

The **Gathered View**

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

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

Announcing: The Clint and Karla Hurdle Endowment for Prader-Willi Syndrome Support

Since shortly after the birth of their daughter Madison, now 9 with Prader-Willi syndrome, Clint and Karla Hurdle have *lived* a deep commitment - to do all they can for “Maddy” and to help others living with PWS. As PWSA (USA)’s National Spokesperson, Clint’s prominence as a major league baseball manager has provided a fantastic platform for spreading awareness of the syndrome – something that Clint does at every opportunity. As a further expression of their commitment, early this year Clint and Karla agreed to have the **Endowment for Prader-Willi Syndrome Support** established in their names.

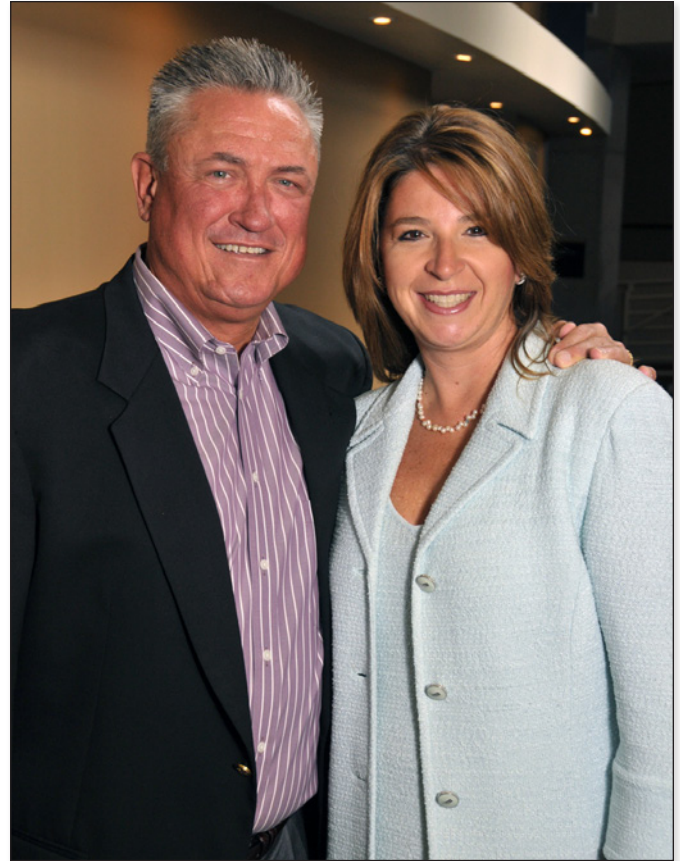
The endowment is an investment in the future! It is a fund which is allowed to grow year after year, with only a portion of the interest or earnings being used annually for Family Support programs. A gift to the endowment is never used up, but, as someone has said, “It is the gift that keeps on giving.”

For our PWS community, a gift to the **Hurdle Endowment** means helping ensure that there will be **SERVICES** like crisis counselors, the new parent mentoring program, support for chapters, and national conferences, and **RESOURCES** like the Packets of Hope, the Medical Alert booklet, *The Gathered View*, and many other print and online items available through PWSA (USA).

The overall goal of the Endowment is to support the highest possible quality of life for each and every person affected by Prader-Willi syndrome, *both now and in the future!*

“It gives Karla and me a unique opportunity,” Clint shared recently, “to reach out to others, to serve, and to give back. To tell the truth, we receive more than we give. It really is an honor.”

Join Clint and Karla. Your support is needed today to help grow the **Hurdle Endowment for Prader-Willi Syndrome Support!** For the sake of families both now and in the future, you, too, can give *the gift that keeps on giving* to the PWS community.



For more information, please contact us at PWSA (USA) 800-926-4797 or at development@pwsausa.org.

To contribute to the Hurdle Foundation, you can send a check to PWSA (USA) with Endowment Fund in the memo line, or donate online at <http://pwsausa.org/support/donations.asp>. ■



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Volume 37, Number 3 ~ May-June 2012 ~ Our 37th Year of Publication

FDA's 1st Patient Advocacy Conference

By Janalee Heinemann, M.S.W., Director of Research & Medical Affairs

Here are some highlights of the meeting I attended presented by the Food and Drug Administration (FDA) that I thought our PWSA (USA) readers would find of interest.

FDA's Office of Special Health Issues seeks a lot of input from patients and patient advocates. They have advisory committee meetings with open public hearings. You can also submit information in writing to the committees. In addition, they have public policy meetings, community meetings and town hall meetings. You can also request a meeting, send an email, or phone with your issues.

Preparation is of utmost importance for these meetings. Organize your arguments and data. FDA is an evidence-based, data-driven regulatory agency. You can work with this office ahead of time to organize and strategize.

This office has a **Patient Representative Program**, and they are continually recruiting and training new patient representatives. For more information see the FDA Web site under "Information for patients and patient advocates." We need to get PWS represented!

The reasons for having patient advocates advocating with the FDA are that they:

- bring a diversity of opinions, of viewpoint, and experience – they often think outside the box of a purely scientific approach.
- have a vested interest in conduct and outcome of trials leading to meaningful therapeutic approaches.
- provide "ground level" input that is based on personal and community experience – *a street sense*.
- help the FDA appreciate patient feelings about balancing efficacy and concern about risks, to help the FDA make better risk/benefit decisions.

Drug Shortage Program

Their mission is to address potential and actual drug shortages, but the FDA authorities are very limited.

What they can require: 1) Notification by sole source manufacturers of discontinuance of a product 6 months in advance--but there is no penalty for not reporting. 2) Notification of manufacturing changes.

What they cannot require: 1) A company to make a drug or to make more of a drug. 2) Notification of most product delays. 3) How much and to whom the drug is sold or distributed.

2011 Drug Shortage Data:

- Over 250 shortages reported in 2011
- A high percentage are sterile injectable products
- Treatments for cancer, anesthesia, serious illness
- Highly specialized manufacturing
- High risk to patients if not meticulous

38 shortages prevented in 2010 – 195 prevented in 2011

The reason was the president's executive order issued 10/31/11 which encouraged more voluntary reporting by manufacturers. There has been a six-fold increase in notifications of potential shortages.

Not all shortages can be prevented, but the FDA will work with the company to encourage smart distribution.

■ Unanticipated problems such as a manufacturing line breakdown or natural disaster.

■ Manufacturer(s) not being able to make up a production shortfall

■ Risks are found to be significant and would potentially cause patient harm

Center for Drug Evaluation and Research (CDER)

CDER rare diseases drug program was founded two years ago to support, facilitate and accelerate rare disease drug development and approval.

Since 2006, CDER has issued 90 approvals for 80 different rare disease indications; now 1/3 of "new" products are for rare diseases

CDER regulates prescription and over-the-counter drugs and therapeutic biological products. It does **not** regulate nutritional supplements, medical foods, medical devices, diagnostic tests, blood products, or vaccines. ■

A special thank-you to Anne Pariser, M.D., Emily Thakur, R.Ph., and Richard Klein, for their interesting presentations on these topics.

2012 PWSA (USA) Awareness & Education of Professionals

Due to a grant obtained from the RGK Foundation, we have been able to have both a tabletop and another large 8x8 foot display made and do awareness booths at the *NIH Rare Disease Day*; the *American College of Medical Genetics (ACMG)*; the *Pediatric Endocrinology Nursing Society (PENS) meeting*; and the *Conference on Research & Theory in Intellectual & Developmental Disabilities*, which focused the theme this year on "A Case Study of 15q."

A big thanks goes to Jim Kane who did the 15q table and Dale and Dottie Cooper who helped me with the ACMG booth. They will tell you how exciting it is to educate a few

continued on page 3

Medical and Research View

Awareness, continued from page 2

hundred geneticists and genetic counselors all in three days – and how many compliments we received from professionals on our Web site! I will also be working with Giorgio Fornasier on an awareness booth for the international ESPE conference in Germany in September. The expenses for this one are paid for by a grant to IPWSO from Pfizer. Although it is a lot of work planning and attending the meetings, it is reinvigorating to see the impact we can have on so many professionals at one setting. It has been encouraging to see the evolution over the last ten years from professionals wanting to know the basics on what the syndrome is and how to test for it – to now knowing how to test for the syndrome and wanting to know how to help educate and support the families. At PWSA (USA) we make a difference every day – and make a **big** difference on the days we do these national and international awareness events. **Thank you, RGK Foundation, for making this possible!** ■

-Janalee Heinemann

Gene Polymorphism and the Effect on Growth Hormone for PWS

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

PWSA (USA) Scientific Advisory Board Chair

I have been investigating an interesting topic recently, related to genes involved in growth hormone (GH) treatment and response specifically for PWS. This involves the study of a polymorphism of the growth hormone receptor gene which is described as a deletion of exon 3 of this gene. This deletion polymorphism when present in the general population allows for more responsiveness to growth hormone and thus the connection to PWS and GH treatment. This polymorphism appears to be present in about 50% of the general population reported in the literature, and one would not expect it to be greater in PWS as the receptor gene is not located on chromosome 15 which is involved in PWS. We have now tested about 100 people with PWS and have found 43% with the deletion polymorphism either on both chromosomes or in a single chromosome containing the receptor gene. **Therefore, one could speculate that those PWS subjects with the gene deletion polymorphism may be overly sensitive to GH treatment and at a greater risk for abnormal IGF-I levels or scoliosis than those PWS subjects with the normal or wild type gene alleles.** If this is further confirmed, it may play a role in how we treat and follow patients, clinically, while on GH (PWS or not with PWS). ■



Janalee Heinemann with the new display at ACMG.



Did you Know?

That the “PWS-like” hyperphagia (uncontrollable drive to eat) impacts a subset of those who have: Angelman syndrome (UPD), Mosaic Down syndrome, and Alstrom syndrome?

Save the date: October 17-20, 2012

2nd International Conference on HYPERPHAGIA

– The Mechanism – The Research

– The Treatment

and

**26th Annual PWSA (USA)
Scientific Day Conference**

and

PWSA (USA)

Professional Providers Conference

and

PWSA (USA) Chapter Leaders Meeting

**Pennington Biomedical Research Center -
Louisiana State University
Baton Rouge, LA, USA**

To learn more: www.hyperphagia.org

From Pain to Hope:

The Coopers' Story

Dottie and Dale Cooper's daughter Shawn was born Nov. 8, 1973. Sluggish before and after birth, she couldn't suck and barely moved. The Coopers were told that tests couldn't pinpoint a specific problem, just a "hint of some sort of neurological disorder. One doctor warned them that Shawn probably would never be able to crawl or walk."

"We had a good cry, then decided we would take care of her," said Dale. Those were the days when the suggestion was often made to institutionalize such a child. "I decided then and there I would devote all my time and energy to finding out what was wrong with Shawn and how to work with it," Dottie said. Twelve years later they would learn about Prader-Willi syndrome.

For two months Shawn stayed in the hospital, fed by eye dropper one drop at a time. A quarter of an ounce gain was cause for celebration. The swallowing muscles were the only ones that seemed to work. She went home on New Year's Day, 1974, still being fed by an eye dropper. Progress continued slowly, with delayed developmental milestones.

Around the age of four, her parents noticed she was getting rather heavy, which at first thrilled them. Then Dottie tried to control it by cutting down on portions, but Shawn gained anyway through sneaking food and begging it at every opportunity.

Shawn's doctors began telling them she really needed to lose weight. They felt like saying, "No kidding—you take her home and see if *you* can do any better!"

Then they began to blame themselves, thinking something was wrong with their parenting. Dottie said, "We thought somehow we weren't doing a good job. We got to where we would holler at her, spank her. We got



Shawn with her beloved Freckles

so frustrated. We felt so cruel. We had to police her. Dale and I were at odds sometimes over how much she should eat."

But they didn't pity Shawn or give up the battle to keep her weight down. By age eight finding clothes to fit became a problem, so Dottie took Shawn to Weight Watchers. The goal was to drop from 88 pounds to 70. Using the lowest-calorie women's diet, seeking cooperation from everyone around her, giving Shawn a reward of a diet soft drink if she met her weekly goal—it took a year at a half pound loss or so a week to reach 70 pounds.

Now they wanted Shawn to take more responsibility for what she ate and relaxed a bit on the supervision; Shawn started to gain again. She was eating her lunch as soon as she got to school, so then she had to check it with the teacher when she arrived. But she took food from classmates' lunch boxes and used her allowance to buy more. She actually would 'fess up to her parents and she understood right and wrong; but that just didn't apply when it came to obtaining food.

The Coopers were hitting rock bottom and for the first time started to think about putting her in a home. But then in 1985 Dottie heard about an AP article that had appeared in *The Birmingham News*—about a rare birth

defect called Prader-Willi syndrome that caused insatiable appetite. It fit. About a month later the diagnosis was confirmed. But still there was no cure, no explanation of the drive to eat, no treatment other than strict supervision which the Coopers were already doing.

A few months later the Coopers met with board members of PWSA in Atlanta, where they met other children with PWS and their parents. Dottie said, "It was the most fascinating thing to be able to talk to someone else who could say 'This is happening to you? It's happening to me, too.'"

Convinced of the value of group support, she then worked to form a southeastern chapter of the association to provide help and information to families who might not know about Prader-Willi syndrome. Thus began their lifelong dedication to the work and mission of PWSA (USA).

Today Dottie says: So that we would know that Shawn will be taken care of when we are unable to do it, we wanted to oversee Shawn's transition to a loving and caring environment with a staff who understands her. Today Shawn is living in a supported living home just 15 minutes away with two other ladies who do not have PWS. Shawn loves her life – going to the work center five days a week, exercising every day, dances, conferences, and outings. She recently finished the bowling and tennis seasons and now is kicking off with her baseball team. Shawn particularly enjoys having her miniature daschund with her – they take Freckles on walks in her puppy stroller and outings (such as the Arts fair); next week Freckles is going to Sunday School with Shawn. When we recently asked Shawn if we could come see her, she replied, "I'll have to check my schedule!" We love it – she has a life. ■

I want to give credit to a July 15, 1986 feature in The Birmingham (Alabama) News about Dottie and Dale Cooper and their daughter Shawn, from which I have taken several verbatim quotes.

-Lota Mitchell, Editor

A Note from the Chairman of the PWSA (USA) Board

By John Heybach, Ph.D.

The PWSA (USA) Board of Directors recently completed two full days of meetings in Bradenton, Florida, at Pirate City, the spring practice facility of the Pittsburgh Pirates. We are grateful to Clint Hurdle, manager of the Pirates and father of Madison, age 9 with PWS, for his continued support of PWSA (USA). This is an excellent meeting location, and we appreciate the opportunity to utilize it.

During our meetings on April 13 and 14, we approved the budget for the 2012 Hyperphagia Conference to be held October 17-20, 2012, in Baton Rouge, Louisiana. More information on the conference can be found on our Web site.

In other business, PWSA (USA) is pleased to announce the appointment of **Dottie and Dale Cooper** (see page 4) as Interim Executive Directors of the PWSA (USA) national office. The Coopers attended the board meeting and are fully up to speed and ready to handle the duties associated with the day-to-day operation of the national office.

Along with years of experience building and leading teams in the corporate world, Dottie and Dale bring to this position a lifetime of experience raising a son and a daughter (Shawn Cooper, 38 with PWS, who currently serves on the PWS Advisory Board). Over the years, the Coopers have been actively engaged with PWSA (USA). They led the efforts to host two regional PWS conferences in Birmingham, Alabama, and served as State Chapter president when Georgia established a group home for persons with PWS and hosted the 1994 PWSA (USA) National Conference. More recently, the Coopers collectively have tenure on both state and national boards of directors. Currently they are working with Emory

University to establish a PWS clinic and are on the organizing committee for the 2nd International Conference on Hyperphagia in October. In their own words, "This is our Association. PWSA has been there for us all these years, and this is our opportunity to give back to the families, chapter leaders, medical professionals and providers who are all a part of our support group. We are honored to join the outstanding team of professionals in the National Office."

We recognize that for many of our families Janalee Heinemann was the face of the organization – understandably so since she was Executive Director for 11 years. Both before and after her time of service, there have been periods of transition and multiple Executive Directors serving within a several-year period. But for 35 years PWSA (USA) has been here for our families. And the organization will continue to be here for the PWS community through this period of transition and growth—evolving to meet the needs of increased awareness and early diagnosis, increased research and new developments in many areas. Just as the syndrome is complex (as all know who deal with it daily), finding the appropriate person to lead the Association in the future is a complex process. Be assured that the Board of Directors of PWSA (USA) is committed to this process and to the continued success of our organization.

Finally, I am pleased to inform you that, similar to the current cooperative efforts around research, the boards and staffs of PWSA (USA) and the Foundation for Prader-Willi Research are also continuing to explore additional ways to expand working together and to build a closer relationship going forward. ■

PWS Carries the Olympic Torch

Stuart Mitchell, 20, of Ely, England, will be one of 8,000 **Olympic Torch** bearers who will carry the Olympic flame on its journey around Great Britain in the run up to the **London 2012 Olympics**. Stuart, who was diagnosed with PWS by deletion at six weeks, is a former member of **Ely Runners**. Stuart was the winner of the club's 10k Handicap Race in 2008 and obtained a gold medal in the 1500m at the Eastern Region Athletics Championships in 2007. He has also run the London 10k event twice and even competed in the Great North Run just seven days after having his appendix removed, earning thousands of pounds in charitable sponsorship.

According to Stuart's mom, Anne, exercise has always been a fun part of his life. He started swimming at age 4 ½ months and continues to enjoy swimming at least once a week. Stuart began horseback riding at 2 ½ years and still rides today. His mother says his competitive spirit has driven him to pursue running, swimming and rowing as club sports. He has never given up trying to excel and beat everyone else. Stuart currently lives in a residential placement, goes to the gym three times a week, swims and goes riding. He helps out in the stable for 2 ½ hours, takes a class in horse care, spends time on his Wii, attends a dance group, and walks 8 to 10 miles at a time. Anne says Stuart "loves the idea of the carrying the torch; we just hope he doesn't drop it!" ■

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.



Spotlight

New Book for Parents of Babies and Children with PWS

Miracle In Potential, by Australian author Joanne Griggs, is an inspirational story and early intervention resource. This sensitively-written 267-page softcover book outlines how Joanne and husband Adam created the Multiple Initiative Approach (MIA) to overcome their daughter Mia's global development delay which was due to Prader-Willi syndrome. With a foreword by Associate Professor Dinah Reddihough, Director of Developmental Medicine, The Royal Children's Hospital Victoria, Australia, this "intervention lifestyle" program is based on the idea that everyday life and resources can be used as intervention, when targeted to bring out your child's potential.

From the time Mia was four months old, the family creatively constructed an approach to combat the difficulties related to low muscle tone, global developmental delay, vision impairment, obsessive compulsive behaviors and other behavioral problems associated with food. The strategies and processes they developed are individualized to your family/child's needs and are easy to follow.

Price, which is high because of shipping costs from Australia, is \$39.00 member, and \$44.00 non-member. Call the national office to order. ■

Bottom-side View

By Jonathan J. Smith, LICSW, Director of Children's Services, Latham Centers, Brewster, MA

Through our website we often hear from many people from around the country about their concerns for their children's hygiene. Unfortunately, poor hygiene can cause health problems and further stigmatization from peers and adult caregivers. At Latham Centers we have discovered a simple solution that can solve the hygiene problem and promote independence with these activities of daily living.

We work with individuals with Prader-Willi syndrome who have a wide range of ability in terms of their self-care. Many individuals have difficulty monitoring their cleanliness, particularly following toileting. Those who are obese are particularly vulnerable to cleaning themselves after using the toilet. Even individuals who are not obese may lack the dexterity or capacity to conceptualize why they need to keep themselves clean. Further, individuals with PWS seem to be "immune" to disgust. As rectal picking is a concern for many individuals, keeping hands and interest away from the perianal area can reduce opportunity. Additionally, keeping the perianal area clean also reduces the possibility of rectal itching developing from bile acids in the stool having contact with the skin. We don't know for certain if that is the case with individuals with PWS due to their decreased sensitivity, but not all individuals are the same.

In our school and residences we have begun to incorporate the use of toilet-mounted bidets. These simple-to-install contraptions have improved the overall cleanliness of many of our students who use them. They are simple to operate, simple to install, durable and cost effective. Some of the models we have used have cost less than \$40 and can be installed in less than five minutes. We have one 18-year-old student who, prior to coming to us, had to take a shower every morning after having a scheduled bowel movement. Now he enjoys much more independence, and he has more time in the day to enjoy activities with peers and staff. Also, he is delighted that he has overcome such an entrenched problem, with a little help from the bidet!

There are probably some individuals for whom this would not be a good idea. Since enough is not enough for most people with PWS, overuse of water might become a problem. But we have not seen this to date. We have found that these simple bidets are both durable, hygienic, maintain existing skills (thorough drying) and safe (we use room temperature water as opposed to heated water). They do not require an electrical source, nor do they require additional plumbing. Most parents could install this on their own toilets by following some simple, easy-to-follow directions. Available at www.amazon.com, the following model has been used by us successfully:

Luxe Bidet Vi-110 Fresh Water Spray Non-Electric Mechanical Bidet Toilet Seat Attachment \$39.95. ■

{Note: PWSA (USA) does not recommend any particular residential place.}

seal with clear tape here

seal with clear tape here

*This is my
Association.*

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

APPLY
FIRST CLASS
POSTAGE HERE

seal with clear tape here

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

8588 Potter Park Drive, Suite 500
Sarasota, FL 34238

Fold here

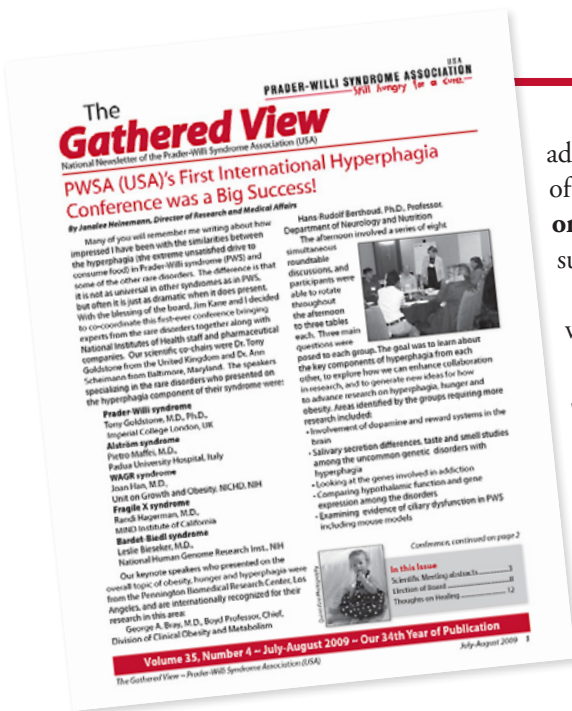
A Short Survey...and a chance to win!

As part of an effort to make sure *The Gathered View* newsletter is addressing the needs and interests of its readers, we are asking members of the PWS community to complete a short survey. You can do this **online** at <https://www.surveymonkey.com/s/pwsagsysurv2012> or use this survey. You may detach and **fax survey** to 941-312-0142 or:

seal survey with tape where shown (NO STAPLES!) after folding where shown, apply postage to the mailing panel above and mail or: **place survey in envelope**, add postage and mail to Prader-Willi Syndrome Association (USA), 8588 Potter Park Dr., Suite 500, Sarasota, FL 34238.

For those who complete the survey and provide their name and contact information at the end of the survey, there will be a drawing for a chance to win one of three prizes: two \$25 gift credits and one \$50 gift credit good for purchasing awareness items and/or publications available through PWSA (USA).

Thank you.



First, please tell us a little about yourself:

Female Male

Age range:

Under 18 18 – 30 31 – 50 51 and above

Your relationship to PWS is:

a Parent a Sibling a Grandparent
 an Aunt, Uncle or other Relative
 a Friend of the Family a Person with PWS
 a Residential Care Provider a Medical Provider
 Other

Country of residence: _____

U.S. Residents - Zip Code: _____

1. *The Gathered View* regularly includes articles or information addressing a number of different topics. Please place an "x" next to each item below to show how valuable the following topics are to you.

Article Topic	Low Value 1	2	Valuable 3	4	Very Valuable 5
Research reports					
Fundraising events					
From the Home Front					
Chuckle Corner					
Counselors Corner					
Chapter News					
Personal stories					
Medical features					
We Remember					
Listing of Major Donors					
Listing of In Honor & In Memory Donors					
International					
Sibling View					
Fundraising announcements					
News of conferences (before)					
Reports from conferences (after)					
Advice & information articles					
Other (please name)					

2. When you receive your copy of *The Gathered View*, what section(s) do you tend to read first? **Please indicate up to 3.**

- 1. Research reports
- 2. Fundraising events
- 3. From the Home Front
- 4. Chuckle Corner
- 5. Counselors Corner
- 6. Chapter News
- 7. Personal stories
- 8. Medical features
- 9. We Remember
- 10. Listing of Major Donors
- 11. Listing of In Honor & In Memory Donors
- 12. International
- 13. Sibling View
- 14. Fundraising announcements
- 15. News of conferences (before)
- 16. Reports from conferences (after)
- 17. Advice & information articles
- 18. Other

3. What do you think about the length of *The Gathered View* (currently 16 pages)?

- too long
- not long enough
- just about right

4. What is your view on the number of issues of *The Gathered View* sent (currently 6 each year)?

- too many (item a)
- too few (item b)
- just about right

If you checked *item a* or *b* above, how many issues would you recommend we send each year?

5. From the topics listed, please place an "x" to show whether you feel *The Gathered View* should include more about a topic, less about a topic, or if, in your opinion, the current emphasis is about right.

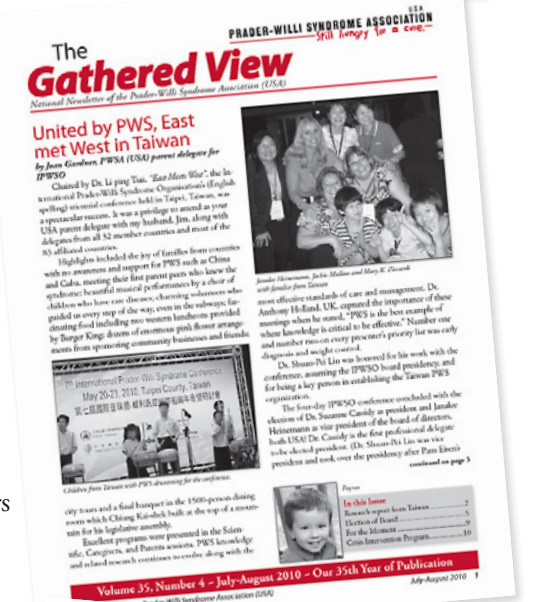
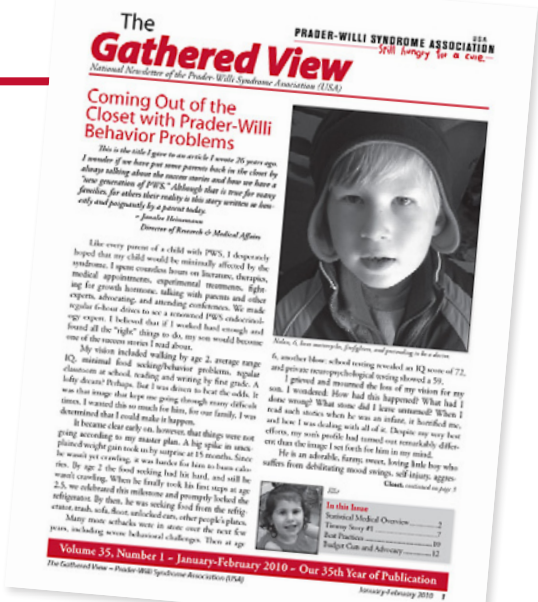
Article Topic	Less	More	About Right
Research reports			
Fundraising events			
From the Home Front			
Chuckle Corner			
Counselors Corner			
Chapter News			
Personal stories			
Medical features			
We Remember			
Listing of Major Donors			
Listing of In Honor & In Memory Donors			
International			
Sibling View			
Fundraising announcements			
News of conferences (before)			
Reports from conferences (after)			
Advice & information articles			
Other (please name)			

6. Given a choice, would you prefer that acknowledgements of major donors and of "in honor of" and "in memory of" gifts were

- listed in *The Gathered View* as they currently are
- listed and sent out in an online version through the e-Bulletin
- do not feel it important to publish this information

7. Place an "x" to rate how well you feel *The Gathered View* covers needs of your age group's interests. Unless you are involved with various ages/ groups, mark only one.

Age Group	Poor	Well		Excellent	
	1	2	3	4	5
0 - 5 years of age					
School age					
Teens					
Adults with PWS					



8. Place "x" to show how well you feel *The Gathered View* addresses the needs of each audience.

Audience Type	Poor 1	2	Well 3	4	Excellent 5
Parents					
Grandparents					
Siblings					
Family member					
Persons with PWS					
Residential care provider					
Medical provider					
Other (please name)					

9. How valuable is *The Gathered View* to you personally? (mark one)

- 1 Low Value
- 2
- 3 Valuable
- 4
- 5 Very Valuable

10. How often would you like to receive *The Gathered View*? (mark one)

- Once every 2 months
- Once every 3 months
- Other _____

11. Do you read *The Gathered View* cover to cover? (mark one)

- Always
- Most of the time
- Sometimes
- Never

12. Rate the ease of reading *The Gathered View* (mark one)

- Very easy
- Easy
- Not easy

13. Rate the overall appearance of *The Gathered View* (mark one)

- excellent
- very good
- good
- fair
- poor

14. **For readers of the online version ONLY:** Compared to the print copy of *The Gathered View*, do you read the online version (mark one)

- more thoroughly
- less thoroughly
- about the same

15. What is your overall rating of *The Gathered View*? (mark one)

- excellent
- very good
- good
- fair
- poor

16. Other comments or suggestions:

To be included in the drawing to win a PWSA (USA) gift credit, please include your name and contact information below. Thank you.

Please print

Name

Address/Email address

Phone number

Racing for Awareness

Copper is my five-year-old nephew and the most exciting thing in my life (actually a tie with his mother, my sister). He is a Valentine's Day baby which makes him even more special. I became aware for the first time of Prader-Willi Syndrome five years ago. I was amazed at how little anyone knew about PWS.

Approximately six years ago I became a crew member on a "Grand Prix" hydroplane racing team and have raced around the country and even once in Canada. Four years ago, six Grand Prix Teams founded a club under the American Power Boat Association and are trying to grow the sport and bring loud, exciting races to venues around the country. I had an idea that our club might be able to spread awareness of PWS around the country by making it our designated charity and highlighting it wherever we went.



In 2009 we raced as an exhibition class at Thunder on the Ohio in Evansville, Indiana; each boat had PWS logos prominently displayed for the fans to see. You can imagine how shocked I was when a group of parents and children (with PWS) came by during the break to say "hi" and cheer us on! IT WAS GREAT! In 2012 PWS is the charity for the Grand Prix West (GPW) Hydroplane Association and each of our boats proudly displays the logo, and

announcements are made throughout the day to get the word out.

Come join us during our race season and come by and say "hi". It'll make our day! You can find out more about GPW and our race schedule at www.GPW Racing.com My Team can be found at www.g-17.com. Look for Larry, and if you are coming to a race, you can email me at larrydlinn@gmail.com. ■

-Larry D. Linn

Congratulations, Jon!

Curt and I want to share some good news about Jon. We have recently learned that his employer, Goodwill Industries, has chosen him to be the "Employee of the Year" 2012! He will be honored at their annual May Luncheon at the Marriott Hotel where there will be about 700 people in attendance. Goodwill services about 300 individuals with a wide range of disabilities and has training and placement in many different venues for them. Jon has worked at Goodwill for over five years and is familiar with their holiday dinners, summer picnics and annual luncheons in large part because food is part of the attraction!

In preparation for this May luncheon, videotaping was done at Jon's job site where he receives donations and properly places them in their respective carts. They interviewed him and his job coach and turned the camera on a couple of his co-workers who asked to be in the videos (no inhibitions there!).

This morning the camera man and team of interviewer, make-up artist, and public relations person all invaded our living room. He took lots of footage while she asked us many questions about Jon and his life and his world. Well, it was quite the experience for Curt and I to pull together responses "on the spot" to paint a picture of Jon as accurately and thoroughly as we could!

Jon is so very, very excited about this award and has asked us to help him with his speech that he is going to give on that day. As we reflect on all of the challenges and struggles of doing life with Jon, it's gratifying to see how he has grown in his sphere of work to the point that others have seen his improvements and have found him worthy of being given this award. Praise be to our God.

-Curt & Marion Shacklett, Oklahoma

“He ain’t heavy... he’s my brother”

Written by a younger sister for the South Africa newsletter

My brother, ten years my senior, will be 40 this year. Growing up with him has been eventful, to say the least.

I’ll tell you this, my brother is not stupid. No one can plan an elaborate scheme like he can. My brother seems to understand the composites on a good symbiotic relationship. He figured out, quite quickly, that wine can be a precious commodity to those less fortunate. So he would get a bottle of wine from the house and trade it for a packet of sweets with the labourer, and I am sure each one came out of the transaction feeling that they got the better end of the deal.

There was the time when we moved into town and had new neighbours. He would chat with them and play with their dogs. Somehow the lady thought it a good judgment call to give him a set of her keys for him to feed the dogs whilst she was gone for a couple of days. She must’ve opened the fridge with quite a shock because apparently he cleaned her out.

My brother has the knack of saying exactly what is on his mind. Once I brought a new boyfriend home to meet my family, and he bought my brother a present. My brother shook his hand wholeheartedly and told the guy that he was his unmarried brother-in-law. My parents found this extremely funny, but I was slightly embarrassed, not to mention the poor boyfriend.

He is quite a good-natured fellow, very religious, and likes copying the Bible. He has comics and CD collections that he loves to read and listen to. He smokes a pipe, which can be quite comical as he hardly smokes it but spends more time cleaning it out and then very carefully putting the tobacco in the pipe. Then he still needs to find a good angle to try and light the darn thing. Then he would sit there with his arms slightly crossed, half holding the pipe, half picking at a scab, with a seriously pensive look on his face. I always wonder what he is thinking about.

So how did having a brother with PWS affect me as a sibling? Sure, there were funny parts where you couldn’t help but laugh for want of crying. But then there were darker days as well. I could also, from a young age, see the immense strain it was putting on my parents. I think what made it even more difficult was the uncertainty. When he was around 7, a doctor even accused my mother of overfeeding him.

My brother wasn’t diagnosed with PWS until he was 12, and even then the doctors were not familiar with the diagnosis. In fact, he was treated more like an oddity, his hospital room crowded by interns and doctors. Yet no one

could or would advise my parents on how to deal with the immense pressure that they were under.

I guess I always knew that he was different, but sometimes children can quite easily accept something that is perceived as different purely because it has always been there. I am very close to my brother; he is my friend and I care for him deeply. I worry about him a great deal, about his future, his health, if he is happy, whether I am doing right by him and so much more. I have learnt a few things in my life, and one thing that resonates with me is that there is no point resisting life because it will just go on and happen anyway.

*You will save yourself a lot of
pain and frustration if you can learn
to embrace life exactly in the way
it has been given to you.*

I think it was Roosevelt that said that you should do what you can, with what you have, where you are.

In the same breath I want to acknowledge that looking after a child with PWS is by no means an easy task. It takes more than it gives. I want to thank my parents for doing the best job they could, with what they had, where they were.

Every time I hear the song “He ain’t heavy, he’s my brother” by the Hollies, I will think of my brother, feeling like my heart was walking a tight rope between melancholy and immense love. I wish I could improve his life so that he could be happier; I wish that South Africa was more equipped to deal with PWS, that there was a respite option for the parents, and a care facility geared specifically toward PWS. He is my big brother; he has shaped my life in every remarkable way, and I wouldn’t exchange him for anything in the world. So many of the most important life lessons I have learnt, I have learnt through him. He can take most of the credit for that which is good in me. I don’t think I would have been half the person I am today if he had not been a part of my life.

I love him dearly. ■



One recent morning Mikey, age 12, was talking about a baby shower his class is having for the wife of one of his teachers.

I asked Mikey if he knows what she's having, and he very proudly said “Yes - meatballs!”

*-Nikki Henshaw
Pennsylvania*

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Counselors Corner

Changes are Coming to Family Support

A new Family Support Team at PWSA (USA) has been hard at work reviewing and updating both our family support and crisis programs since the end of 2011.

One initial area of emphasis has been the Parent Mentor program which serves families of children with PWS from newborns to adolescents. We've added Nina Roberto to the Parent Mentor program to help mentor Spanish-speaking families. We've also updated our policies and procedures for parent mentors and implemented a new follow-up system to better measure the effectiveness of our Parent Mentor program.

In the months ahead we plan to strengthen the Parent Mentor program further by providing additional training and support for our Parent Mentors. If you are interested in becoming part of this exciting support service by serving as a Parent Mentor, please contact our Family Support Advocate, Cindy Beles, at cbeles@pwsausa.org or 800-926-4797.

And be sure to read the next issue of *The Gathered View* for more exciting information about the Family Support Team and its work! ■

-Kate Beaver, Alterman Crisis Counselor