

The *Gathered View*

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

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

I am 66 Years Old!

Editor's Note: I received a lovely email from Boothie this Spring, and was very impressed with her desire to share her story. Below in her words, may I introduce you to "Boothie".

I am writing this about me. My name is Susan Jane Booth. I was born March 18, 1950. My family names are Mr. Willard Booth and my mother name is Millicent Booth. They live in Watertown Connecticut. I have a sister name Sally Welman live in Kennebunk Maine. I born at Waterbury Hospital. I attend Baldwin High School.

I move at Riverbrook Residence in Stockbridge, Mass on September 2, 1963. I am 66 year old. My parents took me to New Haven UConn Clinic. My doctor Suzanne Cassidy she check me over and took blood from my arm then I found out. I felt good I have PWS. *(relief with a diagnosis)* My family feel alright. That **meant to me** that I had to watch what I eat.

I work at many jobs: Marian Fathers in Stockbridge, MA; Riverbrook on Main our craft center in the Stockbridge Town Hall; Roots, Shoots and Blooms is a local landscaping company; Kripalu Yoga Center in Lenox, MA and at Riverbrook's Vegetable and Flower Garden. I put the name on the envelope and put the slip in. Riverbrook on Main I made the product for craft show. Roots Bloom- in Alford at a lady house, I pick off dead buds. Kripalu mail room: I fold paper up put clip on it. Riverbrooks garden, we plant in garden take weeds out.

Community activities: we go to Special Olympics, a baseball game, BCARC dinner dance, fundraisers and holiday events. Trips and travel: I taken to Florida, Mystic, Boston, Maine. In Florida: Universal Studio to see Beauty Beast, Star Wars, and other things. Mystic Aquarium House: to see fish, whales and other things. Boston: we see Boston Tea party. Maine: we went on boat to see whales and baby. I like it very much.

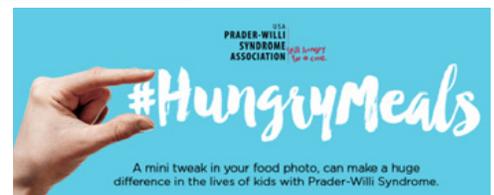
My senior years I like to see baseball game, cruise, go out supper again and other things too. I want a Pen Pal please. ■



Boothie

Please contact the PWSA (USA) office for Boothie's address - Editor

Photo dated 2005



What's #HungryMeals? See page 5 and hashtag a bite for awareness!

Volume 41, Number 4 ~ July-August 2016 ~ Our 41st Year of Publication

Vanderbilt Longitudinal Study

Elisabeth Dykens, Professor of Psychology and Human Development & Psychiatry, Director, Vanderbilt Kennedy Center
Elisabeth Roof, Senior Research Specialist Vanderbilt Kennedy Center

Editor's Note: We gratefully acknowledge this update submitted by Elisabeth Roof

For over 20 years, Elisabeth Dykens and I have been following children and adults with PWS at Vanderbilt. In our longitudinal study, we have seen over 250 people and had over 657 visits since 2003. Participants have come from all over the United States and Canada and range in age from 4 to 66 years old. Our sample is fairly representative of the community - with the mean age being 16 years, 51% female, and 36% UPD subtype.

With each patient, we do a full-day battery of tests including cognitive testing, a variety of tests to assess adaptive behavior, psychiatric and behavioral features, an autism interview, and an EEG that focuses on food interest, memory, and learning. After the assessment and parent report questionnaires have been scored, we generate a comprehensive feedback report that focuses on strengths and weaknesses of each individual and provides recommendations for the next 2 years.

These studies closed May 2016 and the information here has been published or is in the process of being submitted; it supports a comprehensive whole person approach to PWS.

By conducting comprehensive psychiatric interviews looking at specific features of PWS, we have found many important themes emerging.

Autism: Using ASD screeners and clinical assessment, we find that boys with UPD are the most likely to receive a full diagnosis of Autism (ASD). Despite this finding, ASD does affect girls, and a few with deletion and imprinting mutation subtypes. ASD is not nearly as common as some have suggested. The phenotype of PWS includes many aspects of ASD (repetitive behaviors/questions/etc.) so it is important to consider distinguishing features. Those with PWS and ASD seem to have poor social/communication skills and some restricted interests, but retain social motivation. They seem to want social contact, but lack the skills to get or keep friends. Several families have begun applied behavioral analysis and other ASD treatments on their own with moderate success.

ADHD: About 40% of boys with PWS have ADHD, and even some hyperactivity. Those with UPD are more likely to have ADHD and they are younger and thinner than those without the diagnosis, though many aren't taking traditional ADHD medications like stimulants.

Tic Disorder: Similarly, boys (39% vs 16% in girls) are more likely to have vocal and motor tics. More likely to occur

in boys with UPD and they often are noises and sounds that are repeated a lot or movements like shrugging, blinking or nodding. Some seem to get better with age, but more often they morph into another tic that is less disruptive.

Anxiety: Anxiety is the most common issue in PWS, with 42% of our patients showing disruption in their daily lives from anxiety, though not often related to food.

OCD: Obsessive Compulsive D/O is less common, though there are no gender, subtype, or BMI differences in those who have it compared with those who do not. In PWS, anxiety doesn't often lead to depression, with only 8% of the group having the diagnosis.

Depression: Those who have depression are more often: female, older and higher functioning. Depression in PWS doesn't look sad. Instead, we see irritability, behavioral outbursts, changes in sleeping and isolation. Due to its unique presentation, depression is often missed. Treatment is especially important as untreated depression can lead to psychosis.

Psychosis: Only 12% of our sample had past or current psychosis. While they are more likely to have the UPD or imprinting mutation subtype, those with deletions can have psychotic symptoms that are mistaken as being "just PWS" or difficult. Psychosis is often seen as changes in repetitive thoughts, sleeping and eating patterns, and looking disheveled. New, recent changes for concern are ones for those who: just started talking to people that aren't there, if the self-talk becomes very negative or hostile (or the nature of it changes in a negative way), or if it does not go away on its own.

A newly published study about growth hormone treatment in PWS supports the previous link to better cognitive functioning while controlling, and/or for ruling out, socioeconomic functioning. 96 participants were matched on age, income, and gender (32 never on GHT and 64 who were currently or previously on GHT). GHT showed a 12 point increase on Verbal IQ, a 7 point increase on Non-Verbal IQ and a huge 14 point increase on Adaptive Behavior Composite. Lower BMI was seen with GHT, though those effects decreased over time. All effects went away quickly when GHT was stopped. As expected, GHT did not change hyperphagia in PWS and it increased about 25% over the three time points for both groups. These findings have now been published with a special time-sensitive push for insurance companies to cover this vital treatment for those with PWS, both as children and as adults. ■

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PWSA (USA) 2016 Grant Submission Announcement

Celebrating over 40 years as a charitable nonprofit, Prader-Willi Syndrome Association (USA) [“PWSA (USA)”] is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with Prader-Willi syndrome (PWS). PWSA (USA) is seeking to fund projects for a maximum of \$100,000 total per project for a 1-2 year grant support aimed at discovering and developing treatments, cures and technologies benefiting those with Prader-Willi syndrome.

The current focus of PWSA (USA) research is supporting projects that have the potential for immediate and high impact for the PWS community; thus, will support research-based translational grants or those showing high promise for translating basic biomedical knowledge to clinical application. The goal is to fast-track better treatment for the syndrome.

At PWSA (USA), we work to integrate what we have learned about the needs of our families through our support programs -- with research that we think will make an important and practical difference in our children’s lives; thus, the following topics will be the focus area for grants accepted in 2016. For this year, research in these areas will receive priority rating for this RFA:

- finding solutions to dealing with gastroparesis in PWS
- pulmonary embolus- the cause of 7% of PWS deaths (PWSA (USA) current-study of death)
- a retrospective study of the benefits & risks of G-tubes vs NG tubes in infants with PWS
- sleep issues in PWS & how it plays a role in behavior
- understanding the complex issues of an aging population in PWS
- psychotropic medications – what works & doesn’t work with PWS
- motor tics/tardive dyskinesia – reducing the risk; minimizing the impact
- biomarkers for health risk factors in PWS
- postoperative issues & management
- racial disparity in diagnosis & treatment of PWS

Grant Award Timing

GRANT APPLICATION DUE: SEPT 23, 2016

GRANT AWARD: DEC 2016

FUNDING OF GRANT: As soon as all IRB documents are obtained and completed as well as meeting other requirements.

REQUIREMENTS: Please visit the PWSA (USA) website for details on requirements. ■

People who really want to make a difference in the world usually do it, in one way or another. And I’ve noticed something about people who make a difference in the world: They hold the unshakable conviction that individuals are extremely important, that every life matters. They get excited over one smile. They are willing to feed one stomach, educate one mind, and treat one wound. They aren’t determined to revolutionize the world all at once; they’re satisfied with small changes. Over time, though, the small changes add up.

Sometimes they even transform cities and nations, and yes, the world.

- Beth Clark

submitted by Clint Hurdle

PWSA (USA) Commits to Focusing on G.I. Issues in PWS

Besides our focus area for grants, the PWSA (USA) board has made a financial commitment to putting special emphasis on the serious G.I. issues facing our children and adults. The following are current ways in which this will be achieved:

- PWSA (USA) will sponsor an education and awareness booth in collaboration with our international organization, IPWSO, at the World Congress of Pediatric Gastroenterology, Hepatology and Nutrition in Montréal, Canada October 2016.
- PWSA (USA) is developing a trifold brochure that focuses specifically on the G.I. issues with PWS. This will be distributed extensively and be available for parents to have when dealing with medical professionals.
- PWSA (USA) medical team will submit a proposal to present on PWS at the annual G.I. nurse practitioner meeting.
- Research on gastroparesis is one of the major focuses for the new PWSA (USA) grant announcement.
- PWSA (USA) will do a major mailing to G.I. specialists around the nation.
- Remember that the new PWSA (USA) Medical Alert booklets have more extensive G.I. information with a foldout page of the G.I. algorithm that will be extremely helpful for ER physicians. ■

Executive Director View

Introducing Kathryn Clark

Coordinator of Medical Affairs, PWSA (USA)

-Ken Smith, PWSA (USA) Executive Director

PWSA (USA) is justifiably proud of its Family Support Program, which provides information and mentoring to new parents, medical alerts, written and video resources and counseling supports, crisis intervention in many areas, and so much more, to meet the needs of those in the PWS community.

Now I'm proud to announce the addition of a new member of the Team. Kathryn Clark, R.N., M.S.N., became Coordinator of Medical Affairs on June 1, 2016. Kathy will be working three days a week, job sharing with Carolyn Loker.

A certified Pediatric Nurse Practitioner, Kathy has cared for children with various pituitary and chromosomal disorders. In Pediatric Endocrinology at the University of Michigan for many years, she was involved in the initial clinical trials for synthetic growth hormone.

Kathy's special interest in PWS goes back many years, dating to those early days of growth hormone when it was available only to those with growth hormone deficiency. Intrigued by patients who came with diagnoses that no one had ever heard of, she made this her special niche. Then, a former babysitter who had had a baby with PWS, called wanting growth hormone. They were able to get it for him; he is now 17 and, she says, is a superstar, convincing her of its value. FDA approval made accessing it much easier.

Kathy became president of the Pediatric Endocrinology Nursing Society; she also discovered at a Society (PENS) conference that none of the nurses knew about PWSA (USA), and she set about changing that. She has partnered in a few presentations at conferences along with Janalee Heinemann.

She and her husband, Spaulding Clark, have two adult daughters.

Please join us by welcoming Kathy to the PWSA (USA) family. ■



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

International View

PWS Conference in Colombia

Here is one example of our "holding hands around the world"
- Janalee Heinemann

The July 1 PWS conference in Colombia was a total success! It really was an amazing day. Hats off to Johana Rocha, for her dedication to this important and personal cause. (Kevin Quinn and Johana Rocha, are PWS parents who live in Florida; Johana is originally from Colombia.)

Here are the rewards of helping another country: PWSA (USA) sent 600 brochures in Spanish at no cost, and Janalee Heinemann helped them with information and advice. Keynote speaker Dr. Moris Angulo spoke at no charge, and IPWSO has been supportive. About 215 attended in total, 75 from various medical professions. The 21 kids present were well attended to with entertainment, healthy snacks, and exercises. As expected, Dr. Angulo's message was received attentively; his personal attention and humor very much appreciated. We even had national TV and newspaper coverage. Excitement and enrollment for the event pushed the Spanish language Facebook group that Johana runs to 500+ members.

The Instituto de Roosevelt were gracious hosts, and we believe will serve as a radiator of information and hub for connecting professionals well after the conference.

Family testimonials were fantastic, as the plight of a few demonstrated how raw the need is in Colombia. ■

*Thanks again for your support!
So great to see the awareness growing!*
- Kevin Quinn



See the results of your help! - Moris Angulo

eWalk

Please join the 50 plus families and individuals who are already raising awareness and important funds through PWSA (USA)'s online fundraiser, eWalk. eWalk is a fun and easy way for anyone from anywhere to get involved. It easy! Click on the link in the next sentence:



<http://www.firstgiving.com/pwsausa/2016-ewalk> then click on the Fundraise button to create your own fundraising page. In just a few minutes you can start raising funds. To get the word out about your fundraising page, just post your page link using social media and send it out by email to all your contacts encouraging the m to donate. It begins with a community and with your help we can continue to *Save and Transform Lives!* We look forward to seeing you all join this year's eWalk! ■



#HungryMeals

Please join us in raising PWS awareness with our new campaign, #HungryMeals. We are delighted to be partnering with the VML agency, an international advertising firm which was named a top 10 agency of the year in 2015. The New York office of VML is providing pro bono services by their creative and social media marketing teams for this campaign. This is a social media driven campaign targeted to millennials and utilizing Instagram.

Many of us share food photos using social media. Now those food photos of yours can help raise awareness. By taking a picture of your food with your fingers looking like you are pinching it, makes the food look a lot smaller than it is. To eat a normal size salad to us is filling, but for someone with PWS it could feel like only eating a single leaf of lettuce.

So we encourage all of you to join the movement and take a photo of your food and make it seem like you are pinching it. When you post your pic, please include #HungryMeals. If you have Instagram, please follow our official #HungryMeals profile at https://www.instagram.com/hungry_meals/. Mayim Bialik from the hit comedy series "The Big Bang Theory" has already posted pics of her food with this concept using #HungryMeals to spread awareness. With your help, we can make this campaign a viral success! ■

On the Move Events

THANK YOU to our amazing PWS community members that made the following events so successful! Your hard work and commitment to PWSA (USA) is outstanding! Funds raised through *On the Move* events support many different programs for those affected by PWS on both local and national levels.

Florida *On the Move* Walk: \$18,000

Hunter Lens Golf Tournament: \$31,000

Illinois' I Heart Momma 5K: \$6,000



Indiana *On the Move* Walk: \$TBD

Michigan *On the Move* Walk: \$11,000

Minnesota Golf Scramble: \$36,400

Texas' Molly's Pub Golf Tournament: \$75,000

Utah Fitness Fun-Raiser: \$39,000



Wisconsin *On the Move* Walk: \$29,000

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



PWSA (USA) Adds National Special Education Consultant

PWSA (USA) is pleased to announce that Jennifer Bolander has been serving as a National Special Educational Consultant for PWSA (USA) since October of 2015. She is a graduate of John Carroll University and lives in Ohio with her husband Brad and daughters Kate (16) and Sophia (12) who was born with PWS. Over the years, as a special-needs parent navigating the Special Education system for Sophie, Jennifer became interested in learning as much as possible about that process. She began by attending PWSA (USA)'s first Wyatt Special Education Advocacy Training in March of 2013 and went on to complete a rigorous 9-month Special Education Advocacy Training course with the Council of Parent Advocates and Attorneys in May of 2015. This included successfully completing an advocacy internship with PWSA (USA). Jennifer is referred school cases by PWSA (USA)'s Family Support Counselors, and then works closely with parents and schools to review education records, assess the child's situation at school, provide further information about how the syndrome affects the school experience, and create as needed improved IEPs and behavioral plans. Jennifer was excited to take on this role of helping parents in the PWS community to work collaboratively with school professionals and parents to create positive, effective learning environments for children with PWS across the country. ■



Minutes - PWSA (USA) General Membership Meeting

Lake Buena Vista Palace Hotel,
Lake Buena Vista, Florida
Saturday, November 7, 2015

The meeting was called to order by Board Chairman Michelle Torbert at 11:55 a.m., EST.

Clint Hurdle gave the keynote speech and encouraged men to support their wives and engage in the raising of their child with PWS. He also noted the importance of finding an outlet for the sibling, a place for them to vent.

Board members in attendance were introduced. Conference co-chairs were thanked for their work over the past two years. A cake celebrating PWSA (USA)'s 40th birthday was presented.

Dr. Suzanne Cassidy, president of the International Prader-Willi Syndrome Organisation (IPWSO), outlined the structure of the organization and its mission. Details on the upcoming conference in Canada, celebrating their 25th anniversary, were shared.

Ken Smith, Executive Director of PWSA (USA), outlined the support services the association provides. Over 1700 requests for support have been received thus far this year and the organization is on track to exceed the record number of calls received last year. It was explained that a "call" involves many calls and letters to resolve the issue. The family support team and national office staff were introduced. Data was presented on the diverse nature of the support calls. A pie chart was also shared showing how donated funds are used. The new website was announced as well as the initiatives for 2015 – supporting our newly diagnosed families, addressing diversity issues, advocating for residential support, maintaining and enhancing support services at the national level, and ensuring the financial health of PWSA (USA). Despite a successful fundraising year, we may finish the year in the red**, but we are working hard so that doesn't happen again. The reality is our services do have an associated cost. **(Note: Thanks to the generosity of our members, we actually ended the year in the black!!)

Rob Seely, PWSA (USA) Board Member and Co-chair of the Chapter Leaders Team, provided an update on the work of the team in providing support to our families. This year, more fundraising, conferences and events have been held by our chapters than ever before. Our chapters have also actively supported this conference and the upcoming second phase of the Oxytocin study. The chapters are a collaborative partner with PWSA (USA). State chapter leaders and members of the state leadership team were introduced. Anyone who is interested in forming a chapter in their state was encouraged to speak to a member of the chapter leadership team.

Dr. Leon Caldwell, PWSA (USA) board member, announced the launch of a fatherhood support study funded by a grant from PWSA (USA). The goal is to learn how fathers process the diagnosis and how best to support them. This will address the gap in information for this audience, and a gap in services provided. An online survey will be available as well as potential follow-up interviews.

Meeting adjourned at 12:50 p.m.

Respectfully submitted,
Julie L. Doherty, Secretary



PWSA (USA) 2016-2019 Board of Directors Approval of 2015 Annual Membership Meeting Minutes OFFICIAL BALLOT

Voting Instructions:

1. Review the candidates' statements printed on the Slate of Candidates (pages 8-9) Read the 2015 Annual Membership Meeting Minutes (page 6)
2. Cast your vote on the Official Ballot, voting for four (4) candidates only. Note any corrections necessary to the Annual Membership Meeting Minutes. Insert the ballot into the Official Ballot Envelope.
3. Print and sign your name on the Official Ballot Envelope. Affix postage. Mail it to PWSA (USA) postmarked no later than August 19, 2016.
4. If you receive the *Gathered View* only in an electronic form and were not provided with an Official Ballot Envelope, please mail your ballot to:
Julie Doherty, Secretary, PWSA (USA) 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471.
In the return address portion of the envelope, print your name and address and the following statement: I am/We are a PWSA (USA) Member in Good Standing Eligible to Vote.
Place your signature below this statement.

Deadlines:

The deadline for voting is August 19, 2016. Ballots postmarked after August 19 will not be counted.

Confidentiality:

Your vote will be kept confidential. PWSA (USA) staff will verify voter eligibility and separate the Official Ballot from the Ballot Envelope before the Ballots are tallied.

Voting Criteria:

Voting members must be Members in Good Standing with PWSA (USA). Membership dues must be current and paid in full or a dues waiver granted.

Member Types Eligible to Vote:

Each membership type, whether individual, family or professional, is entitled to one vote.

Clip this ballot along dotted line and mail.

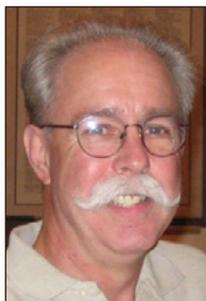
Cast your vote for the 2016-2019 Board of Directors. Vote for four (4) of the candidates listed below.

- | | | |
|---|--------------------------------------|--------------------------------------|
| <input type="checkbox"/> Dan Beaver, M.D. | <input type="checkbox"/> Sybil Cohen | <input type="checkbox"/> Pete Girard |
| <input type="checkbox"/> Jim Kane | <input type="checkbox"/> Rob Lutz | <input type="checkbox"/> Rob Seely |

Corrections to the 2015 Annual Membership Meeting Minutes:

No Corrections Necessary (if neither box is checked, we will assume you have no corrections to the minutes)

Organization News - Meet The Candidates



Daniel Beaver, M.D., Madison, WI

Dan is an emergency room physician who is soon to be retired. He and his wife Kate of thirty-seven years are the parents of three lovely grown children. Hana, the youngest, was adopted from Korea and diagnosed with Prader-Willi syndrome at the age of six. Thus Dan has had extensive experience with Prader-Willi syndrome both on a personal and on a medical level. He has also worked to be a strong advocate for Hana with the state, federal and local agencies.

Dan has had many years of experience working with and on boards, having served on the Drug Abuse Treatment Board in Soldotna, Alaska as well as serving as one of their board members. He has also served as the director of Baraboo, Wisconsin EMS Agency, and the Emergency Room Director of the Emergency Department in Baraboo, Wisconsin. Currently, Dan is the board president of the condominium association where he and his wife now live.

In the past, he has also been active locally in Wisconsin, volunteering at the annual Oconomowoc PWS Hobby Day, as well as presenting at the most recent national PWS Conference 2015.

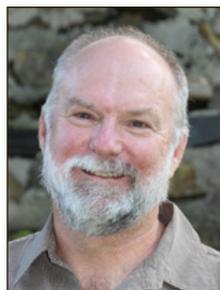
Experience, aptitude, opportunity and a strong sense of commitment now bring Dan to a point at which he is able to contribute more to the Prader-Willi syndrome community on a national level. ■



Sybil Cohen, Cherry Hill, NJ

Sybil is currently serving on the PWSA (USA) Board of Directors. In all her endeavors in the world of PWS, her focus is on family support and educational rights for individuals with PWS. Sybil has a 21-year-old daughter, Rose, with PWS, and lives in Cherry Hill, NJ, a suburb of Philadelphia, PA. Rose was diagnosed with PWS at the age of three.

Immediately after getting the diagnosis, Sybil got involved in the NJ Chapter of PWSA (USA) eventually becoming its president, which she served for ten years. She was a parent mentor for both the state of NJ and PWSA (USA), has presented at PWSA (USA) national conferences, and continually advocates for the educational entitlements of children with PWS. Sybil frequently attends workshops and seminars on special education rights and practices in order to better serve our loved ones with PWS. ■



Peter Girard, Townsend, TN

Mr. Peter Girard has been married to his wonderful wife Gayle, for 34 years.

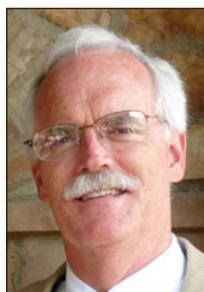
They had two children born in 1987, twins, Amanda and Jeremy. Jeremy was diagnosed with PWS at the age of 9.

He has owned several successful businesses. In 1982 he started his first computer company and later sold it in

1990. In August 1990 he became an Air Traffic Control Specialist with the Federal Government and retired in 2012. During this time he also operated a computer consulting business that he still operates today. In 2008, along with family members, he purchased & renovated a motel in Townsend, TN and is currently the managing partner.

He has served on the Board of Directors of the Lake Conway Woods Homeowners Association as Vice President and is currently serving on the Board of Directors of Mountain Miatas of East TN, a 501(c)(7) organization, as Treasurer. While on the Board of Mountain Miatas, Pete has been instrumental in focusing the club on charitable giving.

He has volunteered at the PSWA (USA) National Conventions since 2003, providing Audio-Visual support. ■



James G. Kane, M.B.A., Baltimore, M.D.

Jim is a recently retired real estate executive, whose experience includes public accounting, finance and over thirty years in the real estate industry. Acting as property manager, Vice President and partner of a private company, Jim was responsible for all the business activities of a commercial portfolio of over 2,000,000 square feet of retail, office and industrial space. Jim and his wife Kit have been married for almost 40 years and are the parents of Kate, 34 years old and Molly, 30 years old. Kate was diagnosed with Prader-Willi syndrome (UPD) when she was five. Kate has had a fairly typical life for a young lady diagnosed with PWS in the early 1990's when many of the medical advances known today were as yet unavailable. Kit and Jim have experienced the trials, tribulations and joys of helping Kate battle the syndrome and the system. Kate currently is very happy in a structured living environment. Jim has been actively involved with PWSA (USA) for many years. Having served as the Treasurer, Board member and Board chair, Jim has seen the organization grow into the dynamic service resource it is today. If elected to the board, Jim hopes that he can help PWSA(USA) progress to new levels of "Saving and Transforming Lives". ■



Robert Lutz, Bryn Mawr, PA

Robert Lutz is the Chief Business Officer of Strongbridge BioPharma, a biotech company that is developing pharmaceutical drugs for rare diseases. In his current role and in his 12-year career in the pharmaceutical industry, he has experience with the people and processes for developing drugs for rare diseases. Rob has an MBA from the Kellogg Graduate School of Business. Rob and his wife Debra have been married for 20 years and have two daughters aged 16 and 13. Their eldest daughter, Isabel, was diagnosed with PWS at six months old. The family has been an active member and supporter of PWSA (USA) since her diagnosis. Isabel is in the 10th grade at the local public school and lives at home and her passion is

continued on page 9

Meet The Candidates

Candidates, continued from page 8

horseback riding. Rob has served on the PWSA (USA) Board for eight years over time and has experience on the Research Committee, Finance Committee, and Fund Development Committee. Rob is committed to help PWSA (USA) accelerate the development of therapies for PWS and support families with education, conferences, chapters, and crisis support.



**Rob Seely,
Dublin, OH**

Rob is currently an Associate Director for an architectural firm working with national multi-unit restaurants and retailers focusing

on the client's objectives for cost, quality and timelines. He lives in Dublin, Ohio with his wife Diane and their thirteen-year-old son Reagan, who has Prader-Willi syndrome. They also have four adult children that live in Ohio. Rob is currently serving his first term as a Board member for PWSA (USA) and is on several committees. He has served on the Board for the State of Ohio Chapter for PWSA (USA) and currently serves on the Board of All God's Children, Inc. In addition, Rob and his wife, Diane, are the founders of Reagan's Reach, which is a non-profit organization committed to addressing the long term residential challenges for those with Prader-Willi syndrome. He also volunteers at his son's school, and for The Ronald McDonald House of Columbus, Ohio.

"I look forward to the opportunity to continue to serve on the Board for PWSA (USA) and I understand the responsibility to represent not only the organization but all affected by PWS. I embrace working with all of those interested in improving the lives of those living with PWS. Through a combined effort of support, research and advocacy we can provide families hope rather than fear. Together, we can work towards one goal, a better future." ■

2016 Casting for a Cause



The 2016 Casting For A Cause Tournament netted over \$110,000. We extend our deepest appreciation to all sponsors, anglers and volunteers for this fun and wonderful event.

2016 Results

Offshore

- 1st place – Alex Torbert on the Rough Operator – 29.0 lb. dolphin
- 2nd place – Javi Lopez on Rezkill – 27.6 lb. dolphin
- 3rd place – Kevin Smith on the Hicks & Spics – 23.8 lb. dolphin

Top Female Angler – Leslie Torbert on Hammertime – 9.2 lb. dolphin

Top Junior angler – Aiden Leach on the Czech Mate – 9.9 lb. dolphin

Inshore Guided

- 1st place – Ride the Lightning with 825 points
- 2nd place – Deep South Fishing Charters with 500 points
- 3rd place – Reel Crazy with 475 points
- Top Guide – Capt. Benny Blanco

Inshore Unguided

- 1st place – Midnight Riders with 325 points
- 2nd place – Waterman with 250 points
- 3rd place – Flats DNA with 150 points
- Top Female Angler – Courtney Heuston with 225 points
- Top Male Angler – Andrew Downing with 250 points



How PWSA (USA) Helps Direct Care Providers

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

An often overlooked but vital part of PWSA (USA)'s mission is to support professionals who provide direct care for people with PWS living in residential program settings. These support services, offered to direct care providers across the United States, can dramatically improve the quality of life for people living with PWS. While there are many components of an appropriate and effective PWS residential environment, one of the most important keys is having a well-trained direct care staff. A consistent theme of concern for parents/guardians is residential program staff who are poorly trained in how to meet the unique needs of residents with PWS. To address this important concern, PWSA (USA) provides an array of services to support direct care professionals serving the PWS community. These services include:

- Supporting the PWSA (USA) Professional Provider Advisory Board. This Board is made up of direct care providers from the PWS community. The Board's responsibilities include:
 - Publishing statements on issues of concern to direct care providers.
 - Creating resources for direct care providers.
 - Coordinating national training conferences for direct care providers on a regular basis.
 - Facilitating a Yahoo discussion group for direct care providers to share questions and ideas.
 - Helping to plan international care provider conferences sponsored by the International Prader-Willi Syndrome Organisation (IPWSO).
 - Contributing to the creation of the IPWSO Best Practices Guidelines for Standard of Care in PWS which is one of the most significant resources developed for direct care providers in the last decade. It is available for purchase at www.pwsausa.org
- Creating resources for providers (written and video) to help with medical and behavioral management and staff training. This includes the very popular book "Supporting Adults with PWS in a Residential Setting" by Dr. B.J. Goff. This book, and a companion training DVD, are available through PWSA (USA)'s website.
- Providing access to PWSA (USA) Crisis Intervention Counselors (medical and non-medical) to consult with direct care providers on placement problems and other issues.
- Funding, out of the PWSA (USA) Crisis Fund, special onsite training by a PWSA (USA) National Residential Consultant to address urgent placement problems that have not been resolved by previous PWSA (USA) interventions.

Being a direct service provider is hard and important work. It involves long hours often at a low wage. So PWSA (USA) also makes an effort to thank and recognize direct care providers who serve the PWS community well. It is a way we can show great appreciation for the crucial role they play in creating a program environment where residents with PWS can thrive. We urge parents and guardians to do the same. Being thanked for a job well done is a great motivator!

Finally, the good news is many direct care providers are doing a great job serving people with PWS in residential programs across the country. But there are still many programs struggling as well as an increase in the need for programs that can appropriately serve people with PWS. For example, many states don't have any PWS specific residential programs available. So we are continually working to expand our reach in the direct service provider community across the United States. If you know of a residential program that is struggling to support residents with PWS, or a newly created program, please share this article with their staff so they will know help, support and appreciation are only an e-mail or phone call away. ■

Research Updates on PWSA (USA) Website

We've been working hard updating the Research section of our PWSA (USA) website with great, new information for our wonderful community to enjoy. Updates include research announcements, grants awarded, requests for participants wanted for research studies, plus many others. Take a look!

Please visit: <http://www.pwsausa.org/research/> to see these updates.

PWSA (USA) Chapter Events

OR & WA NORTHWEST PWS PICNIC AND FAMILY CAMP	8/13
WI GOLF TOURNAMENT	8/20
OH PWSA OF OHIO CONFERENCE	SEPT.
WI BOWLING FUNDRAISER	9/17
FL SARASOTA WALK	10/1
OH PWSA OF OHIO - FALL WEEKEND CAMP	10/14-16
IN MIDWEST CONFERENCE	OCT.

Contact the Chapter for more details.

Awareness and Education My Aunt Andy

Education and awareness about Prader-Willi Syndrome come in many sizes, shapes, formats and packages. How fortunate for this issue, "The Gathered View" was the recipient of stories from two enterprising, passionate, and big-hearted young ladies, who wanted to make a difference for those with a disability.



Hi, I'm Emma Lewis. I have recently done a project on Prader-Willi syndrome. I got interested in researching this by watching a Pirates game one day and Pirates Charities came up talking about this. This was two years ago this May. I had to do a project for school and I decided to do my project on Prader-Willi syndrome. My homeroom/Science teacher loved the project and my friends were proud. I am truly honored in writing this.

The school I attend is St. Joseph School in Verona, PA. Mr. Hazur is my teacher. I'm in the sixth grade and 12 years old. ■

*Editor's Note: Emma and her mother Michelle Lewis are planning an **On the Move** 5k in 2017 to raise funds for PWS.*

By Arielle Zabusky

I recently became a Bat Mitzvah. Part of my Mitzvah Project was learning all I could about Prader-Willi syndrome and getting together a group of people with Prader-Willi syndrome to have a fun party.

This gathering was inspired by my Aunt Andy and the other people living in her Elwyn house and it was held Tuesday afternoon, June 7, at Elwyn, near Philadelphia.

I organized this gathering in honor of my bat mitzvah and I really wanted to help people with a disability I knew about, cared for, and felt connected to.

The outcome was amazing. The people there (including the staff!) had so much fun doing the crafts and puzzles and listening to the music. It was also so much fun to plan and organize. I really hope I can do a similar party with the people with Prader-Willi syndrome of Elwyn again. I would especially like to thank my mom who helped me plan the event, the Elwyn staff for making the party possible and successful, my grandparents for teaching me about Prader-Willi and encouraging me to help out the Elwyn people, and my science teacher for really teaching me about Prader-Willi and other disabilities. ■

Editors Note: Arielle is the niece of Andrea, who lives in a PWS group home. Arielle will be in the seventh grade at Friends Central in Philadelphia this fall.



Left to right Aunt Andy, Arielle, and Arielle's grandfather.

A Brilliant Book! Prader-Willi Syndrome: How Parents and Professionals Struggled and Coped and Made Genetic History

This new 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." Author John Hernandez-Storr, father of a daughter with PWS, spent years doing personal interviews with many key PWS professionals and parent pioneers.

Jackie Waters, PWS parent, IPWSO board member, PWS Association UK employee writes: *I am currently reading the book*

and I must say, it is absolutely riveting. Congratulations to John Storr. It is a brilliant book. I am going to make it required reading for staff at PWSA UK and write a review for the next Newsletter.

It is especially poignant for me as Esther was born in 1978, just as all these breakthroughs were being made.

Please pass on my congratulations to John Storr – it is a brilliant book.

John Hernandez-Storr has very generously offered to donate ALL proceeds for books sold through PWSA (USA) back to the Association. Order your book NOW. Visit: <http://bit.ly/1Tz8FCi> Cost: \$15 plus shipping. ■

Expressing Motherhood

By Jessica Patay

Editors Note: Jessica granted PWSA (USA) permission to reprint her blog article from January. We are grateful to share a story from a PWS mom.

This past weekend I had the privilege to be a part of the Expressing Motherhood—South Bay Showcase. Created by Lindsay Kavet and Jessica Cribbs in 2008, it's a stage show of writers, sharing or performing their pieces on motherhood. Any take is welcome. You will laugh, cry, be inspired, and be validated or encouraged as you listen to diverse stories that resonate somewhere within us all.

I poured my guts and tears into my piece. (I was the Serious One on stage.) It's a re-vamping of an earlier blog post, yet much more revealing, raw, and honest.

Here it is:

I didn't ask for a disabled child.

But he was given to me on Friday, June 27th, 2003.

My son – Ryan Bradley Patay.

No mother puts on her pregnancy wish list—“unhealthy child, with a genetic syndrome that NO ONE HAS EVER, EVER heard about, tremendous heartache, a side of stress, preferred moments of depth and wisdom, plus personal injuries like a bruised tailbone.”

No mother. And certainly not me.

I cry, I cuss, I pray.

But then sometimes, when I look at my little Ryan, all snuggled-up on the sofa, I momentarily forget about my anger and my angst, and my hacked-up heart, because all I see is his beauty and peaceful face.

I see his long, skinny limbs outstretched, mouth open, breathing loud. Not quite a snore. His own sounds. It's family movie night, a Friday. And of course, Ryan, our little narcoleptic, lasts half an hour before he is asleep. He even missed the popcorn! How did that happen, when that is all he REALLY cares about?

When I look at my sleeping prince, I am overtaken by an avalanche of love and compassion. I think about his brain, all wired wrong thanks to missing parts of chromosome 15. I think about his muscle tone, so low, so weak, contributing to small frame. How his muscles had to be taught to move, activate and strengthen. Until, at last, at age 3 he walked. FINALLY. With his own Ryan-gait-and-rhythm.

I think of his little hands that can't give a firm handshake. Straw-like fingers with nails that grow way too fast. Nails that undo my skin during meltdowns. The fingers that struggle to close buttons and zippers. He has yet to learn how to tie his shoes, but I refuse to buy any more baby Velcro sneakers. He is 12 years old now. With pubic hair and hormones.

For a moment, ever so brief, I forget about Prader-Willi syndrome.



I forget about calling 911 when he was so out of control that he lurched at me from the back seat while we were driving home. It too, was a Friday. He was out of his mind anxious and agitated, like a cat ready to pounce at any moment. I pulled over to the side of Via Del Monte, a main artery in our neighborhood. He was clawing and scratching and grabbing at me, practically sitting in the driver's seat with me. I was then balling uncontrollably and could barely get the words out to the 911 dispatcher. We were tracked by my iPhone. Of course, as friends passed by, three cops are trying to help us and I still could hardly talk through my tears. Eventually Ryan calmed down, and one of the officers kindly followed us home.

I was mortified, scared, angry, grieving, and this time, this crisis, I was without compassion. Once again, I could not believe this was my life. This is my Motherhood? Dramatic, traumatic and uncontrollable. When I was breathing in Ryan's newborn smells, I never imagined this happening 12 years later. I never imagined being AFRAID of him.

I look at him and think how tortuous it must be to have his level of anxiety. So riddled daily with insecurity about potential

continued on page 13

Motherhood, *continued from page 12*

changes or his next meal. He asks and asks and asks about his food schedule and his menu.

“What time am I eating?”

“Where am I eating?”

“Why do I have to wait until 6?! Why can’t I eat at 5:30?!”

“What are you making me? How many things will be on my plate?”

In rapid-fire succession over and over.

Only us Prader-Willi families talk about food all the freaking time. All day, every day. It’s exhausting.

Sometimes, in a “normal-happy” moment, I just see God’s gift to our family. That I get to unwrap every day.

I just see the ONE child of mine that everyone says looks like me, with his blond hair and blue eyes.

I just see his grateful heart, and recognize once again HOW MUCH he has taught me—to be grateful for the tiny-priceless-life-moments.

And yet—I don’t unwrap this gift every day with joyful expectation.

I flip. I flop. I grieve, I grit my teeth, or I get lost in my love for him.

If this Motherhood Journey were easy-peasy, I wouldn’t need an effing tattoo that says GRACE on my wrist. It says GRACE to remind me every day, that I AM ENOUGH, and I DO ENOUGH as his mom.

I needed this inked on my body permanently, because I forget and doubt myself, ALL THE TIME.

I take deep breaths and look at Ryan. I stare at him. I drink

in his innocence, his goodness, my boy who’s so polite and an immense pain in my...heart.

And in those pure moments, I forget all the “WHAT IFs.” And I wonder—how many Fridays do we still have left together?

<http://jessicapatay.com/>



SAVE THE DATE!
Nov. 15-18, 2017

Caribbean Nights
(Together in Paradise)

Caribe Royale - Orlando, FL

The PWSA (USA)
34th National Convention



Watch for details to follow.

Just the Beginning

I cannot believe it has almost been a year since I started writing for the *Gathered View* and working towards my Integrative Nutrition Health Coach Certification. This journey has been an eye opening experience that has made me realize how much I want to work with moms and especially those with children with special needs. I graduate in July so my journey has just begun. Getting involved with PWSA (USA) has been one of the best decisions I have made. My eyes have been opened to so much more than just my world with PWS; I have found community. This past year has brought new learning experiences with my schooling that I will be able to apply to my coaching practice. An example of this that I can actually apply to my son is that “one man’s food is another man’s poison...” Meaning: not one diet is going to work for everyone. I found this out the hard way when I changed Ronan’s diet to a low carb high fat diet. The LCHF diet has been used by many individuals with PWS and so I figured I would try it. To my horror, Ronan gained 2 pounds in just a short week and a half. At that point, I switched him back to what we originally

were doing, which that was later modified by Dr. Miller and Hannah, her dietician.

Another component of my schooling which I had briefly spoken about in my first article is that of Primary Foods. Primary Foods are not those in which you eat; it is what nourishes your heart and soul. Our relationships, physical activity, career, and spirituality is the driving force in our day-to-day efforts with how we are feeling. If any of these components are out of balance, then an individual may feel stressed out, overwhelmed and have a lot of anxiety. I know many of us with children with PWS or have taken care of an individuals with PWS have felt these feelings over and over. Flipping the coin, if you have balance with these, one may feel happy, fulfilled, and full of joy. Life has its ups and downs and it’s up to us on how you fill those moments. Having the PWSA community has brought me such relief around Ronan’s diagnosis and I want to thank each of you for being part of it. I will continue to write for the *Gathered View* which is an honor and I hope that you all find your inner light. ■

Thank you
Kathryn Lucero



We Remember

“Harry was one of the founders of the Prader-Willi Alliance of NY. He was a fearless advocate for all families he knew with children with PWS. He was always willing to help to the best of his ability in any way he could. His motto was “always help anyone you can” and he lived by those words. He was an amazing man.”

~ Nina Roberto



Harry, far right, attended the 2015 New York conference with his wife, Muriel.



Harry Persanis of Wantagh, Long Island died peacefully on February 13, 2016. He was born in Manhattan to the late Nicholas and Diamondo Persanis. After graduating from Stuyvesant High School, Harry earned an Associates degree. He married the love of his life, Muriel in 1963 and was happily married for 50+ years. Employed as a Director for the Department of Motor Vehicles, Harry enjoyed many hobbies and interests. He loved his time spent with his family and was truly a one-of-a-kind person. Harry’s true gift was his love of helping others and his generous, compassionate nature.

Harry leaves his beloved wife Muriel, son Matthew and his wife Claire, daughter Christine who has Prader-Willi syndrome, and two grandsons, Luke and Caleb Persanis. ■

“You have to train your brain to be positive just like you work out your body.”

-- Shawn Achor

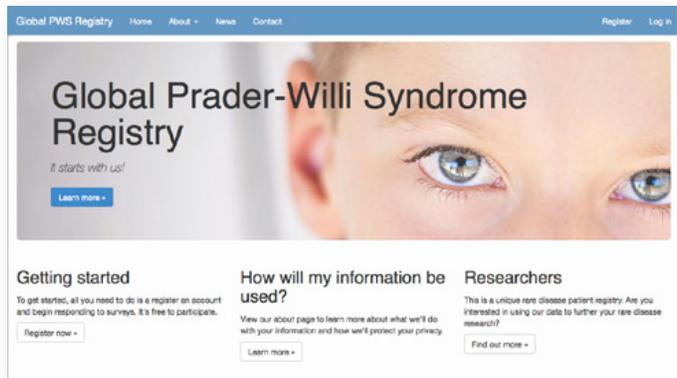
submitted by Clint Hurdle

Every Person Matters

Register Now Global Prader-Willi Syndrome Registry

Advance PWS research faster than ever by providing researchers with comprehensive, accurate, and research-ready data that is easily accessible. The Global PWS Registry is a secure database compliant with U.S. Health Information privacy laws, and FDA regulations that will: **Document** the full range of PWS characteristics – across the lifespan, **Expedite** completion of clinical trials, **Drive** unmet research and treatments, **Guide** standards of care and **Improve** the lives of those affected by PWS.

To achieve these goals, and 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. 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. It is also a powerful reminder that every person with PWS matters – and so does their unique life experience. So 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 ■



USA
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 for a cure.*

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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 website: www.pwsausa.org for downloadable publications, current news, research, and more.

The Members Only section requires a password: member20

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

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

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

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Now Available!
 By John Hernandez-Storr
 see details on page 11



Mark Your Calendar!

We are excited to be participating in the 24-Hour Online Giving Challenge again this year on September 20-21. Last year we raised over \$68,000 in donations and matching money in just 24 hours! This year, **matching incentives are even bigger!**

- A returning donor from last year will receive a 1:1 match up to \$100. Your \$100 donation will become \$200!
- A new donor (someone who did not donate in the 2015 challenge) will receive a 2:1 match up to \$100. Your \$100 donation will become \$300!

Plus, the matching funds are unlimited and there's additional prize money to be won throughout the 24 hours! This means there's LOTS of FREE BONUS money to be claimed! Please help us reach our goal of raising \$100,000 by donating online on September 20 & 21. We'll be sending more information as we get closer; WATCH your emails. Follow us on social media for more details too. BE THE ONE to help us win big this year! ■



Read the rewards of helping another country.

See page 4

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