how to love? In our pursuit of intellectual greatness, have we lost our ability to feel?

Has our desire to become smarter, inhibited our ability to become deeper, throwing us off balance, creating an emotional vacuum, abhorred by nature? Have we become a humanity incapable of love, respect and compassion for others?

Are we forgetting the simple things?

Why is intelligence and power considered a strength, while compassion viewed more as a weakness?

My son Nicholas is not an intellectual mastermind. Physicians have diagnosed him as cognitively-delayed. Other students have called him a retard. He has been described as a human being who is somehow less, a victim of our society's obsession with the mind.

Think about the words we use to describe those lacking in superior brain power; they are feeble, incapacitated, dim. Words that suggest weakness, inability, or an absence of light.

But I am Nick's mother, and although I may not have a superior IQ, what I see in my son is **not** something less, it is something **more**.

Perhaps you believe I am deluding myself in an effort to "super humanize" my inferior child? And maybe you are right.

But what I see is the truth, of a young man who engages **always** with his heart, not his head.

His life is heart-full. His spirit is bright and strong. He sees the beauty in the simple things. He loves from his soul. He is present, a young man who loves wholeheartedly and unconditionally, who brings forth smiles from the disheartened.

And although he may be defined by some as "simple" I believe his purpose here on earth is complex.

With the purity of his compassion, he educates, teaching the world of the shining and seemingly forgotten truth that:

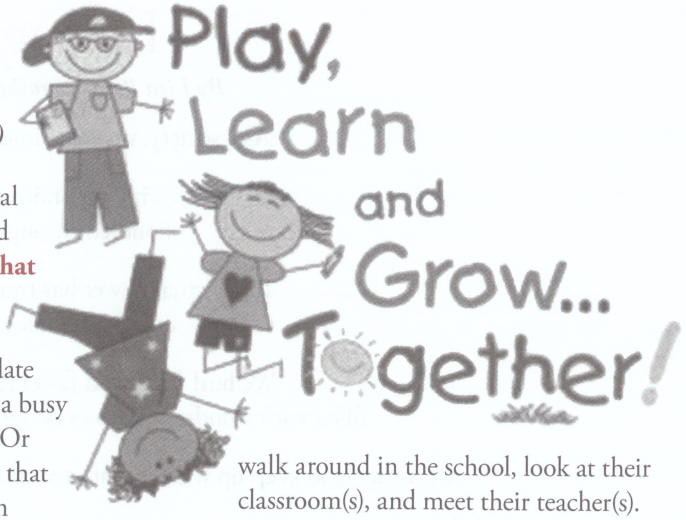


When we see with our brain, we judge.

When we see with our heart, we accept.

Are You Ready for the 2017-2018 School Year?

By Jennifer Bolander, Special Education Specialist, PWSA (USA)



I hope you all have had an enjoyable summer! The summers seem to pass very quickly – which may be a good thing since our children do like the routine and structure of school.

Here is a list of suggestions to help everyone get back into the school-year mindset:

1. Round up all of your child's documentation and paperwork. It is a good idea to do this now, when you probably don't have any meetings scheduled. Finding all of your child's IEPs, evaluation reports, progress reports, FBA reports and BIPs and putting them in one place will help you be better prepared for the next meeting.

2. Review your child's most recent IEP, as well as the FBA data and the BIP if applicable. This will refresh your memory on what your child's goals are and where/how they are spending each day at school.

3. On the IEP document, find the document's 'expiration date'. This may also be labeled the 'next annual review date'. **Make note of that date**; your child's next IEP annual review meeting should be scheduled **before that date.** Look ahead on your personal calendar – does that date happen to fall during a busy time for your family? Or does it occur on a day that is a scheduled vacation or no-school day in your state/district? As a parent/legal guardian, you are a member of the IEP team and can initiate communication with the team about the scheduling of team meetings and IEP annual review meetings. At least three weeks before the IEP annual review date, send an email to all members of your child's IEP team with at least two date/time meeting suggestions which would work for you. It is good to be proactive about this, especially if there are many people on the IEP team and/or you are bringing an additional person to the meeting.

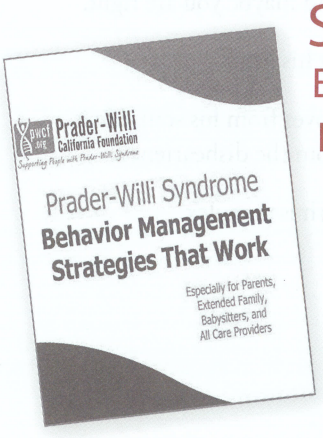
4. Attend any "Open House" or "Meet the Teacher" times scheduled at your child's school, so that they can walk around in the school, look at their classroom(s), and meet their teacher(s). If the school doesn't have anything like this scheduled, call the school office approximately one week before school starts and ask for a good time to come up and walk through the school. This is also a great opportunity, if at all possible, to provide the teacher with a one-page printout of basic information about your child (strengths, challenge areas, interests, a photo).

5. Gather the names, titles and email addresses of everyone on your child's IEP team. Communicate your concerns and requests in writing to the entire team!

Wishing everyone a productive and calm school year! ■

DVD- Behavior Management Strategies That Work

Especially for Parents, Extended Family, Babysitters, Care Providers



New in 2015, this **DVD** provides strategies to avoid, reduce and manage unwanted behaviors frequently associated with PWS. Parents of the toddler or young child will learn how to create a foundation that encourages cooperative interactions throughout the lifetime. Parents and care providers of the older child, teen, or adult will learn strategies to improve the flow of the day and everyone's quality of life. To purchase visit: http://bit.ly/2eHJKllPWSbehaviorDVD Total run time: 3 hours. $30.00 ■

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!

Meet the Junior Advisory Board of PWSA of WI, Inc.



The Junior Advisory Board members are from left to right: Makenzie Gaulke, Maya Luening, Maddie Tula and Kameron Boser.

PWSA of WI, Inc. realizes that engaging the growing number of interested youth is a natural step in creating the next generation of philanthropists. In 2017, the Junior Advisory Board of PWSA of WI, Inc. was developed as a way for youth ages 10-17 to learn about philanthropy and gain hands-on experience in event planning, volunteerism, program development, and fundraising within the Prader-Willi syndrome community.

The Junior Advisory Board will develop personal and professional skills that will prepare them for future board service and careers. The PWSA of WI, Inc. Board of Directors is extraordinarily supportive of the youth and will assist the members of the Junior Advisory Board with learning these skills.

If you are interested in learning more about this board, contact the program director, Joshua Escher at progdir@pwsaofwi.org or 920-733-3077. ■

Texas Prader-Willi Association CAMP Coming Soon!

It's coming soon! Attend our weekend overnight camp Oct. 27-29, 2017 for our PWS loved ones. Campers must be 8+ (7 if their parent attends), are provided one on one counselors, a PWS-friendly diet and a fabulous weekend with friends in Burton, Texas. Spots are VERY limited! Register now before sell out. Use PREGAMING for a $10 early bird discount.

Visit our website for info and register campers and counselors https://heartnater.wixsite.com/peoplewithsmiles2017 ■

For questions regarding camp, contact aggiearcaya@yahoo.com

SUCCESS!

The 7th Annual Molly's Pub Charity Golf Tournament benefitting Texas Prader-Willi Association was a huge success, raising just over $77,000! 46 teams had a great time. Our sponsors and goody bags were incredible! Subway again provided lunch, and The Olde City Pub provided barbeque dinner. There was lots to eat and drink and play and win…many thanks to all! ■

CHUCKLE CORNER

While traveling home from South Africa, my daughter Justice was randomly selected for extra screening at one of the checkpoints at the airport. They sent us over to a long table where other people were being screened and they searched her backpack. While that was being done, another officer asked her to put her hands out. Justice was very unsure of what they were asking and after I demonstrated what they wanted, she put out her hands and they swabbed them for explosives. They stuck the cotton swab in the machine and we waited. The security officer told us she failed the test and that they would have to swab her again. This time they swabbed her hands, pants and her shoes. Once again we were told she had failed. We now had quite a few security officers standing around us, talking amongst themselves in Afrikaans. They then asked me if they could search Justice. Of course I gave permission and a female officer began to pat her down. As she put her hands around Justice's waist a look of total fear came over her and she backed up quickly with her hands in the air. There was a lot of confusion and many words exchanged between the security guards, all of which we could not understand. When I realized what was happening I quickly pulled up Justice's shirt to expose her scoliosis brace. It took a lot of explaining to get them to understand that her brace was not dangerous. I will never forget the look on the security guards faces. At the time I didn't think it was very amusing, but now I look back and can't help but laugh!

~ Kristi Rickenbach, Blaine, Minnesota

Together in our Prader-Willi World- PWSA of Oregon and Washington

Submitted by Vonnie Sheadel, President, PWSA of Oregon and Washington

The Oregon and Washington chapters were separate and strong in the past. They helped families, informed doctors, changed laws, etc. After about 20 years, the chapter in Washington dissolved and participation declined in Oregon. We saw the need in Washington state and reached out across the Columbia River to invite them to our events and offer support. We had the opportunity to serve more and more families in Washington and we grew stronger in number.

In December 2014, PWSA of Oregon became PWSA of Oregon and Washington, allowing us to be more effective in providing resources and sharing funds over state lines. We also cooperate with PWSA of Idaho and BCPWSA. Our Northwest group is growing and we can learn so much more and help so many more people together! At this time, we have information on 207 people with the syndrome in these 2 states combined. There are certainly more. We continue to reach out and connect through Facebook and our website.

On August 11-13, we hosted a family campout in Amboy, Washington. We also held an annual picnic there on Saturday, inviting families and group homes. This year there were group homes in attendance. When they attend, it is helpful for parents of transition-aged kids to meet the caregivers and ask questions about life in a group home. One of our teens with PWS is an outstanding athletic director for this event. Tristan brings and sets up games, and also teaches other campers of all ages (with and without PWS) to play. We also enjoyed hiking and boating, fed the trout, and roasted fresh vegetables on the barbecue. We were fortunate to have Deanne and Jim Wells, Co-presidents of the Idaho chapter; and Heather Beach, President of the British Columbia Chapter join us for the fun and time to learn and share. It also gave us valuable opportunities to talk about the unmet needs in this area of the United States and Canada.

The most meaningful moments I notice at the picnic are parents talking to each other – sometimes for hours. There is no substitute for being able to connect with another parent with a child with PWS. Nobody "gets it" like we do! It was heart-warming to see how kids with PWS connected so well with their peers, and the adults with other parents. Everyone is so understanding and helpful! It was like our private, happy world of PWS! We welcome anyone who could benefit by the experience of spending time with people with PWS and their families. One year we had a family from Japan. They were planning to relocate to the West Coast. This gave them the opportunity to talk to residents of Oregon and Washington about what services, doctors and other living factors they needed to consider for their relocation. Sometimes we meet a new family who has never before met anyone else with the syndrome. Fast friendships are formed – and lifelong friends are made.

A **Contact Sharing List** is another valuable service we provide. It is a list of parents who gave permission to share their contact information with other families. It allows them to find and get in touch with other families in their area and/or of similar age as their person with PWS. We also offer information about doctors and specialists available in their area, whenever we can. We have a Prader-Willi Syndrome Oregon/ Washington Facebook page. It's a good resource among families for sharing and supporting our friends with PWS there. Events are posted to that page and also on our website, www.pwsaoregon.org. Check us out!

PWSA of Oregon and Washington celebrate and come together for the annual Christmas Party. It is typically held in the Portland/Vancouver Metro area on the second Saturday in December. In 2017 (and when possible), the party is followed by small group meetups. These meetups consist of topics of discussion such as IEP, baby/toddlers, transition to adulthood, parents of

continued on page 13



Jayne McMillan and Karin Ross helping with meal prep and setup at the picnic



Yeanna Woo and Mika Woo Nelson, enjoying fun on the paddleboat



Spenser Thomas and Tristan Passemard

PWSA OR-WA, continued from page 12

adults, etc. These topics are determined by the interest of those attending. Our guests with PWS enjoy a movie or activities with volunteer supervision during that time.

Some of our members are collaborative with other PWS organizations; we are happy to share event information and invite each other's groups to our events.

Our membership ranges in age from just a few months to 53 years. Most of them prefer to stay connected through e-mail and don't join us for events. We send out information that helps them know about events, research, health alerts and other Prader-Willi news. We offer advice such as acquiring guardianship, where to find advice for behavior, health issues, school, etc.

We do not have an active lobby group at this time. We do send out information when important issues affecting the disabled community arise. This way families can actively engage, and contact their respective senators/representatives.



Oregon, Washington, Idaho, and British Columbia chapters joined in the fun of meeting and spending time with other states.

New families often find us through our website, Facebook page or via referral from other families. We receive calls from caring social workers, school employees, family members, as well as parents of newly diagnosed infants throughout the year.

I encourage our membership to create an On the Move Walk or event. Our events and website are funded by membership fees and through generous donations of our PWS community, family and friends.

To our knowledge, there is one Prader-Willi specific group home in Woodinville, Washington and a handful of homes surrounding the Portland, Oregon area. There are also other group homes in Washington and Oregon which serve clients with PWS in the same home with non-PWS clients. For some, this has been successful.

Seattle Children's Hospital has an outstanding PWS clinic for children. We have hopes of facilitating development of a PWS clinic for adults in the Northwest, perhaps Washington State University or Oregon Health Sciences University. There is definitely a need.

In a perfect world, we want to convince states to our need for an inpatient hospital for PWS adults, similar to what was in Pittsburgh. Yes, it's a huge dream and we're a small organization; but everything begins somewhere! ■

IPWSO
INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

Update from IPWSO

Dear Friends and Colleagues,

A change in our leadership was anticipated at our General Assembly in Toronto, July 2016. Professor A.J. (Tony) Holland is now our President. Emeritus Professor of Psychiatry at Cambridge University in the United Kingdom, Tony has had a long engagement with Prader-Willi syndrome over the years, as well as President of the PWS Association (UK). Under Tony's guidance, IPWSO is progressing well.

We're becoming a Registered Charity in the UK and establishing "Friends of IPWSO", based in the USA. (Until then "Friends of IPWSO" contributions sent to PWSA (USA) "for international purposes" will be the most efficient and only tax deductible method to contribute to IPWSO). The most expedient, safe and secure method of donating to IPWSO is via iDonate.

We work around the world: supporting three new emerging PWS Associations (Morocco, Singapore, Georgia); we sent seven parents and professionals to our PWS International Conference, allowing them to return to their countries and disseminate information in their own languages; helped a young Moroccan woman whose brother has PWS establish a PWS Association in a country where disability doesn't always have a voice (she's now helping us support other Arabic-speaking parents in UAE, Jordan, and Libya). A parent in Georgia (also a pediatrician) has traveled throughout her country seeking families with PWS who need help. Our grant allowed her to attend the PWS conference in the U.S. and translated info for her outreach into Russian and Georgian.

In 2018, Singapore will host its first PWS Conference, gathering Asian countries together to share experiences and gain knowledge. New Zealand and Australian PWS Associations are helping this conference.

IPWSO is far-reaching and so important to those in need of support, information and development. We offer free diagnosis (in countries where diagnosis is not available), translation services and continued support at the grassroots level to desperate families seeking help. People like YOU help us continue our international mission!

Learn more about IPSWO via our website, www.ipwso.org, and YouTube videos. Thank you for your support and helping us spread awareness. ■

~ Tony Holland, President and Joan Gardner, USA Parent Delegate

Behaviour in PWS - Where? What? Why?

IPSO
INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

By Linda Thornton, Communications Coordinator, IPWSO

In .52 of a second, Google furnished me with a choice of 158,000 articles on behaviour in Prader-Willi syndrome. It is overwhelming and if I were a new parent, I would not know where to start. In fact, I probably would yell at Google, close the page and burst into tears. There are scholarly articles, there are profiles of behaviours, advice on managing behaviours of pre-schoolers, toddlers, pre-teens, teens, adults and so on. After 20 pages of Google and in amongst all the PWS articles, suddenly I find a page on growing marijuana and by this stage, I'm thinking "what a good idea!"

Personally, I think that finding a PWS Association either online or in reality, is the best possible thing to do. To be able to talk to someone face to face, or on the phone, or even just an email, will result in a calmer, easier-to-understand answer than trying to assimilate information from 158,000 different articles. That's just frightening.

The best possible thing you can learn about behaviour and PWS is that children and adults are all different. They are people first, and just happen to have Prader-Willi syndrome. Knowing your child, what motivates them, what they love and who they love, what scares them, what makes them anxious, and so on, is the first step towards understanding behaviour. When you stop and think about it, everything we do, from getting up in the morning to going to bed at night, invokes behaviour of some kind or another. Our behaviour sends messages to others in many different ways – no matter whether we have a disability or not. It's how we interact.

I've watched the behaviour of my 32-year-old over the years and can read her like a book. But I can also do this with my other children as well, the only difference is that my 32-year-old has more pages in her book. That's life. Whether her behaviour is challenging, whether she's testing whatever system that's been put in place, or whether it's her every-day behaviour, for me the most interesting thing is how she interacts with other people. I used to worry that she would 'snap' if someone said or did the wrong thing – and by this I mean a stranger, not someone she is familiar with because the more familiar she is with someone, the more likely she is to let loose!

The other day, for example, I listened to her on the phone to her bank. She was polite, very clear in her request to transfer funds and knew exactly what she was talking about. She quickly and efficiently changed one automatic payment into another. No problem at all.

I've heard her ring and make a doctor's appointment; phone the library and request a particular book; she manages a visit to the Vet with her cat perfectly well and asks all the right questions and makes sure she knows the answers. In an emergency (her concept of one) she will get herself down to the Emergency Department at the local hospital (with a staff person) and wait until she can be seen. She knows when she is ill (see previous blog on gastroenteritis). By being able to do these things, she avoids becoming anxious, frustrated, and angry. It has become so clear to me over the years that by first teaching her about making good choices, she is able to do so much more for herself.

Sometimes, in the middle of a catastrophic outburst, I tend to forget everything I've just said above and feel as though I'm clinging to the life-raft for all I'm worth. Just getting through to the other side of the meltdown is all I'm hoping for at this stage! I hate it when these happen because I know how terrible it is both for her, and for the person she is focussed on.

I began to wonder what sort of chemical imbalance might be in place when these meltdowns got underway. So I asked Tony Holland about this and about his research with vagus nerve stimulation. He responded,

"Our work on vagus nerve stimulation suggested that people with PWS essentially have a a low threshold for such outbursts and also impaired emotional control - in other words, people with PWS are easily triggered. Once it starts, such an outburst more easily builds up and leads to loss of control when compared to people without PWS. This appears to be improved by vagus nerve stimulation. The vagus nerve is part of the autonomic nervous system of the body that manages our response to threat - what we think vagus nerve stimulation is doing is normalising that response. The other rather different issue we are beginning to look at are two chemical (neurotransmitter) systems in the brain - GABA and glutamate - the former is inhibitory and the latter, excitatory. It may be that an imbalance of these two systems is important - a new study we are starting uses brain imaging to explore this hypothesis."

So, although I know that there is much behavioural research going on with Oxytocin* (Google: 1.10 seconds, 115,000 articles) and the vagus nerve stimulation** (Google: .72 of a second, 60,600 articles), I can't help but think that deep down it pays to really understand your child and what makes them tick. You may be surprised.

Editor's Note:
Linda founded the PWSA (New Zealand) in 1989, five years after the birth of her daughter with PWS. She was on the inaugural IPWSO board and has since served a further term before taking up her current position. She wrote much of the NZ publications and designed caregiver training programmes and is a Winston Churchill Scholar. In 1999 she received a Queen's Service Medal for her work with PWS in New Zealand.

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

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

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Attention Chapter Leaders!

Don't forget to register for the upcoming Chapter Leaders Meeting November 15-16 at the 34th PWSA (USA) Convention! Each chapter is allowed to have one representative attend for free (breakfast & lunch included). Need child care? No worries as we will be offering that as well. To register, please visit: https://pwsausa.regfox.com/chapter-leaders-day In addition, if you have ideas or topics you would like discussed, please email Crystal Boser at crystal.boser@aol.com or post them on the Chapter Leaders FB group. ■

The Medical and Scientific Conference at the 2017 National PWSA (USA) Convention will feature a new format. See page 2 for details.

Register PWSA (USA) as your charity of choice when shopping on Amazon and they will donate a portion of the price of your eligible **AmazonSmile** purchases to Prader-Willi Syndrome Association (USA) when you shop on **AmazonSmile.**

To get started: https://smile.amazon.com/ch/41-1306908

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