

# The *Gathered View*

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

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

## Just a Mom Who is Casting for a Cause

By *Andrea Glass*

The PWS community is fortunate that time and again people get involved with the National and/or State organizations and make a large contribution to the overall health and vitality of our associations. Michelle Torbert of Southern Florida, who currently serves as chair of the PWSA (USA) board, and President of the Florida state chapter, is one of these people. She has a busy life of her own, with a husband, four boys, a daughter with PWS, and a family produce business that requires some travelling. She still finds the time and drive to commit to various charities and fundraisers. Her past volunteer efforts include the Red Cross, the local hospital foundation, and her children's school board of trustees. She also volunteers herself and her daughter for research studies and clinical trials to help find cures and therapies for PWS.

If you went to National conference this past fall, Michelle and Jackie Mallow were the planners and coordinators and have volunteered to do it all over again for conference in the fall of 2015. Additionally, she plans two conferences each year in the state of Florida, including various *On The Move* fundraisers. These fundraisers help fund the Florida chapter and the national association. The funds are donated to families or individuals with PWS throughout the state. When you



*Torbert Family: Back row, left to right: Alex (19) Eric (22) Tommy (Dad), David (21) Thomas (24)  
Front row, left to right: Michelle (Mom), Leslie (16 - PWS)*

hear her speak about these families that could not afford to go to conference

*The tournament has netted \$100,000 almost every year since its inception, for PWS.*

or PWS individuals who live in group homes that have no families to give them money for extras, or a group home that needs remodeling, you are instantly aware of her passion for these causes.

As PWS parents, we all know that it takes passion

and action to accomplish everything we need for our children. Michelle takes her passion for helping our associations to a very high level; not only in her commitment of time and energy to help them run, but in her ability to effectively raise funds to make them solvent. This is the sixth year of "Casting for a Cause". The tournament has netted \$100,000 almost every year since its inception, for PWS. In 2014, the national office was the beneficiary. This is not a simple tournament. If you know anything about fishing tournaments, they are not simple.

**continued on page 8**



*A winning team! Congratulations! See more photos on page 8.*

**Volume 39, Number 4 ~ July-August 2014 ~ Our 39th Year of Publication**

# PWSA (USA) Medical Database ~ We Need Your Help

PWSA (USA) has been collecting data from our families with loved ones who have PWS since 2004 and continues to this day gathering information for our researchers to learn more about the medical and behavioral concerns of those we serve. As of today, we have 1,961 records in our primary survey. Our second survey covers behavior, school issues, food seeking, housing, and medication usage. We have additional surveys covering scoliosis, assistive reproduction, and autism with PWS. All surveys are on [www.pwsausa.org](http://www.pwsausa.org) under “**get involved.**” We also have these forms available for downloading or mailed to families for those unable to use the web-based forms.

At one time, many of you helped us by doing this survey. Today, we ask you to go online at [www.pwsausa.org](http://www.pwsausa.org) and click on the link on the home page under highlights.

Please use your child’s date of birth and the ID number of {ID} to update the information. If you received an email and/ or remember your ID number – please edit the information you provided before.

If you need to confirm the ID number, please call (941) 487-6730 or email [bkarp@pwsausa.org](mailto:bkarp@pwsausa.org). You must be the name on the account and provide the name/DOB of the person with the syndrome to request the number. For confidentiality, all requests will be verified.

If you don’t think you filled in this form before, please add your information as a new entry.

Please be sure to update the weight and height if it has changed!

PWSA (USA) currently has the largest collection of information on individuals with Prader-Willi syndrome; however, some of it needs updating or lacks essential

information that could be crucial to improving the medical care of our PWS loved ones. With your help, we will improve our database by increasing the size and accuracy of the information we have currently.

***There is power in numbers!*** If we can acquire a more comprehensive database, National Institutes of Health (NIH), the FDA, and other sources will be more willing to help our children through funding and approving research in PWS and obesity! **You do not need to be a member of PWSA (USA) to be included in this essential collection. ■**

~ *Janalee Heinemann*

*As an example of the importance of this information, below is information collected from our initial general medical survey that has been very helpful to clinicians, researchers, and those seeking services:*

## PWSA (USA) Database Collections

### Zero to Five Years Old (Total respondents 301)

#### Major Medical Concerns – Current or Past:

34%	Weight related	7%	Hypothyroidism
30%	Sleep apnea	N/A	Pubic or axillary hair before age 8
19%	Aspiration	N/A	Hormone replacement therapy (e.g., estrogen/testosterone)
4%	Cor Pulmonale	<1%	Gall bladder disease
30%	Other respiratory complications	0%	Pancreatitis
8%	Heart problems	7%	Gastric/intestinal disorders
0%	Osteoporosis	<b>Birth</b>	
16%	Curvature of the spine (scoliosis, kyphosis)	1%	Twins – identical
3%	Fractures – explain	3%	Twins – fraternal
6%	Hip dysplasia	6%	Assisted reproductive techniques-
3%	Other bone problems	26%	Breech
18%	High pain tolerance	29%	Premature
30%	Severe skin picking	32%	Emergency c-section
1%	Mitochondrial disorder	51%	Tube feeding
6%	Seizure	<b>Eye</b>	
6%	Autistic behavior	19%	Strabismus
0%	Diabetes	4%	Patching
		10%	Other

### Six to 18 Years Old (Total respondents 459)

#### Major Medical Concerns – Current or Past:

62%	Weight related	8%	Hypothyroidism
42%	Sleep apnea	40%	Pubic or axillary hair before age 8
8%	Aspiration	<1%	Hormone replacement therapy (e.g., estrogen/ testosterone)
8%	Cor Pulmonale	<1%	Gall bladder disease
19%	Other respiratory complications	0%	Pancreatitis
8%	Heart problems	8%	Gastric/intestinal disorders
<1%	Osteoporosis	<b>Birth</b>	
35%	Curvature of the spine (scoliosis, kyphosis)	<1%	Twins – identical 2% Twins - fraternal
13%	Fractures – explain	3%	Assisted reproductive techniques-
7%	Hip dysplasia	23%	Breech
5%	Other bone problems	24%	Premature
46%	High pain tolerance	32%	Emergency c-section
34%	Severe skin picking	53%	Tube feeding
1%	Mitochondrial disorder	<b>Eye</b>	
9%	Seizure	40%	Strabismus
17%	Autistic behavior	15%	Patching
10%	Diabetes	11%	Other

### Over 18 Years Old (Total respondents 478)

#### Major Medical Concerns – Current or Past:

82%	Weight related	9%	Hypothyroidism
43%	Sleep apnea	11%	Pubic or axillary hair before age 8
5%	Aspiration	26%	Hormone replacement therapy (e.g., estrogen/ testosterone)
10%	Cor Pulmonale	10%	Gall bladder disease
14%	Other respiratory complications	0%	Pancreatitis
8%	Heart problems	16%	Gastric/intestinal disorders
22%	Osteoporosis	<b>Birth</b>	
46%	Curvature of the spine (scoliosis, kyphosis)	<1%	Twins – identical <1% Twins - fraternal
23%	Fractures – explain	2%	Assisted reproductive techniques-
6%	Hip dysplasia	23%	Breech
<1%	Other bone problems	17%	Premature
63%	High pain tolerance	15%	Emergency c-section
49%	Severe skin picking	33%	Tube feeding
1%	Mitochondrial disorder	<b>Eye</b>	
13%	Seizure	41%	Strabismus
12%	Autistic behavior	12%	Patching
21%	Diabetes	13%	Other

### 35 Years Old and Older

#### (Total respondents 164)

#### Major Medical Concerns – Current or Past:

87%	Weight related	13%	Hypothyroidism
38%	Sleep apnea	6%	Pubic or axillary hair before age 8
4%	Aspiration	22%	Hormone replacement therapy (e.g., estrogen/ testosterone)
12%	Cor Pulmonale	9%	Gall bladder disease
13%	Other respiratory complications	0%	Pancreatitis
32%	Osteoporosis	16%	Gastric/intestinal disorders
38%	Curvature of the spine (scoliosis, kyphosis)	<b>Birth</b>	
23%	Fractures – explain	0%	Twins – identical 0% Twins - fraternal
26%	Hip dysplasia	2%	Assisted reproductive techniques-
10%	Other bone problems	23%	Breech
63%	High pain tolerance	9%	Premature
46%	Severe skin picking	4%	Emergency c-section
<1%	Mitochondrial disorder	21%	Tube feeding
10%	Seizure	<b>Eye</b>	
12%	Autistic behavior	35%	Strabismus
26%	Diabetes	6%	Patching
		13%	Other

## Aging and Dental Issues = Problems for PWS

By Janalee Heinemann, M.S.W., PWSA (USA) Director of Research & Medical Affairs

I have been receiving more and more calls on major dental issues regarding our people with Prader-Willi syndrome who are aging (35 years of age or older). Although we've had a dental article recently, I thought perhaps we should expand on this topic.

### Dentures & PWS

The following is in an email with advice to a parent from Dr. Thomas Hughes, who is a dentist and has a daughter with PWS. This is not necessarily advice recommended for all people with PWS getting dentures.

"As for your son, I would suggest you think about getting 2 regular dental implants and a bar that connects them or 4 mini implants put in after his extractions heal on the lower arch. The upper arch has plenty of bone to support a denture in most cases but the lower arch/ridge is very small and will not support a denture the long haul. The 2 implants in the area of what was tooth #23 and #26 with a bar connector or 4 implants in the area from teeth #28-21 would provide a long-term stable lower denture which would allow your son to eat almost any kind of good food he would need. Also they would not decay. Because of the low salivary flow of a person with PWS dentures in themselves will be harder to get to stay in place because of the lack of fluid to make the seal possible."

### Dental Lifeline Network

The **Donated Dental Services (DDS)** program provides free, comprehensive dental treatment to our country's most vulnerable people with disabilities or who are elderly or medically fragile. These are people who cannot afford necessary treatment and cannot get public aid. The program operates through a volunteer network of more than 15,000 dentists and 3,600 dental labs across the United States. Since its inception in 1985, their DDS

program has surpassed \$250 million in donated dental therapies, transforming the lives of more than 120,000 people. DDS operates a program in each state. Go to <http://dentallifeline.org/about-us/> to review qualification guidelines and an application for the state where you reside, or call 312-527-6764. ■

### International Prader-Willi Syndrome Organisation 7<sup>TH</sup> Scientific Conference ~ May 20-21, 2010, Taipei, Taiwan Salivary Flow and Oral Abnormalities in Prader-Willi Syndrome

Ronnaug Saeves<sup>1</sup>, Hilde Nordgarden<sup>1</sup>, Ivar Espelid<sup>2</sup>, Kari Storhaug<sup>1</sup> <sup>1</sup>TAKO-centre, Lovisenberg Diakonale Hospital, Oslo, Norway; <sup>2</sup> Department of Pediatric Dentistry, University of Oslo, Norway.

**INTRODUCTION:** Persons with Prader-Willi syndrome (PWS) have sparse, thick and sticky saliva. High caries activity, poor oral hygiene and extreme tooth wear have been described in case reports. Oral and dental problems have received little attention by researchers. The aims of the study were to examine salivary flow rate and describe oral and dental characteristics in Prader-Willi syndrome.

**METHODS:** Fifty-one individuals with PWS, aged 5-41 years and an age and sex-matched control group were examined with regard to salivary flow rates, dental caries experience, gingival inflammation, enamel defects and tooth wear. Both unstimulated and chewing stimulated whole saliva as well as taste-stimulated parotid salivary flow rates were measured. The presence or history of dental caries was evaluated both clinically and on radiographs. Tooth wear was evaluated according to a 4-point scale, the Jonkoping-index. An individual tooth wear index ( $I_A$ )

*A follow-up to the story on Julie Mitchell's "Dental Double Trouble" (in the GV September-October 2013 issue): After oral surgery in May 2013 removing all her upper teeth, Julie received her new upper denture in October and is doing well now with a beautiful new smile.*



was created on the basis of the scores of incisal or occlusal wear for each tooth.

**RESULTS:** The average flow rate for unstimulated saliva (UWS) was  $0.12 \pm 0.10$  ml min<sup>-1</sup> for individuals with PWS compared with  $0.32 \pm 0.20$  ml min<sup>-1</sup> for controls ( $p < 0.0001$ ). Chewing stimulated flow rate (SWS) was  $0.41 \pm 0.35$  ml min<sup>-1</sup> for the PWS group compared with  $1.06 \pm 0.65$  ml min<sup>-1</sup> for the control group ( $p < 0.0001$ ). Taste-stimulated parotid saliva was not found to differ significantly between the persons with PWS and healthy controls. There was no significant difference in caries experience in the primary dentition. Caries experience in permanent teeth (persons >18 years) was higher in the control group ( $p = 0.04$ ). The median GI-index (gingival inflammation) was significantly higher in the PWS group compared with the control group ( $p = 0.04$ ). The number of surfaces affected with enamel defects was  $3.5 (1.0-8.8)$  in the study group and  $4.0 (0.5-7.0)$  in the control group ( $p = 0.76$ ). The median tooth wear index  $I_A$  was  $7.5 (0-100)$  in the PWS group and  $2.2 (0-10.7)$  in the control group ( $p < 0.0001$ ).

**CONCLUSIONS:** Low whole salivary flow and tooth wear are very common in individuals with PWS. Taste stimulation may increase salivary flow rates in this group. The oral hygiene in the studied population with PWS was generally poor but the dental caries experience was not increased. This may reflect a low sugar diet and tight follow-up regimes. ■

## From Top to Bottom – G.I. issues with PWS

By Janalee Heinemann, M.S.W., PWSA (USA) Director of Research & Medical Affairs

We are learning more about the fact that people with Prader-Willi syndrome are at risk throughout the G.I. tract system.

**Esophagus:** We do know in our medical and study of death surveys that 39% of families reported choking episodes and 12/152 PWS deaths were choking deaths (not infants or toddlers but much older than the norm with an average age of 24). This does not include a very recent choking death reported. There is a swallowing study going on right now by Dr. Gross and Dr. Cherpes and sponsored by PWSA (USA) where preliminary results have shown that participants had a significant amount of esophageal

residue but they thought the food all went down, creating a risk factor for aspiration/choking.

**Stomach:** Dr. Ann Scheimann reports that the PWS stomach is thin-walled and doesn't produce a lot of fluid. She and Dr. Klish are doing a G.I. study sponsored by PWSA (USA) which has shown that a significant number of people with PWS have slow stomach emptying/gastroparesis. We have been aware for some time about the risk of G.I. necrosis and perforation deaths in PWS, and now suspect the gastroparesis may be adding to this risk factor.

**Colon:** A new Denmark study titled, "*A descriptive study of colorectal function in adults with PWS: high prevalence of constipation,*" confirms what we have known all along, that our children and adults with PWS have a high prevalence of constipation. The G.I. transit time was over three days in 5/21 with PWS and none of the controls. 8/20 (40%) fulfilled the

criteria for constipation. 12/20 (65%) had fecal mass in the rectum vs. 3/25 (12%) of the controls.

My personal concern, due to taking the medical calls for 17 years, is that even though we have known unofficially for a long time that constipation is not at all unusual with PWS, when a person with the syndrome goes to the ER with G.I. symptoms, often they take an x-ray and see that the person is constipated and think that is the only problem, thus often overlooking a more serious problem. Also, constipation may increase the risk for rectal picking behaviors.

Parents will sometimes ask, "Since growth hormone strengthens muscles, shouldn't it strengthen the motility of the entire G.I. tract?" Unfortunately, the answer is no. As we learn more about these G.I. issues, and document them through studies, hopefully we can find some resolutions for the safety of our children and adults with Prader-Willi syndrome. ■

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## iHOLA!

By Nina Roberto, E.D. of the New York Association and on the State Chapter Leaders Team as representative to Spanish-speaking families with PWS.

iHola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi.

Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que necesitan informacion y ayuda. Les quiero dirigir a [www.pwsausa.org](http://www.pwsausa.org) donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, [ninaroberto@verizon.net](mailto:ninaroberto@verizon.net). ¡Hablamos pronto! ■

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## Research Study Volunteers needed

Is your child with PWS 8 to 16 years old? Are you having trouble motivating him/her to do enough exercise? This research study may be the ideal way to turn that around. There are a lot of incentives for the child with the syndrome including an interactive Wii console and multiple gift cards.

Dr. Marilyn Dumont-Driscoll, a pediatrician at the University of Florida in Gainesville, is seeking participants to complete a research study examining the effects of a home-based physical activity program for PWS. Although it means visits to the University of Florida, sometimes those visits can be coordinated in conjunction with other visits you may have with Dr. Dan Driscoll or Dr. Jennifer Miller. You do not have to live in Florida to participate. Email Dr. Dumont-Driscoll at [dumonmd@peds.ufl.edu](mailto:dumonmd@peds.ufl.edu) to get more details. ■

# Chapter Relations Committee

PWSA (USA) is currently reaching out to its chapters and affiliated organizations to renew our chapter agreements. To complete this task, the board of directors has created the Chapter Relations Committee.



Ken Smith,  
Executive Director

The Chapter Relations Committee is led by Crystal Boser, President of PWSA-Wisconsin, and includes board members Michelle Torbert, Michael Troop, Rob Seely, Sybil Cohen, Jim Koerber, Lisa Thornton and Ken Smith. Each member has been assigned to be a direct liaison between the chapter and the national office.

Each member has been assigned to several states tasked with reaching out to each state.

### Committee Responsibilities:

1. Maintain a list of current presidents with contact information
2. Update current board members and officers of each chapter
  - a. Check with the president for changes to officers and board.
  - b. Keep a list of updated email addresses
3. Collect state chapter financial data, minutes, and other documentation
4. Conference Grant responsibilities and instructions about how to sponsor families
5. Yearly Dues and expected donation reminders
6. Contracts with National about other PWS organizations
7. Presidents Day at conference – agenda, topics, advertisements and other solicitations

PWSA (USA) is listening to the feedback provided to the organization and wants to help each state as much as possible

This year PWSA (USA) is committed to working toward the following goals to assist chapters:

- Develop, strengthen, and nurture state chapters and affiliates. This goal will be accomplished through the sharing of best practices, educational webinars, fundraising assistance, and sharing lists.
- Continue to build our Special Education Advocacy program, which is unique within the rare genetic disorder community. This includes the work of Wyatt Special Education Advocates in several states, sharing of new school resources, the distribution of the school e-letter “School Times”, and as always the work of our Crisis Intervention/Family Support counselors who are just a phone call away for parents who need individualized help and support with IEPs and other school concerns.
- Provide support and growth of medical clinics throughout the United States. This goal will be accomplished by defining what a clinic is, sharing what clinics already exist, identifying demographic areas where clinics are needed, and facilitating the opening of a clinic. ■

*“We must remember that one determined person can make a significant difference, and that a small group of determined people can change the course of history.”*

*~ Sonia Johnson*

*contributed by Clint Hurdle*

## NEW! Publication now available!

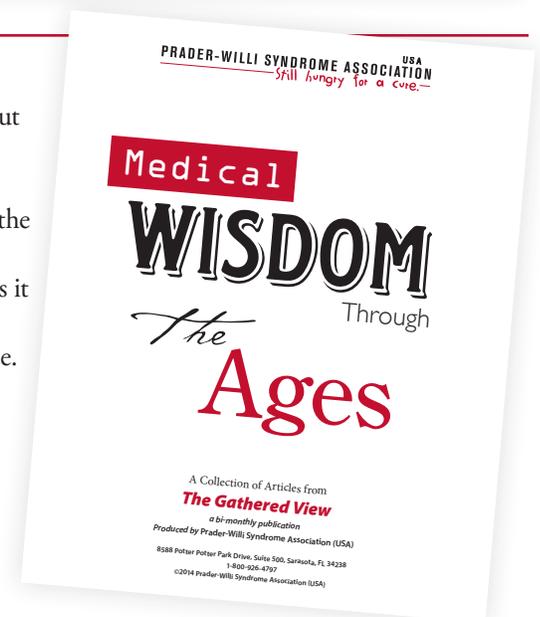
There has been a wealth of medical information on PWS published throughout the years that we want to share with our current generation of parents and professionals.

This new published booklet is a collection of articles (most from the pages of the PWSA (USA) newsletter, *The Gathered View*), pieces of parental wisdom derived from experience, and information about the syndrome and the unique challenges it presents in the health and medical area.

If you wish to place an order for this booklet, please contact the national office.

The cost for this nearly 200-page informational booklet including tables, research data, etc. is \$20 for members and \$25 for non-members.

In closing, a debt of gratitude to all of our dedicated medical professionals on our Clinical and Scientific Advisory Boards for their many dedicated hours of volunteer work for PWSA (USA) through the years, and for their donation of articles to our newsletter, *The Gathered View*. And thank you also to the other medical professionals who donated articles on needed topics at our request. ■



# PWSA (USA) 2014-2016 Board of Directors - Approval of 2013 Annual Membership Meeting Minutes and Election

### Voting Instructions:

1. Review the candidates' statements printed on the Slate of Candidates. Read the 2013 Annual Membership Meeting Minutes.
2. Cast your vote on the Official Ballot **located on page 7**. 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 30, 2014.
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 30, 2014. Ballots postmarked after August 30 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. ■

## Board of Directors Nominees



### Daniel J. Driscoll, M.D., Ph.D.

Dr. Driscoll is a Professor of Pediatrics and Genetics, as well as the Hayward Professor of Genetics Research, at the University of Florida College of Medicine. He has been conducting clinical and laboratory research on Prader-Willi syndrome since the late 1980's. He has been a major contributor to the understanding of the genetics of Prader-Willi syndrome (PWS) and genomic imprinting in the PWS region as well as to the elucidation of the natural history of PWS. He is widely published on PWS and a major spokesperson on PWS in the US and internationally. He is the principal investigator for the Prader-Willi syndrome component of an NIH funded 11 year national Rare Disease Center grant.

In 2006 he was elected to the prestigious Society of Scholars at the Johns Hopkins University based on his seminal research contributions to the field of genetics. He is currently a member of the Board of Directors and Chair of the Clinical Advisory Board for PWSA (USA). In addition, he is a member of the Medical and Scientific Advisory Board of the International Prader-Willi Syndrome Organization (IPWSO).



### Tammie R. Penta

Ms. Penta, of Tuscon, Arizona, has been a police officer for 26 years and a sergeant for the past 18. A recognized expert in elder and child abuse investigations, Tammie has spent 10 years conducting criminal investigations from family crimes to organized crime. She also spent four years as a field training supervisor at the Southern Arizona Law Enforcement Training Academy. There, Tammie developed training programs as well as assisted in the Crisis Intervention Training (teaching law enforcement, the Department of Developmental Disabilities and citizens with special needs or a family with special needs, and also taught Southern Arizona Officers how to address crisis situations with people with developmental or mental health issues). Specific to this training was how to address the issues with several adult PWS homes located in Southern Arizona. This training, taught in this area for nearly 10 years, continues to be successful in educating local law enforcement. Tammie has sat on the Arizona chapter for Prader-Willi Syndrome since 1996 and was certified through the (WSEAT) Wyatt Special Education Advocacy Training in 2013. Tammie and husband Phil have been married for 21 years. Children include son Victor, age 20, diagnosed with PWS at the age of two, currently living at home while completing high school, son Nick (23) and daughter Raquel (18).



### Denise Westenfield

From Eden Prairie, Minnesota, Denise Westenfield is Vice President, Controller and an officer for Datalink Corporation in Minneapolis, Minnesota. She earned an MBA from St. Thomas University and a BS in Accounting from the University of Minnesota. She currently serves as Head of Delegation for a local Special Olympics team supporting 150 athletes and 9 sports offerings throughout the year. Denise has a son Erik, 17, who was diagnosed with PWS at two weeks of age. In addition to Erik, she has been married to Karl for 26 years and has a daughter Kristen (23) and son David (21). Denise has been involved with the PWS-MN organization for more than twelve years serving on the Board of Directors and holding various officer positions including

Secretary, Vice President, President and is currently Treasurer. She is also on the annual golf tournament committee which raised almost \$30,000 last year. She would be honored to serve on PWSA (USA)'s Board of Directors and believes that her financial and fundraising experiences would be very beneficial to the organization.

# PWSA (USA) Telephonic General Membership Meeting

Sunday, December 8, 2013

The meeting was called to order by Board Chairman Michelle Torbert at 8:03 p.m., EST. She welcomed our newly-elected board members: Rob Lutz, Sybil Cohen, Rob Seely and Michael Troop. She thanked our board members whose terms ended in 2013: John Heybach, Steve Leightman, and Mary K. Ziccardi.

At the September board meeting, Ken Smith was elected as chair of the board, and Michelle Torbert as vice chair. In November, Ken was offered the position of Executive Director of PWSA (USA), which we are pleased to say he accepted. In accepting the ED position, Ken immediately stepped down as the chair of the board.

Dale and Dottie Cooper served as Interim Executive Directors for over a year and brought skill and leadership to the organization. They resigned at Conference and can now enjoy their retirement. They will both continue to be involved in the organization through their volunteer efforts. We are honored to have someone with Ken's qualifications to lead PWSA (USA). His professional qualifications and the extent of his involvement with PWSA (USA) over the past 20 years were outlined.

Attendees were referred to the website to learn more about the board members and office staff.

Conference 2013 took place in Orlando last month and was a tremendous success. The presenters were educational and informative and the YIP/YAP participants had a wonderful time. A contract for Conference 2015 is being negotiated.

The 2013 Angel Fund Campaign has been kicked off electronically, and the mailed cards will be sent shortly. This campaign provides the funds needed to run the day-to-day operations

of the organization and support the many services we provide to the PWS community. The goal for this year is \$130,000.

PWSA (USA) is continuing to work on establishing a closer relationship with FPWR, and is collaborating with them on many projects.

**Finance Committee:** The Financial Report was reviewed, outlining the sources of our income and expenses. Revenue through the third quarter of 2013 has increased \$20,000 over this time last year, and the expenses are below the approved budget levels. A new website is currently under design and a webinar series has been added. As awareness grows, so do the needs of the association. There has been an operating shortfall in 2013. A balanced budget will be presented for 2014.

**Crisis team:** In 2013, the first Wyatt Special Education Advocacy Training program was held in which 11 volunteers were trained. The first issue of an E-letter entitled *School Times* was released in August. It is the first publication to deal exclusively with PWS educational issues. The Older Child E-book debuted at conference and includes one and two-page handouts on topics such as food and behavior, marriage and family, an exercise DVD, and two medical alerts. It's available on a zip drive. PWSA (USA) has learned of over 95 newly-diagnosed individuals this year, including 11 international families. To help

meet this increasing need, 14 new parent mentors have been recruited.

**Publications:** New publications produced in 2013 include *When Your Baby is in the NICU*, and the extensive book, *Medical Wisdom Through The Ages* has been completed, and will be available pending final review and design. *Supporting Someone with PWS* and *Someone You Know Has PWS* were updated. The Estate and Guardianship book is also being revised. *A Book of Bullies*, written by Katherine Stanley, a 16-year-old girl from N. Carolina with PWS, debuted at conference and was a sellout. Katherine held book signings during conference breaks. The book has been re-ordered and is available by calling the office. Many new logo items are also available by calling the office.

**Executive Director:** Ken Smith was introduced. He thanked the board and the association members for the notes and letters he has received since accepting the position – it's very gratifying. He will be in Sarasota for the next week and a half, with the intent to eventually relocate permanently. He noted this is an extremely active, working board of directors, all of whom are volunteers. He embraces a board that is connected and involved with the association's operations. A few of the

continued on page 12

## OFFICIAL BALLOT

Cast your vote for the 2014-2016 Board of Directors. Vote for three (3) of the candidates listed below.

- Dan Driscoll
- Tammie Penta
- Diane Westenfield

Corrections to the 2013 Annual Membership Meeting

Minutes: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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

# In Honor and Love of Our Children

Losing a loved one is sad to talk about, but I will, because it is our reality with having children/adults with Prader-Willi syndrome. Our children/adults can have more medical complications than a typical child/adult. What do we do about it? It is a new mission of mine to investigate, converse, get records, autopsies, etc., about the deaths of our loved ones. I believe that looking with a fine tooth comb at these deaths we can come up with explanations and then preventative measures that will let our children/adults live a long life.

A month ago, I took on the volunteer position as coordinator for the Study of Deaths and Bereavement Programs for PWSA (USA). We have a team of doctors and specialists that are on the Study of Deaths committee, led by Dr. David Stevenson with the University of Utah. This committee has been somewhat on hold since the death of our volunteer coordinator, Norma. But now, our doctors will again be getting medical records and autopsies and then collaborating together which will give us answers, protocols, and the need to further research in specific areas. The doctors will also again be able to write and publish case studies



and articles for medical journals. This will help create more awareness and better treatment for our loved ones when they are in a hospital or medical setting. You will be able to advocate and take care of your loved one with recommended protocols.



Dr. Jim and Carolyn Loker

Please don't forget that PWSA (USA) exists. [www.pwsausa.org](http://www.pwsausa.org). This is what we do, this is part of our mission to help you help your child. Let's do this so we can honor our loved ones and the parents who have lost their child/adult. This is my mission because I want better treatment options for my daughter Anna, and for your loved one. I love our kids! If you hear of one of our loved ones passing, please...contact PWSA (USA) so we can proceed with our mission.

Many Hugs, Carolyn

## Casting for a Cause, continued from page 1

There are many boats that compete both in and off shore. Each angler pays an entrance fee and there is a \$5000 prize for first place. There is a dinner and silent auction at the end of the day. Most people who participate have no connection with PWS. They are attracted by the large purse of the tournament and the great cause. Michelle plans and advertises the tournament, collects the silent auction items and finds corporate sponsors. This year she added a 50/50 raffle which added additional funds to the final tally. For more information and fundraising ideas check out the "Casting for Cause" website <http://www.castingforacause.com/>. ■



Winner of the Offshore Division Diane Slager and her team. Presenting the check are Steve Jacques and Michelle Torbert, tournament co-chairs.



Awards dinner, tournament participants L-R David Torbert, Libby Delemos, Ashley Chalker, Thomas Torbert, Lyndsay Woske, Wesley Berry



CFAC Committee: L-R Bobby Hoffman, Sara Hoag White, Rosa Borgert, James Accursio, Michelle Torbert, Steve Jacques, Sharon Dumond, Crystal Vinck

## A Legacy of Extraordinary Service

By Evan Farrar, Crisis Counselor

The Family Support Program at PWSA (USA) continues to give thanks for the life of our dear colleague and friend David Wyatt, whose life was celebrated at a beautiful memorial service in Sarasota, Florida, at the end of May. If you would like to learn more about this remarkable man, you can watch the entire service on YouTube at [https://www.youtube.com/watch?v=gTBx0xTn3\\_Q](https://www.youtube.com/watch?v=gTBx0xTn3_Q) or by searching for David Wyatt Memorial. David's professionalism, kindness, and generosity of spirit will continue to animate our family support program as we build on the legacy of extraordinary service he left us.

One way we honored David's legacy is by creating the *David Wyatt Crisis Fund*. This fund will be specifically dedicated to meeting emerging crisis and family support needs in the PWS community. A gift to this fund will go 100% to provide programs and materials to make sure that people living with PWS and their families have a place to turn when they need help now and in the future – just as David would want it.



*David touched thousands of our families over the years. David's dedication and inspiration went a long way, helping this organization throughout these years. R.I.P.  
- Jeff Fender*



Sail on dear friend, sail on.

The *David Wyatt Crisis Fund* will also be used to continue developing the special education advocacy initiative named in David's honor which began with the first *David Wyatt Special Education Advocacy Training* (WSEAT) in March of 2013. During the initial training, eleven people from the PWS community were trained as "Wyatt Special Education Advocates" who are now helping to educate parents of children with PWS in their home communities. With the help of the new *David Wyatt Crisis Fund*, our goal is to plan another special education advocacy national training and more!

So if, like us, you believe in the vital importance of PWSA (USA)'s mission to support families raising a child with PWS, we hope you will consider giving a gift to the new *David Wyatt Crisis Fund* so that David's extraordinary legacy of service will continue to benefit the PWS community long into the future. ■



# On The Move "It's a Wrap...or is it?"

By *Ben Karp*

Thank you, families and friends, for all of your hard work for Prader-Willi Syndrome Association (USA) and for coming out to the many events across the country! Your May 2014 fundraising efforts have led to our most successful Awareness Month ever. We had a great time, and event stories continue to arrive. See photos we've received from events across the country at [www.pwsaonthemove.org](http://www.pwsaonthemove.org).

Your hard work will provide much needed funding for support, awareness and advocacy programs, continued research, and education, plus:

- Distributing hundreds of informational packets to care providers, medical, and school professionals.
- Offering an understanding and supportive ear when parents need a place to talk.
- Utilizing educational and residential consultants for expert training to schools and residential programs across the country.
- Designing creative new resources such as the Older Child Package, to assist families and caregivers of PWS.
- Increasing advocacy efforts to promote the support needs of people with PWS and their families.
- Participating in IEP meetings for students with PWS across the country to answer questions about PWS and recommend PWS appropriate educational and behavioral strategies.

With your help, we will build on that momentum and continue our *On The Move* Events for the rest of the year! Create, participate and support an *On The Move* awareness event by going to [www.firstgiving.com/pwsausa](http://www.firstgiving.com/pwsausa) or contacting our grassroots fundraising coordinator at 941-487-6730 or email [bkarp@pwsausa.org](mailto:bkarp@pwsausa.org).

We cannot thank you enough for your efforts and continued support! ■



## ATTENTION Federal Employees!

If you work for the Federal government, the Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all." **PWSA (USA) CFC ID # is 10088**

For more information about the CFC program and how it works, go to their Web site at <http://www.opm.gov/cfc/index.asp>, or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee. ■

## On October 18 - Take it to the Courts!

Mark your calendar for TAKE TO THE COURTS benefiting PWSA (USA).

Join us for an afternoon of instructional tennis clinics with local pros, an after-party luncheon, complimentary wine & beer, raffles, silent auction and special guest appearance by 2014 Tennis Hall of Fame and legendary coach Nick Bollettieri. 11 o'clock registration at The Meadows Country Club, Sarasota, FL.

- \$50 per player  
- \$30 per non-player, includes after-party luncheon & silent auction

For more information, contact Pamela at 941-487-6743 or [pferrara@pwsausa.org](mailto:pferrara@pwsausa.org). ■

# The Suncoast Saltwater Shootout

By *Pamela Ferrara*

Big fish, beautiful boats, an exciting live open-to-the-public weigh in and live band all wrapped up on a huge dock party at Marina Jack, that's the Suncoast Saltwater Shootout! The Suncoast Saltwater Shootout will hold its 2nd Annual Fishing Tournament, September 17-20, to benefit the Prader-Willi Syndrome Association (USA). This "Shootout" is the biggest and "funnest" tournament on the Suncoast. Swordfish, huge tuna, wahoo and dolphin are on the scales. See monster grouper and snapper from offshore teams, plus an inshore division bringing trophy redfish and trout to the dock, all for big prize money. Marina Jack, the Suncoast's premiere marina, is an amazing venue and host to this annual event. Serious anglers participate and huge audiences come out to see the action.

Bid on fantastic silent auction items such as vacation stays and the opportunity to drive a Porsche for a weekend. Andros, Marina Jack, The Ritz Carlton, Suncoast Motorsports and Budweiser are leading the charge on this first class event. Other participating companies for this high caliber event include Evinrude, Underarmour, and Garmin. Together, they are helping to raise urgent funds for the children affected by Prader-Willi syndrome.

If you're in Sarasota in September, join in the festivities! Registration forms and sponsorship opportunities are still available. For more information contact Pamela @ [pferrara@pwsausa.org](mailto:pferrara@pwsausa.org) ■

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](http://www.pwsausa.org)

## An All-Star Performer

From Ben Karp, as contributed by Jennifer Valentine

Our beautiful daughter, Chelsea, was born September 19, 2013, on her late-grandmother's birthday. It was a very special day. As the obstetrician was delivering her, he said, "Look at all the blonde hair!" In an instant I knew something was not right, but I had faith that everything would be ok. I delivered Chelsea via C-section and she spent the first three days of her life in the room with mommy and daddy at the hospital. She would hardly wake to feed, and my hopes to breastfeed pretty much evaporated within the first day. Doctors were not overly concerned with her "floppy" state, or that she hadn't had hardly a drop of milk in twelve hours! I knew in my heart that something was wrong. By day three of poor feedings at the bottle, mommy was discharged from the hospital and Chelsea was moved to the NICU (neonatal intensive care unit). We were told by the geneticist that she suspected Chelsea had Prader-Willi syndrome, characterized by her fair features, almond-shaped eyes, and hypotonia (severely low muscle tone). We were told she would most likely spend two to three months in the hospital NICU, and that when she did go home, it would be with a feeding tube. We were devastated! Our poor little baby...how could this be? She was quite dehydrated and spent a few days on IV, and with supported oxygen, and a feeding tube, but when she gained back her strength we were able to remove all three! Our little girl was discharged after two weeks, not two months, and went home feeding from a bottle! The geneticist



Chelsea's photo contributed by Erin Galardi, photographer

*The geneticist referred to her as an "All-Star" and said she'd never seen such strength in a baby with PWS.*

referred to her as an "All-Star" and said she'd never seen such strength in a baby with PWS. That's not to say Chelsea was toned and alert when she got home. Bottle feedings were hard on mommy and daddy (Jimmy), and Chelsea slept so much of the day away. Every day she gets stronger though! She is very busy with physical therapy three times a week, developmental therapy once a week, not to mention the weekly visits to numerous doctors, which include: pediatrician, geneticist, feeding and speech therapist, endocrinologist, pulmonologist, chiropractor...I'm sure I'm forgetting some. Chelsea truly is a loving, angelic child, and my hope for her is that she loves this life and all the wonderful things it has to offer her, despite the struggles that her syndrome may cause her. ■

**About PWS:** Prader-Willi syndrome (PWS) is a complex, life-threatening medical disorder that affects the body's hormone system; muscle strength; pain, sleep and temperature regulation; cognition and learning; behavior and appetite. For persons with PWS, the brain does not regulate emotions and appetite normally. Behavior problems are common, worsened by an unrelenting, and overriding physiological drive to eat. Normal satiety, the feeling of fullness after eating, does not

exist. Undiagnosed, unmanaged and without 24/7 supervision, Prader-Willi syndrome leads to obesity-related illness and premature death. Prader-Willi syndrome is one of the 10 most common syndromes seen in genetic clinics and the most common genetic cause of obesity. Although research has made great strides to increase our understanding of Prader-Willi syndrome, there is no treatment to control or even reduce the insatiable appetite, no medication to treat all of the behavior and psychiatric

symptoms. There is no cure, but with your help, there is hope!

We ask for your support in raising money for a foundation that supports us in our journey, and in the research efforts to finding a cure! Many thanks for all your support.

- Jennifer Valentine

See Jennifer's PWSA (USA) fundraising page here:  
<http://www.firstgiving.com/fundraiser/chelsea-valentine/on-the-move-new-jersey>

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## How Our Organization Helped

# Elana's Family

By Denise Servais

PWSA is here when you need them. That's what many people have experienced, including Cheryl Hardy. Hardy has called the PWSA (USA) office on different occasions when she needed help at different stages of her daughter's, Elana's life. Elana, aged 21, with PWS, had recently graduated from high school. Cheryl recently called National, and spoke to Evan Farrar. Hardy was looking for help to figure out what programs exist for Elana, now that she had graduated from high school.

"He (Farrar) gave me some phone numbers to call...I found a day program where Elana can go and get out."

Hardy also emailed the PWSA (USA) office a graduation picture of Elana. "I wanted people to see how she had grown." Hardy explained how many people remembered Elana as a young girl from the book, "My Ragdoll." Hardy is the author of "My Ragdoll," which is a publication that can be purchased online through PWSA (USA). In the book, Hardy shares her experience raising Elana as an infant through kindergarten. This book's content was taken from Hardy's diary. Hardy credits Janalee Heineman, from the PWSA (USA) office, for helping her get the book published. After the book was published, Hardy said she got positive emails from all over the world. "It doesn't matter what your child might have, Prader-Willi syndrome, Down syndrome, or whatever, we all go through the same emotions. No matter what it is...This story has a good ending."



Photo of Miss Elana Couch provided by Gloria Stults Photography

Cheryl and Elana live in Meridianville, AL. Elana has 2 brothers and one sister. In her free time, Elana loves going on the computer, playing the Wii, and watching her favorite TV program, "COPS."

"My Ragdoll" (2000) by Cheryl Couch, #234, age birth to 6. Softcover, 229 pages. \$16 (M) \$18 (NM) ■

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## How Our Organization Helped

*This story came from a post from Julie Casey on Facebook:*

"10 years ago this beautiful little guy was born. 10 years ago today he had already been admitted to the NICU and we didn't know what was going on (the PWS diagnosis came about a week later). Once we found out Ryan had PWS we were devastated; the initial information was pretty depressing, but thankfully we got in touch with Prader-Willi Syndrome Association (USA) and Prader-Willi California Foundation right away; because of the support and guidance of these two organizations we have a 10 year-old who is doing incredibly well, and PWS is nowhere near as scary as we thought it would be." ■

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### Annual Meeting Minutes, continued from page 7

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priorities he has are: Fundraising, chapter development, FPWR relations, and assessing the current office team and identifying needs for further development. The website upgrade is a Herculean project and all of the staff is working diligently to move it forward.

**Fund Development:** Rob Lutz, Chair of the Fund Development Committee, stressed the importance of fundraising so we can continue to offer more services over time. Last week, the E-version of the Angel Fund card was sent and approximately \$20,000 was raised. The printed cards should be mailed shortly. The Fund Development Committee will meet in a week to develop a strong strategy and plan for 2014. They will identify how many On The Move events will be needed, how many memberships are needed, etc., to meet our goals, as well as a plan for how to accomplish this. We will continue to partner with the chapters to help them fundraise for themselves. Ken noted the fundraising efforts are being categorized as nationally, state and regionally focused, as well as the unique opportunities available in the Sarasota area. New contacts are being established in Sarasota for the first time.

The call was opened to questions from attendees.

Meeting adjourned at 8:35 p.m.

Respectfully submitted,

Julie L. Doherty, Secretary ■



Heard at a Pennsylvania Chapter meeting: Parents of Shane, age 8, related that he had been having some instruction at school about using 911 and emergency situations. When asked what he would do if his house was on fire and his parents had passed out, his immediate response was "Go to the kitchen!"



### Brandon Mosley

With a smile on his face, Brandon Darrell Mosley went to the arms of his heavenly Father on May 20, 2014. Brandon graduated from Moore High School in 1993. Born July 31, 1974, in Oklahoma City, OK, Brandon had a life-long struggle with Prader-Willi syndrome, but that did not define the wonderful person that he was. He never met a stranger and his passion was his love for God and his family. He is survived by his parents, Russell and Daphne Mosley; one sister, Tiffanie Mosley; two nieces, Maddison and Lauren; and one nephew, Hunter - whom he loved very much! A huge extended family of aunts, uncles, cousins and the Prader-Willi families of Oklahoma. In lieu of flowers, donations may be made to: The Prader-Willi Syndrome Association of Oklahoma, 12300 Market Drive, OKC, OK 73114.



### Shirley Neason - A Pioneer with the Prader-Willi Syndrome Association (USA)

On June 16, Shirley Neason passed away. Married to T.G. Neason in 1954, Shirley had their first child in 1956, the second in 1958 and a third in 1966. She was a full time parent. Shirley's third child, Daniel, had a birth defect called Prader-Willi syndrome. The syndrome had recently been identified and not much was known about it. She helped form a parent's organization to support study of the syndrome and to share information among parents of children who had the syndrome. Daniel preceded her in death in 1980. Shirley was our VP and the first newsletter editor for the GV.

Diagnosed with multiple myeloma in 2002, she continued to teach children as much as she was physically able. Shirley lived a full life as a wife, mother, grandmother, teacher, and multiple other roles. She never failed to put God and then her family above all others. She is now surely doing what she loved more than anything – singing hymns to the Lord.

A donation may be made in Shirley's memory to the Prader-Willi Syndrome Association (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471, via the web site <http://www.pwsausa.org/give.htm>, or calling (800) 926-4797. ■

*Note: Shirley and her PWS legacy will be featured in an upcoming issue of the GV.*

## Fighting the Fight

By Patrice Carroll

In the final week of PWS awareness month, I have been thinking ahead to the possibilities that this new generation will have but am distracted by the current state of insurance claims being cast aside, accommodations for a fair education being refuted and needed in-home services being rescinded. It confounds me how we are still fighting this battle and then I realized why- because they don't know our kids. That's all. If they knew them, they would love, admire and fight for them the way that we do. They would not give indirect answers denying their necessary accommodations to get a fair education. They would not use their antiquated laws to refuse our kids, the support that they need in adulthood, and they would not reject scientifically proven medications because a simple modification to their insurance policy would just be

too overwhelming for them to manage. If they knew our kids they would make the changes, find the loopholes, fight the system. But they don't know them so they don't bother and that is the greatest injustice I can think of; to blindly turn away.

We are not asking to give people with PWS a great advantage, simply to give them what is needed to be safe, healthy individuals with the same rights as every other citizen. That is not too much to ask and yet we are still fighting. So what do we do? We make it personal, because it is. We create teams of people who know and love our children to make the calls, insist on the meetings, reject plans that are subpar, that don't stop even when the odds look incredibly stacked against you. It may take an army, but guess what? We have one. May ends in a few days but our fight doesn't and we have what it takes to make the changes that will allow our kids to get the services that they deserve. I'm in. Are you? ■

### Another David Wyatt tribute

*"Debbie Lange said it well: a tremendous man who was an angel on earth and now in heaven. I am blessed to have known him & worked with him. MANY lives are better because he lived. R.I.P. David. We'll miss you!"*

*Jodi O'Sullivan*

## Hurdle to be honored for his community service Pirates manager named 2014 recipient of Brooks Robinson Award

Clint Hurdle is no stranger to awards, but this one is a little different from the sports-related ones. The Brooks Robinson Community Service Award is given annually to a current or former big leaguer and will be awarded at the Legends for Youth Dinner in New York City in November. The dinner aims to recognize former Major League players for their baseball accomplishments

coupled with their off-the-field contributions to communities across the nation.

Hall of Famer Brooks Robinson played for 23 years for the Baltimore Orioles (1955-1977) and has been acclaimed as the greatest defensive third baseman in major league history. He was tireless in his efforts to better the lives of people and youth in his community.

Hurdle is being recognized for his work as the national spokesperson for the Prader-Willi Syndrome Association (USA), and he and his wife, Karla, have hosted an annual fundraising campaign with ROOT Sports and Pirates Charities each year to assist The Children's Institute of Pittsburgh's Center for Prader-Willi Syndrome.

Congratulations, Clint, and Go Bucs! ■

## Corbin Educates Hawaii



Aloha,

Everything worked out nicely for our son Corbin's year-end teaching presentation on PWS awareness to his fourth grade class. With the assistance of his one-to-one, Corbin handed out a flyer and a test, read through a few slides, showed the "Understanding the Student with PWS DVD, finished off reading his slides, and I joined him for a brief Q & A. Corbin passed out the sticky pads to thank his friends.

We are planning and looking forward to attending the National Conference in 2015.

Mahalo,

Clinton Soo ■

## Contribute easily through AmazonSmile!



Now here is something to smile about! AmazonSmile is a simple and automatic way for you to support PWSA (USA) every time you shop at Amazon, at no cost to you. The AmazonSmile Foundation will donate 0.5% of the purchase price from your eligible AmazonSmile purchases. When you shop at <https://org.amazon.com/>, you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to PWSA (USA).

To shop at AmazonSmile simply go to [smile.amazon.com](https://smile.amazon.com) from the web browser on your computer or mobile device. On your first visit to AmazonSmile, you need to select a charitable organization to receive donations from eligible purchases before you begin shopping. Amazon will remember your selection, and then every eligible purchase you make on AmazonSmile will result in a donation.

There is no cap on the amount Amazon will donate and almost every physical product sold by the company is eligible, which means tens of millions of items. Everything else about the Amazon online shopping experience stays the same, including the shopping cart, wishlists and shipping options, and other account settings.

Please see complete program details on AmazonSmile. ■

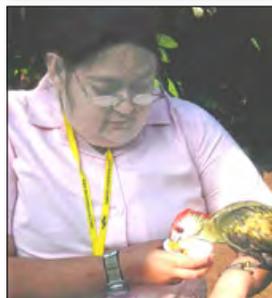
**Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School student-sponsored "Spirit Week" Fundraiser in Greenville, South Carolina.**

*Editor's Note: Do you have a support story you would like to share with our readers? Please submit your story, along with your name, telephone number and digital photos, if available, to [pwsaeditor@pwsausa.org](mailto:pwsaeditor@pwsausa.org). We'd love to feature your story!*



## Samia's Squad

About two and a half years ago, my cousin Samia, aka Bujo by her younger cousins, passed away. Needless to say it was a hard time for our family. We decided that we would have a celebration of her life: to remember all the great things about her. I created a slideshow of pictures of her set to some of her favorite songs, including "I believe I Can Fly". The whole community came together to remember our angel. We all reminisced about the wonderful memories we had of her, despite her battle with Prader-Willi syndrome. Of course we were not ignorant to the fact that she had not lived a perfect life, but it was beneficial for everyone to sit and think of how she still had a smile on her face every day.



After about six months I was pondering of a way to keep her spirit alive. I finally decided on having wristbands made with the words "Samia's Squad" and a little angel engraved on them. I presented the idea to my aunt and uncle and we decided that any money received from these wristbands would be given towards research. We contacted Janalee Heinemann to let her know



what we were doing. Donations came from family and friends around the world; including Canada, Pakistan, and here in the United States. Even friends from my high school donated and wore the wristbands proudly, without ever even knowing Samia.

As a year passed by, more ideas on how to keep Samia's Squad going came in. My youngest aunt had t-shirts and pens made. I made a Facebook group and people started making goals in honor of Bujo. In April of 2013 my mother, two sisters and I ran a 5K here in Illinois while wearing our new Samia's Squad t-shirts and wristbands. My youngest sister and mother made the trip down to New Jersey in May 2012 and 2013 to celebrate her life once again with our family. Every time there would be more donations given and people would recall memories of Bujo.

So after 200 wristbands and numerous t-shirts and pens we managed to collect about \$500 to go towards research for the cure of Prader-Willi syndrome in honor of our angel who will forever be in our memory, Samia. ■

- Amun Chaudhary



## Youngsters reach across the world to promote PWS awareness.

*Janalee Heinemann traveled to the United Kingdom and was given a poster created by Japanese children. She recently displayed it at a conference in New York.*



## The Torch Bearer

By Sara Dwyer

This issue of *The Gathered View* is my first as Editor. I was introduced to PWSA (USA) in 2008 via a referral through Harry Persanis (New York chapter). A previous designer was no longer available, so I stepped up to the plate. I locked arms with Lota Mitchell, whom I admired and respected from Day One, not only as a great

editor, but a very giving person; working with her was so much fun! Ditto for so many others I have met either electronically or in person on visits to the Sarasota office.

I had never heard about the syndrome before 2008, but immersed myself – brain, body and soul – into the PWSA (USA) family. Many thanks for your infinite patience and answers to my questions. With 30+ years in the creative industry (both agency and client sides), my mission is to maintain the high standards of *The Gathered View*. Email me at [pwsaeditor@pwsausa.org](mailto:pwsaeditor@pwsausa.org) with your comments and feedback; it's all good! ■

## 2014 Angel Campaign

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The following names are those who donated to the 2014 Angel Drive (February-May).  
either **In Memory of (IMO)** a person whose memory is deeply treasured. or  
**In Honor of (IHO)** someone very special to them.

### ANGEL IMO

**Daniel Alvarz**  
Catherine and Rudy Alvarez  
**Bill Barber**  
Curt and Marion Shacklett  
**Annette Baudo**  
Carol Matza  
**Wilfred Bernhardt**  
Dave and Ruth Pansch  
**John Casa**  
Louis and Sandra Casa  
**Ben Centrella**  
VFW 2179 Ladies Auxiliary  
**Paul John Cirino Jr**  
Frances Cirino  
**Colleen Doherty**  
Bill and Connie Devitt

**Gretchen Fritz**  
Jan Parys  
**Gavin Gill**  
Richard and Reggie Kanaskie  
**Sidney Greenswag**  
Louise Greenswag  
**Valerie Grivakis**  
Brian Baird  
**Mary Halter**  
Nancy Slye  
**Nancy Ann Jones**  
Barbara Trimble  
**Michael Kilgallon**  
Margaret and Mike Kilgallon  
**Debbie Kubichek**  
Luis and Judith Kubichek

**Debbie Leatherberry**  
Richard Leatherberry  
**Mark List**  
Sandra List  
**David J. Mears**  
Frank and Cecilia DiMarzio  
**David John**  
Diane Mears-Ghinelli  
**Tim O'Leary**  
Judy O'Leary  
**Teresa Redmond**  
Jeannie Redmond  
**Lindsay Rich**  
Cathy Ameling  
**Patricia Roberts**  
Philip and JoAnn Hall

**Phillip J. Russell**  
John and Nancy Nason  
**Isabella Stahl**  
Sandra and Sam Wood  
**Karen Ward**  
Jason and Denise Hodges  
**Michael Weeks**  
Rose Weeks  
**David Wyatt**  
Pamela Alterman  
Ann and Jerry Seigel  
Paula and Mike Watney  
**Lester Yinger**  
Sharon Yinger  
**Trent Le Youngblood**  
Wayne Youngblood

### ANGEL IHO

**Joyce Abell**  
Donald Boemker and Susan Caschera  
**Ian Adams**  
David and Lesley Pincus  
**Andy Alterman**  
R Hal Jr and Jo Lanier Meeks  
**Kandra Anderson**  
Nancy Henderson  
Marilyn Torosian  
**Stephanie and Nicole Appel**  
Gloria and Jim Servais  
June Varcoe  
**Ethan Arbuckle**  
Lorraine and Robert Arbuckle  
**Mr. and Mrs. Donald Armento**  
Margaret Oneill-Driscoll  
**Ethan Arubuckle**  
John and Michelle Yager  
**Rebecca Baird**  
Lois and Jeffrey Pallotta  
John Vaghini  
**Linda Lee Barnett**  
Robert and Deanna Barnett  
**Hannah Behnken**  
Ann and Jay Behnken  
**Peter Behringer**  
Martin and Dolores Walsh  
**Brandon Bernstein**  
Sheila and Gerald Levin  
**Suhani Bham**  
Autodesk Matching Gifts Program-USA  
**Samuel Bladel**  
Joanne Bladel  
**Isabella Bocanegra**  
Jose Venegas  
**Sophie Bolander**  
Richard and Jackie Bolander  
Mary St. John  
Douglas and Paula Thompson  
Roger and Sara Wenner

**Nolan Bonk**  
Grace Bonk  
Donna Griffio-Johnson  
**Nicole Burns**  
Frank and Joan Napolitano  
**Nicholas Busfield**  
Lenore Trimmel  
**Jeff Bush**  
Beverly and Harvey Bush  
**Richie Butts**  
Richard Butts  
**Lea Capraro**  
Susan M. Cassidy  
Timothy and Andrea Radigan  
**Ryan Casey**  
Julie and Dan Casey  
**Bianca Nicola Cimpeanu**  
Nancy Mueller  
**Christian Coats**  
Jim and Judy Coats  
**Rose Cohen**  
Jane Rose  
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 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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### The Gathered View (ISSN 1077-9965)

Sara Dwyer, Editor  
 Lota Mitchell  
 Andrea Glass  
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Sign up today at [www.pwsausa.org](http://www.pwsausa.org)!

## PWSA (USA) & FPWR Collaborate on Meeting with the Federal Drug Administration

As we go to press with this newsletter, we are busy putting the final preparations on a meeting we will have in Washington, D.C. representing Prader-Willi syndrome as patient advocates with the FDA. With several drugs in the pipeline that could potentially be significantly helpful to PWS, we want to make sure that the FDA has all the information they need on the syndrome, and to know the potential need for accelerating these drug studies. This has been a collaborative effort between PWSA (USA) and FPWR. We were



*Left to Right: Jim Kane, Janalee Heinemann, Rob Lutz, Theresa Strong*

excited to find out that several divisions of FDA are eager to learn more about PWS and will be represented at the meeting. Representing Prader-Willi syndrome at the meeting will be me, Theresa Strong (scientific chair of FPWR) Jim Kane (PWSA (USA) Research Advocacy Chair), and Rob Lutz (PWSA (USA) board member and coordinator of the PWS Therapeutic Development Team). The long term goal is to establish an ongoing relationship with the FDA. This is exciting times – never before in my 30+ years with the Association have I seen this much interest by pharmaceutical companies in developing drugs that will benefit our children! ■

~ Janalee Heinemann

### In this Issue

<b>Medical Database Survey</b>	
Update your records .....	2
<b>Dental Issues</b>	
A program for support in the home.....	3
<b>Getting to the bottom of G. I. issues</b>	
Research, information on risks .....	4
<b>Annual Meeting minutes and Board Elections</b>	
Your vote counts!.....	6-7
<b>A Legacy of an Angel</b>	
Learn about the David Wyatt Crisis Fund.....	9