

The *Gathered View*

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

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

Year-End Angel Campaign

PWSA (USA) needs your help to meet the record demand for our services that we continue to experience. These include assisting with medical emergencies and school issues, Medicaid waivers, residential placement, assisting families who are dealing with behavior or medical issues, and many other daily support activities requested by the families who have loved ones with PWS. Did you know that our new parent support and mentoring program will serve over 200 newly diagnosed clients in 2016? PWSA (USA) provides immediate emotional and medical support to these families in need.

Your tax-deductible donation today will make a difference in the lives of people with Prader-Willi syndrome. In 2016 we provided support to families in all 50 states and 33 countries. Without your financial help, PWSA (USA) could not meet the increasing

needs of the PWS community. Often, there is no one else for families to turn to, and we could not meet their needs without you!

After 41 years, we are proud to have created the most innovative and unique family support programs in the rare genetic disorder community. Because of your past support, when a parent of a child or adult with PWS needs help, we are ready to answer the call.

PWSA (USA) is saving lives by a focused support for research that has the potential for immediate and high impact to the PWS community. The goal is to fast-track better treatment for the syndrome. Be an angel and make a donation to fund this life-saving research.

What are parents of loved ones with PWS saying about PWSA (USA) support?

“Thank you so much for your help. We got the letter saying our daughter is now on Medicaid Waiver! You have been a tremendous help in getting all this done so quickly. Thank you. It has not gone unnoticed.”

“You have been a great supporter and I can’t thank you enough for believing in me and my son and for giving me the tools and courage to do what is right for our son.”



*Martina,
age 10*

“Thank you for all of your help. You were there every step of the way and that means a lot to me.”

“Thanks for all you do. I always feel we have a friend to turn to in need.”

“I am in tears now. Every single time I reach out to you, you turn my cloudy day into sunshine by opening my mind for understanding with the information you provide.”

“You guys are incredible. Thanks for all your hard work and dedication.”

PWSA (USA) is a one-stop shop for families needing support across the life span of their loved ones with PWS. Nobody is ever turned away for financial reasons. **Help us keep answering the call by making a generous donation to our year-end Angel campaign.**

Watch for your Angel letter in the mail or donate online at www.pwsausa.org/angel-drive ■



Ethan, age 2

Volume 41, Number 6 ~ November-December 2016 ~ Our 41st Year of Publication

World Congress Pediatric GI – Montreal October 5-8, 2016

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

I attended this meeting to increase awareness of the new findings of urgent and chronic gastro-intestinal (GI) problems in persons with Prader-Willi syndrome. My travel was sponsored by both PWSA (USA) and IPWSO. Professionals from over 37 countries spoke with me at our exhibit. This was a very large and dynamic meeting of 2,800 doctors, nurses, and dietitians from around the world

Attendees were delighted with IPWSO's Medical Alert booklets in many different languages. The new PWSA (USA) Medical Alert booklet in English was the most requested item; this booklet has a helpful fold-out page for GI emergencies. I had

excellent conversations with many attendees. Most had seen children with PWS and thought they were familiar with the syndrome, but did not realize they had motility issues or mortality related to this. Many wanted to talk at length about challenges they had seen. One group of dietitians was hopeful that we could provide clear guidelines for them, and I was able to provide them with PWS nutrition booklets.

International attendees often were unfamiliar with the syndrome; I was told many times that this must be “more common” in the United States, and that it was “not seen” in their country. Many of these doctors could not believe that a normal weight could be achieved. I provided information about genetic testing through IPWSO, which many physicians were grateful to receive; I explained that genetic testing was the clearest way to make a diagnosis. In my opinion, this is a very important audience that we need to continue to try to educate on the syndrome. ■

Kathy Clark, PWSA (USA), eagerly shared great information, news about the organization, counseling, research, the syndrome, etc. with many attendees from around the world.



Carry PWSA (USA) Wherever You Go!

By Evan Farrar, M.A., Crisis Counselor, PWSA (USA)

Are you carrying PWSA (USA) in your pocket? If not, why not?

Because now you can by downloading the **FREE** PWSA (USA) app for your smart phone. With this app, you will have immediate access to all the important information you need on the PWSA (USA) Web

site with a touch of your phone screen. Forget a handout you wanted to share with a teacher or doctor? No problem. It's all on your phone! Through this app you can:

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

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

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

Executive Director View

By Ken Smith, Executive Director, PWSA (USA)

Through this column in recent issues, you have met Kathy Clark, whose area is Medical Affairs, and Stacy Ward, Counselor with our Family Support Team. It is good for our members to know about the people who through our national office are working for them to fulfill the mission of PWSA (USA).

In this issue I want you to meet someone who is not new like Kathy and Stacy, but has been with us for over a year as intern, consultant, and as of two months ago, became part of the staff. **Jen Bolander** is now our Special Education Specialist, a very important area of concern for parents of our school-age children.

Jennifer has a daughter in seventh grade, Sophie, age 12, who has PWS. Because of her, Jennifer became active in

School staff...are often quite surprised when...behaviors that are so troubling to them, are "normal" for those with PWS.

her Ohio state chapter, serving as president at one point. She also became interested in advocacy and education. She did a nine-month training with the Council of Parent Advocacy and Attorneys (COPAA), participated in the first Wyatt

Advocacy Training in Florida, and took the training offered by Wrightslaw. Being on-the-job is different, she has found, from reading it in a book!

When parents call national, if there are educational issues, their case or part of the case is referred to Jennifer. Her role is to reach out to the parents and, if appropriate, to the schools. She has done school training and attended IEP meetings via conference calls. Face-to-face would be nice, but she finds that the conference calls are generally effective. School staff, she notes, are often quite surprised when she tells them that the behaviors that are so troubling to them are "normal" for those with PWS. Yes, normal!

The youngest of ten children, Jennifer has been married for 21 years and has another daughter, Kate, who is 17 and a senior in high school. A graduate of John Carroll University in Ohio with an English degree, she loves to read and writes some, and she has fun playing with Henry, their 40-pound golden/collie (maybe) mix. ■

PWS Mom Leading Development on Carbetocin

By Rob Lutz, Research Chair, Board of Directors, Prader-Willi Syndrome Association (USA)

Sara Cotter, mother to a child with Prader-Willi syndrome (PWS), has formed a company dedicated to advancing treatments for PWS and related disorders. The company is called Levo Therapeutics (www.levotherapeutics.com). Sara has years of experience in the pharmaceutical industry, most recently as an analyst with UBS. She recently left her job to pursue the leadership of Levo Therapeutics full time. Her commitment to PWS through Levo Therapeutics is a positive step for development of therapeutic options for the PWS community.

Levo Therapeutics has announced that it has agreed to terms to obtain worldwide rights to Carbetocin from Ferring Pharmaceuticals. Carbetocin is closely related to oxytocin- it was specifically designed to have the benefits of oxytocin while limiting its potential unwanted side effects.

See the full Levo Therapeutics press release by visiting this link: <http://bit.ly/2fVETg9PWSAUSA>

Ferring has completed a successful Phase II study of Carbetocin, in PWS. There are three phases in drug development and Carbetocin is ready to enter the third and final stage. Carbetocin is the fastest and best chance for a therapeutic option for an oxytocin-like drug. Levo Therapeutics plans to complete its transaction with Ferring Pharmaceuticals and build financial and human resources to perform a Phase III trial with PWS. If successful, they could then be in position to seek approval from the FDA for its use in PWS.

Exactly how the funds we raised to support the further development of "oxytocin" may be best used with Carbetocin/oxytocin is being evaluated. It is, however, clear that through our raising of substantial funds as a PWS community, we have spurred increased activity on oxytocin/Carbetocin that led to this announcement.

The result of that activity- having a talented PWS mom leading the development of Carbetocin- is a very exciting step forward! ■

*"You may not control all the events that happen to you, but you can decide not to be reduced by them."
- Maya Angelou*

Warning – Medication combinations may fatally impair breathing in PWS!

Kathy Clark, R.N., CS-BS, Coordinator of Medical Affairs and Janalee Heinemann, M.S.W., Coordinator of Research and International Affairs, PWSA (USA)

We want to remind parents that impaired breathing is a leading cause of death in people with PWS. After the recent unexpected death at home of a young person with PWS, we want to alert parents and professionals to the potential risk factors with combinations of medications, especially after surgery. PWSA (USA) continues to collect and analyze valuable data from families who generously offer information after a death has occurred.

Communicate about medications with every health care provider

Bring a detailed list of every supplement and medication by name and dose to every health care visit, and be sure this is updated at each office, every visit. It is also helpful to bring all current medications to each visit. This includes vitamins, dietary supplements (such as MCT oil) or over-the-counter supplements (such as coenzyme Q 10 or melatonin); allergy medications (Flonase, Zyrtec). Some over-the-counter products can play a part in creating serious drug interactions (such as Benadryl). Well tolerated prescription drugs (such as clonidine) can cause increased sleepiness and decreased breathing after surgery or in combination with a new pain medication.

Medication issues unique to PWS

We know that people with PWS often absorb and keep medications in their system longer than the average person. The medications of greatest concern include prescription pain medications, anesthetics, and psychotropic (behavior) medications, all of which have the potential to depress breathing in any person. Combinations of several new medications create the most worrisome situation and is most likely to occur after surgery.

Anesthesia: While your child will be monitored closely during the procedure and in the recovery area, remember that it often takes longer for the effects of anesthesia to wear off in individuals with PWS. This is a greater concern in outpatient surgeries, where the goal is to send the patient home as soon as possible. We believe it is important for persons with PWS to be monitored longer (with many people with PWS staying overnight) to be sure that breathing and alertness have returned to normal.

DO NOT allow your child to eat after surgery until they are fully awake and alert. Insist that the progression from liquids to solid food take longer

We know that people with PWS often absorb and keep medications in their system longer than the average person.

than the surgical team usually suggests.

Choking is a significant risk in PWS and it increases with sedation. Gastroparesis (stomach stops sending food to the intestines) can occur after anesthesia which can create a blockage, which is a medical crisis. This can be avoided if the digestive system is given more time to “wake up”.

Pain medication: People with PWS are less sensitive to pain than typical people and lower doses are recommended. The combination of anesthetics and pain medication can lead to excessive sedation and decreased consciousness. Since both of these substances may take longer to clear in individuals with PWS, great caution is needed.

What are the warning signs?

A valuable and early sign is a change in your child’s personality, alertness, liveliness, talkativeness or sense of humor. After a surgical procedure, do not take a child home from the hospital on pain medication who “looks medicated.” Let the professionals monitor your child in a safe place until they are fully recovered.

Breathing issues are **always** an emergency. Sleepiness may be a sign of slowed breathing (too out of breath to stay awake). **Lip color** should be monitored if sleepiness occurs – bluish lips are an emergency. The person who is overweight is always at a higher risk for breathing problems.

Pain is also a warning sign. Most pain medications and anesthesia slow down digestion, and abdominal pain can occur. Take **abdominal pain or a distended abdomen** very seriously and head to the ER when this occurs.

PWSA (USA) has additional handouts explaining the gastrointestinal, anesthesia and surgery considerations for persons with PWS on our PWSA (USA) app and our Web site – www.pwsausa.org.

Reviewed by Elizabeth Roof, MA, as well as members of the PWSA (USA) Scientific Advisory Board (Merlin G. Butler, MD, PhD) and Clinical Advisory Board (Janice Forster, MD, Linda Gourash, MD, and Daniel J. Driscoll, MD, PhD). ■

Butler Honored with Award for Genetic Research

Dr. Merlin Butler, a professor and researcher in genetic disorders at University of Kansas Medical Center, was a selected recipient of the 2016 Chancellors Club Research Award for his research and teaching by KU Endowment's Chancellors Club. He was recognized at the Oct. 21 Chancellors Club celebration in Lawrence.

Butler, a leading researcher in the rare, genetic obesity-related Prader-Willi syndrome, has been a faculty member at KU Medical Center since 2008 in the departments of Psychiatry and Behavioral Sciences and Pediatrics. He also is the director of the Division of Research and Genetics for the clinical department and the medical director of the Genetics Clinic.

Butler has invested much of his research career in the delineation of complex genomic mechanisms, specifically in Prader-Willi syndrome (PWS), the most common known cause of life-threatening obesity in children and in increasing awareness to improve care for those affected with this disorder of genomic imprinting.

“What I find to be the most rewarding part of my work, and in which I am the most proud as a researcher, is the positive changes made in translational research, in treating and caring for patients with rare genetic conditions, and in being a small part of improving their quality of life and outcome,” Butler said. “What we have contributed to the study of PWS has led to the discovery of new genetic principles and concepts in the field of medical genetics by the characterization of a new class of genetic defects that play a role in development, cancer and aging.”

Butler's research in the 1980s led to an increase in knowledge and understanding in genetics, including the cause and diagnosis of Prader-Willi syndrome. Butler was the first to characterize differences in chromosome staining properties in families with PWS; he found that chromosome 15 donated by the father led to chromosome deletion in the child. A similar deletion was found when the chromosome came

from the mother, though it resulted in Angelman syndrome. This research led to a new discovery in genetics referred to as genomic imprinting.

“These discoveries began his pursuit to unravel the genetic mystery behind the causes and unusual mode of transmission underlying these syndromes,” wrote Ann Manzardo in her nomination letter. Manzardo is associate professor of psychiatry and pharmacology at KU Medical Center.

Butler is chairperson of the Scientific Advisory Board of the Prader-Willi Syndrome Association (USA) and received the Lifetime Achievement Award from that organization in 2008.



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Butler is prolific in publishing about his research. He has published more than 400 research articles and multiple book chapters, and he has edited several journal issues and two textbooks. Among his published works is a standardized growth chart for PWS infants and children with and without growth hormone, published in 2015 in the journal *Pediatrics*, which serves as a guideline for growth hormone treatment in PWS.

The University of Kansas is a major comprehensive research and teaching university. The university's mission is to lift students and society by educating leaders, building healthy communities and making discoveries that change the world.

Source: bit.ly/2eBKfPRpPWSAUSA ■

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

Development/Communications



November and December are wonderful months to help raise funds for PWSA (USA). Your friends and family are looking to give to a cause they care about during the holiday season. By creating an

online fundraising page, you can provide them an easy way to make a difference!

Setting up your page only takes a few minutes. Once completed, you will be able to send out a link to family and friends through social media and email, asking them to make a donation to PWSA (USA) on your behalf. It feels good to make a difference, and it doesn't get easier than this to do so! Help all those touched by PWS this holiday season by creating your page today.

Go to <http://www.firstgiving.com/pwsausa/2016-ewalk> and click the "fundraise" button to get started today.

For questions or assistance, please contact Leanne Gilliland at LGilliland@pwsausa.org or 941-312-0400 ■



A BIG thank you to our generous community that helped make the **2016 Giving Challenge** a huge success! Over 430 donors helped us exceed our goal of \$100,000 by raising over \$109,000

for PWSA (USA) in 24 hours! We couldn't have done it without you. ■

Dedicated golfers made our day a HUGE success!



On Saturday, August 20th **PWSA, WI, Inc.** held its 16th Annual Golf Benefit. Although the skies opened up and flooded portions of the course forcing us to cancel the actual

Prader-Willi Syndrome How Parents and Professionals Struggled and Coped and Made Genetic History

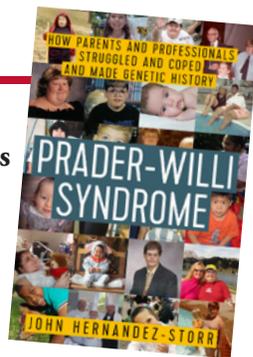
By John Hernandez-Storr

This amazing 256-page book gives never-before-told historical facts on the evolution of the medical world working to understand Prader-Willi syndrome (PWS) entwined with intimate, personal stories of the original PWSA (USA) pioneers. As the BlueInk review states, this book is "A seamless blend of case history, detective story, and medical mystery." The author, John Hernandez-Storr, who is the father of a daughter with PWS, spent years doing personal interviews with many of the key PWS professional and parent pioneers.

John Hernandez-Storr has very generously offered to donate all of the proceeds for books sold through PWSA (USA) back to the Association.

To order your copy, go to:

<http://www.pwsausa.org/product/prader-willi-syndrome-parents-professionals-struggled-coped-made-genetic-history/> or call 941-312-0400. Cost: \$15 plus shipping ■



Doing some holiday shopping online? Don't forget to register PWSA (USA) as your charity of choice when shopping on Amazon! Amazon will donate 0.5% of the price of your eligible **AmazonSmile** purchases to Prader-Willi Syndrome Association (USA) whenever you shop on AmazonSmile.

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

golfing, we made the best of it by hosting fun activities, such as a putting contest and 14th hole contest inside the clubhouse. Once the rain stopped, the fun was moved outdoors where people competed to win cash and prizes. Attendees enjoyed a

delicious lunch, participated in the silent auction and went home with a door prize. Thanks to dedicated golfers, the day was a success! ■



Kenley and Dylan Nissen met Clint Hurdle during batting practice after winning the Meet & Greet package during the Golf Benefit silent auction.

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From the Home Front

Joan Gardner: My IPWSO Story

- As edited by Andrea Glass



Joan and Jim

One morning, I woke up and found myself the USA Parent delegate to the International Prader Willi Syndrome Organisation (IPWSO) with a life full of new friends and amazing experiences. How did this happen?!

In December of 1968, our son Larry was born and by March we learned from a pediatric neurologist that he had Prader-Willi syndrome. Forty-eight years ago, there was no internet and actually only two medical journal articles which Larry's doctor withheld for several years despite my complaints that we wanted them. He was "afraid to scare us"! Really, an exact quote!

Minnesota, our home state, was the repository of PWS information in the early days. We can take no credit



Larry and his best friend

but the first successful dedicated PWS home was founded here for 15 residents by determined parents who collected donations at an exploratory meeting. They gathered \$15 and went to work. Marge Wett, then PWSA executive director, worked with the national board for 14 years out of her house here and the first and fourth national conferences were in Minnesota.

As energy had slowed down in the older families, my husband Jim was elected president at a PWSA of MN meeting that he had not even been able to attend. We began gathering and networking our Minnesota families. We had a pool of names and old attendance sheets in a tin box that still smelled of old cigarette smoke. Jim also served as treasurer of PWSA (USA) for many years. We became devoted attendees of the PWSA (USA) annual national conferences, where we learned all the new research and management advice, such as it was at the time. Still, there was no Internet.

Fast forward to 2001, as complete amateurs, we hosted a combined IPWSO and PWSA (USA) conference



Larry with the biggest fish!

in Minnesota. There were 1250 attendees: over 200 scientists, 120 professional caregivers, 300 people with PWS, including babies and adults (requiring 100 volunteers a day!) and 500-plus parents. We had no staff and little experience but an amazing cadre of volunteer friends and truly expert international program chairs. I still cringe when I enter the conference hotel, but it was a huge success and even provided funds to MN, PWSA (USA) and IPWSO for future programming. We were very lucky!

IPWSO has taken us to Italy, Romania, Taiwan, New Zealand, Cambridge and, of course, Canada. Attending an international or regional conference is an incredible experience and worth every extra effort. There are scholarships if one needs financial help to attend. If you can afford it, contributing to someone else's experience is just as rewarding. PWS conferences are unique. The experts come to share with each other in order to advance PWS knowledge and management. Even more amazing, they come to share their time openly with us, the families and our children. Informal encounters in the hall, lobby or meeting breaks are times to connect with them. They welcome us and no one is too important to spend time with an interested family.

IPWSO provides an opportunity for people around the world to get an official diagnosis, learn how to care for their child, receive information in their own language, attend a conference, or even put on a program for the first time. Sharing together is what has brought us to this extraordinary level in Larry's 48 years. ■

PWSA, WI *continued from page 6*

The 2nd Annual **Strike Out PWS** bowling event was held on Saturday, September 17th at AMF Bowlero. This year 107 people, including 63 individuals with Prader-Willi syndrome, bowled and participated in the 50/50 raffle & silent auction. Everyone had a blast visiting with their friends here in Wisconsin along with a few who came from out of state. It was a great day for "getting our roll on". ■



Congrats to Laura Schutz, seen holding the handmade quilt she won in the silent auction at the Strike Out PWS event.



Prader-Willi Syndrome Association (USA) 34th National Convention

November 15-18, 2017 Caribe Royale in Orlando, Florida

Convention Co-Chairs: Jackie Mallow & Michelle Torbert

The 2017 National Convention Planning Committee is well underway in creating an experience that will enhance the quality of life for everyone who is touched by Prader-Willi syndrome (PWS). Professionals will have the opportunity to enhance their skill set as they network with fellow colleagues in the field in workshops, seminars and meetings. For families, this is especially a unique opportunity for those from around the United States to meet, ask questions, and feel supported by some of the world's experts. At the same time, your children, young and old, will have fun, make new friends and become reacquainted with those they've met in past years. ■

Schedule of Events / Committee Chairs

Wednesday, November 15th

New Parent Mentors & Chapter Leaders Meeting -
Lori Moline/Diane Seely & Crystal Boser/Rob Seely
New Parent Mentors & Chapter Leaders Reception
Clinical Advisory Board Meeting - Dan Driscoll
Scientific Advisory Board Meeting - Merlin Butler
Professional Providers Advisory Board Meeting -
Patrice Carroll/Mary K Ziccardi

Thursday, November 16th

Chapter Leaders Meeting - Crystal Boser/Rob Seely
New Parent Mentors Meeting - Lori Moline/Diane
Seely
Scientific Conference - Merlin Butler supported by Dan
Driscoll/Jim Loker/Kathy Clark & Ann Manzardo
Professional Providers Conference - Patrice Carroll/
Mary K Ziccardi
Scientific Reception
Welcome Reception/General Conference - Debbie
Peaton

Friday, November 17th

Rare Disease - Merlin Butler
General Gala - Debbie Peaton/Kristi Rickenbach
YAP Gala - Debbie Peaton

Friday and Saturday November 17th & 18th

PWSA (USA) General Conference - Kristi Rickenbach
Family Support - Kate Beaver/Evan Farrar
Youth & Infant Program - Michelle Holbrook
Youth & Adult Program - Kim Tula
Sibling Program - TBD



Photos on pages 8 and 9 are of attendees at the PWSA (USA) Convention



Great Ideas for the Holidays!



From a 0-5 e-mail group comes a list of non-food related activities and ideas for the holidays. Start a new tradition this year and share with us!

1. Ring bells for Salvation Army
2. Participate in or host a Turkey Trot
3. Christmas Lights Appreciation Walk
4. Design luminarias to decorate your walkway
5. Go on a hike
6. Pull out / make CDs of favorite songs to sing and dance to
7. Put on a "Family Dance" with a special family music album
8. Put together puzzles
9. Take gifts to neighbors
10. Sing carols at homes for the elderly
11. Make a family scrapbook of memories from past holidays/family events
12. Create scrapbook pages for photos you will take during the holidays
13. Play a pick-up game of softball, waffle ball, hockey, kickball - you get the point!
14. Play board games (You can even have a tournament if you like competition!)
15. Decorate ornaments
16. Host an ornament-making party
17. Go caroling!
18. Visit local attractions (parks, museums, etc.)
19. Make homemade holiday cards
20. Collect leaves to make leaf-rubbing cards



21. Watch holiday movies
22. Share your favorite holiday memories
23. Read holiday books such as "T'was the Night Before Christmas"
24. Create a Family Tree - make a holiday tree with homemade ornaments using family pictures
25. Go for a hike to find and see wild turkeys
26. Scavenger hunts foraging for greens and such for decorations
27. Write your own Christmas story; make a book
28. Fill a count-down calendar with good thoughts for the day. Every day open a good thought. A good opportunity for positive reinforcement for good behaviors
29. Make puzzles out of old holiday cards, pictures, etc. (Put velcro on the back for extra OT work pulling and putting them together)
30. Tobogganing
31. Walks all bundled up, in the evenings after dinner, whenever there is snow falling.
32. Go to the neighborhood rink for a make-shift hockey game
33. Build a snow family
34. In the snow banks created from the snowplows, we love to dig a snow fort
35. Snow ball battle with the neighbors (their fort is always right across the street from ours)
36. Make homemade Christmas wreaths
37. Take small gifts, stockings etc., to a local children's hospital



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

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

PWSA (USA) Member Benefits include:

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

e-News...

Reminder – stay informed and current with PWSA (USA)'s free e-News. Sign up at www.pwsausa.org and watch for the next update!

Chapter Spotlight - Indiana

By Brandon Watson, Chapter President
(as interviewed by Kathryn Lucero)

I became involved with PWSA of Indiana after attending a local conference in Indiana organized by then President Amy Pfeiffer. She encouraged me to become involved, and I have been with the organization ever since. I have worked as a residential provider for individuals with disabilities including PWS for over 10 years in Indiana. I served as chair of the board for two years before becoming president of the chapter this year.

- Brandon Watson

KL: Has your Chapter been active for a long time? Talk about the support you have received from other chapters, past officers, national. Is your member list all part of national? Do you have any other ways to alert people that there is a State chapter, i.e., the medical community?

BW: We have been around since 2008. We have had enjoyed support from the Wisconsin chapter and have had assistance from PWSA (USA) specialists like Mary K Ziccardi, Elizabeth Roof, and Tammie Penta. We have recently been working with IU Health and Dr. Johnson to let families know what support is there for families. We are fortunate that we have a lot of former presidents involved including VP Amy Pfeiffer (chapter founder), Jim Koerber and Teresa Walker, who both serve on the board now.

KL: What is your vision for the Chapter?

BW: Every individual with Prader-Willi syndrome will achieve their maximum potential through our research, education, awareness, lobbying, advocacy, and support of families and caregivers.

KL: Number of members, age range of family member with PWS: Do you have any idea how many people with PWS in the State?

BW: We know of about 125 individuals in the state with PWS and estimate by census there are about 400.

KL: What types of social functions has the Chapter sponsored? Has the Chapter sponsored an educational type meeting?

BW: We started the year with a great baseball outing at Victory Field in Indianapolis with a game between the Pirates and Reds. PWSA of Indiana obtained a block of tickets and gave them out for free to our families. Clint Hurdle did a private meet and greet with our group prior to the game.

Also, we started a teacher recognition program where members nominated teachers who went above and beyond with their work with PWS and we would go to the schools and honor them with a certificate and gift card.

We held a regional conference October 15 featuring Janice Agarwal, Mary K Ziccardi, Tammie Penta, Dr. Nancy Johnson and Jessica Rorrick, Jackie Mallow, Sara Clemson, and Nancy Anker-Wright. We covered a variety of topics with our diverse range of experts, and the audience was very engaging. Highlights included local and national resources available to families and providers in attendance. Thanks to Riley Children's Hospital for being a great host.

KL: Is there a doctor network that the Chapter has built or is trying to build? Is there networking to share doctors?

BW: This past year IU Health, under the guidance of Nancy Johnson, started PWS Clinic days, due in part by the efforts made by PWSA of Indiana and FPWR. Additionally, we are in the process of collecting information to create a doctor database for families to use. This is exciting.

KL: Are there any fundraiser plans? Have there been past fundraisers?

BW: Our annual OTM event was the largest fundraiser this year.

We also held a brains and brew event September 30 in Mishawaka. We had a team trivia contest which sold out at a local pub; another local charity, Girls Pint Out, teamed up with us to raise awareness and funds for PWS.

KL: Do you have a Web site?

BW: We do! www.pwsaindiana.org

KL: Has your state or does your state have plans for political or legislative activism?

BW: We have had preliminary talks with some legislators and plan on building on that in the upcoming year.

KL: Are there ties with advocates for school related issues? Ties with Department of Developmental Disabilities?

BW: We have a very diverse board that had experience with Indiana's Department of of Developmental Disabilities including residential providers, case managers, and behavioral therapists. We have provided trainings and support to residential staff, inpatient units, and schools across the state free of charge. We have had members of the chapter present at international and local PWS conferences on residential supports.

KL: Are there group homes in your State? Are the providers members of the Chapter?

BW: Indiana has group homes and a model called waivers. The waiver system is typically two-three individuals in a home-like setting with staffing supports, and we have PWS-specific waiver homes throughout the state. We had two providers that were members of the chapter in this past year, The Mentor Network and ResCare. ■

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Regional Meeting in New England

By Andrea Glass

On October 1, 2016 a regional PWS conference was held in Burlington, MA. The conference was sponsored by three organizations: Advocates, Latham Centers and the Prader-Willi Syndrome Association of New England. There was a social evening the night before and a full day schedule on conference day.

Dr. Jennifer Miller provided a keynote seminar on diet and supplements. She shared the current changes taking place in the PWS diet thought process, which includes using a diet with lower carbohydrates and higher fat and protein. Dr. Miller emphasized that caloric requirements and specific macronutrient composition of the diet need to be individualized – there are no recommendations that apply to all individuals with PWS. The diet eliminates sugars, artificial sweeteners, and sugar substitutes (including Stevia), reduces carbohydrates, emphasizes that even good carbohydrates should always be accompanied by protein, and substitutes unsweetened flavored almond milk for cow milk. Latham Centers has changed the diet of all residents to this new way of thinking and reports that the individuals with PWS have responded well to these changes in diet. There is anecdotal evidence that an increase in protein and fat at breakfast time can help with hunger. Dr. Miller also shared information regarding supplements that parents have been trying. Emphasis was placed on the fact that every child with PWS is an individual and, therefore, has different needs for possible supplements. Each parent should discuss supplements with their child's doctors before starting them to learn about the



A few of the attendees at the regional meeting in Burlington, MA.



Dr. Jennifer Miller



Jackie Mallow

risks and benefits of the various supplements, and they should only be tried with a doctor's permission and dosing recommendations. At lunchtime, Dr. Miller shared information regarding all the current research and clinical trials. Parents and those with PWS hung on every word of hope for a breakthrough.

Consultant Jackie Mallow presented a seminar on the hot topic of housing advocacy. There are many changes in both federal and local regulations regarding housing for the disabled. Many of these changes have affected current PWS residences and will impact the creation of new residences. The issues include limits on the size of group homes, shared living arrangements, civil rights, and work environments. Jackie addressed staffing requirements and training, parent and community involvement and what it takes to be successful. She emphasized that

24-hour awake supervision leads to less anxiety, and a specialized home works best and that the number of roommates depends on the individuals.

Tammie Penta, a retired police officer, handles crisis calls for PWSA (USA) when law enforcement issues arise. She advised that parents and residential providers should reach out to a community resource sergeant of the local police; you may be able to fill out a blue form. This alerts the police to the special needs of the PWS individual. (Please check with your local authorities for best practices regarding such issues, alerts, and forms.) Additionally, neighbors need to understand about PWS and what they could possibly encounter. This seminar was not for the novice PWS parent. Arrests of PWS adults can be made for disorderly conduct (tantrums), assault (during tantrums), theft (in a store), or damage (during tantrums). It is always helpful as now for the parent, guardian or provider to stay calm in all situations that involve the police. If someone with PWS is arrested or brought to the hospital for out-of-control behavior, call PWSA (USA) immediately for help. The other speakers and topics included: Sexuality (Marc Ewings and Cheryl LeBlanc from Advocates), Home/School Collaboration (Kathy Marvelle, Merrimac Schools and Laraine Wilson, Cotting School), Transitions (Scott Fitzgerald and Melissa Hyer from Latham Centers), Mental Health (Barb Drotos), Positive Behavior Intervention and Supports (Maureen Tracey), and Person-Centered Planning (Cheryl Chan from Person-Centered Planning Partners). ■

My Aunt Donna

Good morning!

I thought I would share my aunt's story with you. She was a miracle at birth and is still a miracle to this day.

Her name is Donna Pabich. She now lives in a nursing home in Wisconsin. And yes, she is 63 years old. She will tell you the story of when she was born. How the doctors told her mother she wouldn't live very long. So her mother put her in a cigar box by the wood stove to keep her warm. Lo and behold, she has outlived many of her siblings!

Her mother was her caregiver for many years until failing health prevented her from taking care of her. Donna was transferred to Clark County Health Care Center in Owen, until she was accepted into Western Wisconsin Cares. She then lived in assisted living with her roommate, Sandy, for almost 20 years! They were best of buds until Sandy had to move out of their apartment.

I didn't really understand Donna's syndrome in my years of growing with her. I just knew she stole food all the time and my grandma would scold her. And her physical and mental condition were just "different". I would play ball with her, color with her (Donna loves to color!), etc. I wasn't in her life that much in my later years. She would come for Christmas at my parents' house (both of which are now deceased). My mom was her guardian until her passing two years ago. Then I became Donna's guardian. Since then, I am very much a part of her life and find out more and more about her every day! It was so cute to visit her and Sandy in their apartment. Everything had to be separated. Sandy couldn't touch Donna's things and vice versa. Everything was labeled with their names. One couldn't even put trash in the other's garbage!! And yet, these two had a bond for many years, until this past year when Sandy moved out.



Since January, Donna has been in and out of the hospital. She never recovered well enough to go back to her apartment; hence, the nursing home where she is living now. She is doing well. I am told she is in "uncharted" territory as she is the longest living person with Prader-Willi syndrome in the state. And perhaps the country? If true, perhaps your organization would like to follow her situation, as it may be helpful information to others.

That's the story of my wonderful aunt. Shown is one of my favorite pictures of Donna and my Grandma on the farm. The other picture is recent.

Thanks for your time. I hope sharing her story can help someone in some way. ■

Submitted by
Deb Hollman (Brahmer)
Medford, WI

Editor's Note: At press time, we learned Donna Pabich had passed away.



Counselors Corner

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

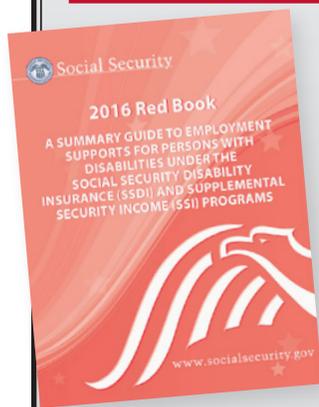


Did You Know about this resource for support to families who have an adult child with PWS living at home?



Did you know the International Prader-Willi Syndrome Organisation (IPWSO) has a project called FamCare which develops resources to support families with an adult child with PWS living at home? The resources can be downloaded directly from the IPWSO Web site. Each resource is available in a variety of languages including English and Spanish. Topics covered include: basics of a Healthy Adult Life, coping with change, and a variety of behavioral challenges are addressed. Although the materials are designed primarily for adults, several of the resources include information and strategies that can be useful to parents of younger children with PWS. PWSA (USA) Family Support Counselor, Kate Beaver, works with the FamCare project and has contributed to the content of many of these great resources. So when you have a moment, check out this amazing webpage and visit it often as new resources are posted on a regular basis. ■

<http://www.ipwso.org/famcare>



Did you know people with disabilities receiving Supplemental Security Income (SSI) are eligible for work incentives? These incentives are summarized in a Social Security Administration (SSA) publication called the **Red Book** which is updated every year. Many parents/guardians, and even professionals in the disability field, are not aware of these incentives which are designed, in part, to help people with disabilities to work more hours while maintaining their SSI benefit. We encourage all parents/guardians of a working age person with PWS to find out more about these incentives by reviewing the Red Book available online. Knowledge is power and in this case your adult son or daughter with PWS might be eligible for an incentive that expands their ability to work. – Evan Farrar, PWSA (USA) Family Support Counselor ■

<https://www.ssa.gov/redbook/>

CHUCKLE CORNER

My daughter Aimee is 6, and we like to think of her as Amelia Bedelia of the children's books. She is a very literal child who does not always understand sarcasm or grey areas. One night at dinner I noticed she was eating everything but her peas. I told her if she wanted her seconds, it was time to hit the peas. So she promptly began to hit her peas with her fork. After a laugh on my part, I corrected myself and told her to EAT her peas.

~ Dawn Atwood
Burlington, Massachusetts

[Ed. Note: This is a great example of how our kids take everything literally – that they have trouble with abstract thinking.]

Want to Share YOUR Story?

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

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

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

Reese, Hudson, Stephanie and Benjamin are all smiles about Hudson's Hope's success!



Stephanie and Benjamin Petrie of Columbus, Ohio, hosted a cocktail party in honor of their son, Hudson, on October 7th. “Hudson’s Hope” was a great success! Friends, neighbors, and providers all came to support Hudson and his family. The evening included raffles, a photo booth and a great speech from big sister, Reese! Over \$9,000 was raised in support of PWSA (USA) and nine runners on **Hudson’s Team of Hope** in the Nationwide Children’s Hospital marathon. A big THANK YOU to the Petrie Family!

Hosting a local fundraiser can be an empowering way to raise awareness and funds. Whether organizing a jeans month at the office, hosting a walk, or setting up a lemonade stand—you can make a difference. Contact Leanne Gilliland to get started planning today! Email LGilliland@pwsausa.org or call 941-312-0400. ■

Best Practices Publications from PWSA (USA)

Looking for a BIG collection of best practices? Our mission is to promote awareness and education to our families, healthcare community and the public; PWSA (USA) is proud to present “Best Practice Guidelines for Standard of Care in PWS.”

Here are presentations, abstracts and guidelines for presenting standards of care in over 80 nations. With over 200 pages, this breakthrough guide is for all caregivers, parents, teachers and healthcare providers. This invaluable collection features guidelines and models developed for use across all environments where people are caring for individuals with PWS.

From IPWSO Caregiver Conferences in 2008 and 2009, both print and CD versions are available via our Web site. Get your copy of this publication on the PWSA (USA) Web site shop by visiting: <http://www.pwsausa.org/shop/> ■



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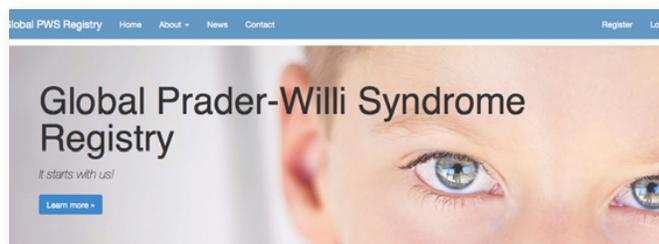
Global Prader-Willi Syndrome Registry

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

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

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

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



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

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

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

The Members Only section requires a password: member20

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

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- Sara Dwyer, Editor
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- Andrea Glass
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- Kathryn Lucero

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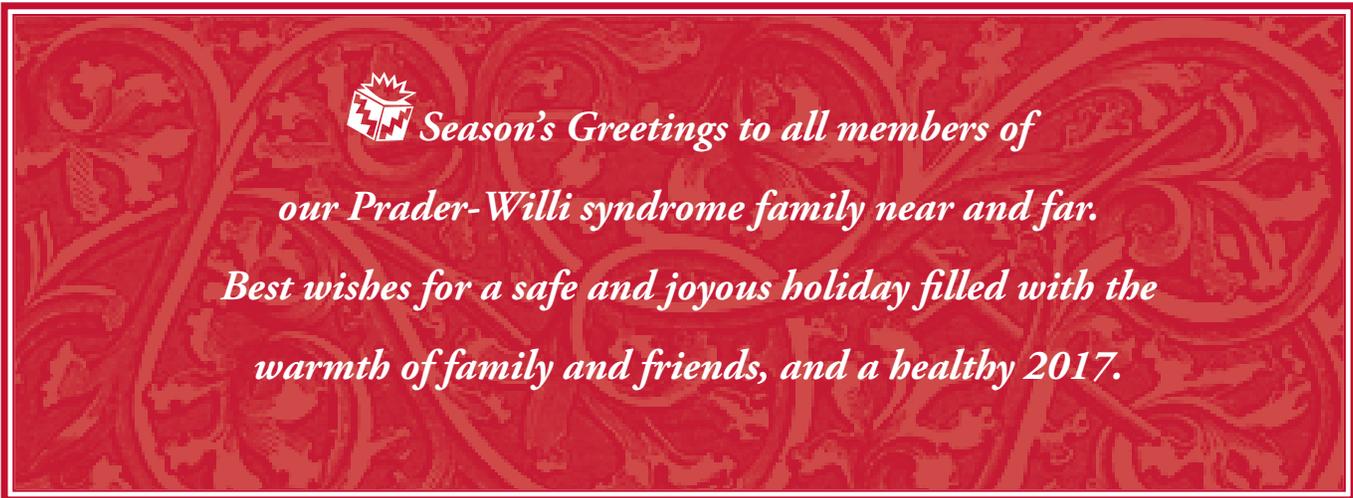
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