

# The *Gathered View*

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

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

## The Pirates and PWS

By Lota Mitchell, Editor

Pittsburghers are delighted that Clint Hurdle is going to be managing the Pittsburgh Pirates. As everyone knows, Pittsburgh is a big sports city with recent championships by the Steelers in football and the Penguins in hockey. But the Pirates have unfortunately been residing in Baseball Basement, and if anyone can pull them out of there, it's Clint! The Pirates hired him as their 39<sup>th</sup> manager 10 days after interviewing him.

Pittsburghers who have a child with Prader-Willi syndrome are even more thrilled. Clint's daughter Madison, age 8, has PWS, and he is the national spokesperson for PWSA (USA). Ever since her birth, he has been on a mission to spread awareness about PWS and to raise money for the important research and support programs of PWSA (USA).

Hurdle was one of eight candidates interviewed for the position. He also interviewed with the New York Mets, but the medical and facility expertise in PWS (i.e., The Children's Institute) in Pittsburgh had some influence on his preference.

He is a person who has had success with an underperforming team. While he managed the Colorado Rockies, who hadn't finished better than third in the National League West since 1997, they made the playoffs in the World Series in 2007. He was the Texas Rangers' hitting coach for the 2010 season. Clint himself played 10 seasons in the major leagues and had 32 career home runs with a career average of .259, reduced from an earlier average of .329 by a back injury.

PWSA (USA) Executive Director, Evan Farrar, said, "We are delighted the Pirates hired Clint not only because he is a great baseball manager but also because this means he will be here with the Pirates during spring training in Bradenton, FL (very near our home office in Sarasota) which will help us spread PWS awareness locally." Farrar added, "Hurdle works tirelessly to promote awareness of PWS. Every person and family living with PWS celebrates his accomplishments both on and off the field."

Janalee Heinemann, director of research and medi-



L to R: Clint, Madison, Karla and Christian  
Photo courtesy of Sandy Puc' Portrait Design, Littleton, Colorado

cal affairs, observed that the Hurdles were like any other parents of newly-diagnosed children when they first called the national office. They were looking for guidance, support and education. Not long after that initial phone call, Hurdle became the association's national spokesperson.

"I was really impressed with how open he was willing to be about his daughter's diagnosis so early on," she said. "For a lot of people, it takes time to regroup and think through things, but from the time she was a newborn, he was willing to be honest and say what she had and spread awareness. A lot of people in his position would just say, 'I'm going to the best doctors and doing this all privately,' because they can. But for him it wasn't enough to just help his child. He wanted to help all children who have Prader-Willi syndrome."

**GO CLINT! GO PIRATES!**



### In this Issue

GI Alert.....	3
Fish Oil .....	3
Advisory Board Meets.....	7
Special Olympics Equestrian .....	8
Angel Flight.....	8

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### Dear Family and Friends,

I want to invite you to consider being a part of PWSA (USA)'s 9<sup>th</sup> Annual Valentine's Research Fund Campaign. We need your help more than ever this year to support research.

In the past six years, PWSA (USA) has committed over a million, two hundred thousand dollars to fund research. In 2010 our four grants targeted the hyperphagia (uncontrollable drive to eat) which is the most life limiting aspect of the syndrome.

**In the past six years  
PWSA (USA) has  
committed over \$1,200,000  
to fund research!**

This year our goal is to raise \$50,000 through the Valentine Drive for research, to include the possibility of funding a **very exciting study with real potential for providing therapeutic relief from the hunger.** This study would explore a procedure that has successfully changed food craving in healthy subjects, to see what the response is in persons with PWS. Data from a very small test group of adults with PWS has shown encouraging results. As we all know, finding a way to reduce the hunger craving that our loved ones experience would be a tremendously important discovery.

I work every day with our wonderful Scientific and Clinical Advisory boards which are comprised of doctors and scientists who are internationally renowned for their research on PWS. The studies sponsored by PWSA (USA) over the years have been very diverse, targeting various aspects of this complex syndrome, with a special focus on treatment options. Almost every major breakthrough in PWS has been made by our

PWSA (USA) scientists! These scientists mentor new researchers in the field of PWS as well; PWSA (USA) is currently sponsoring two of these young researchers through fellowships. To assure that the research PWSA (USA) supports is not only of quality but is also very pertinent to the needs of our children, we have strong review processes in place for all of our research, led by PWS parents who are professionals.

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All of PWSA (USA)'s programs focus on educating and providing critical support both to our families and to professionals. It is the synchronicity of this *real-people-support* and the dedication of our scientists that has pulled the world of Prader-Willi syndrome from the darkness we lived in when my son, who has PWS, was young, to the new world of hope, light and joy.

**Please consider being a part of the Valentine Campaign to support research. PWSA has everything in place to make this a very easy fundraiser for you to do. With your help, we will alleviate the hunger and other symptoms in our children's lifetime -- or continue to fight for a cure until our last breath!**

Thank you,  
Janalee Heinemann, MSW  
Director of Research & Medical Affairs  
PWSA (USA)

**The schedule for the Valentine Drive is  
January 1 through February 28.**

**For more information and  
to get started, go to  
[www.pwsausa.org/valentine](http://www.pwsausa.org/valentine)  
and click on the link at the end of the page,  
or call the office.**

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School in Greenville, South Carolina.

### Important! Gastrointestinal (GI) Alert!

By Evan Farrar, Executive Director

As PWSA's new Executive Director, I've been given a unique opportunity to learn how much hard work goes into creating and updating the many support services we provide to people and families living with PWS. Recently, Janalee Heinemann, our Director of Research and Medical Affairs, along with several key physician volunteers moved quickly to create and disseminate a new critical alert about an important medical issue facing some people with PWS, the risk of **Stomach Necrosis and Rupture**. Janalee explains:

*"We are putting this alert on the web site and distributing it to all of the agency providers in our database. We thank Drs. Susanne Cassidy, Ann Scheimann, Dan Driscoll, Merlin Butler, and David Stevenson for their input. Although this GI crisis needs a strong warning and we will certainly use it when communicating with emergency medical personnel and in other crisis situations, it is important to remember that by far, most children and adults with PWS who die do so due to obesity-related causes."*

To access the Alert, go to [www.pwsausa.org](http://www.pwsausa.org), click Medical, then Severe Gastric Illness. Or call the office for a copy.

This is what support for people with PWS looks like: providing timely information and services to make an immediate and important positive difference in lives. I hope, as you read this alert and share it with others, you will also consider helping us to continue to have the financial resources to maintain and improve our support services now and in the future. ■

## ASK THE PROFESSIONALS

### Fish Oil Supplement

**Q: I want to start giving my son fish oil, but don't know how. Is there fish oil for children? The only one I saw at the pharmacy was for adults. How many milligrams (mg)? He is 29 months old. I appreciate any information about this.**

**A 1)** Coromega makes a fish oil for kids - available in Lemon Lime and Orange. I have heard some of our parents say the kids like it. I have attached a link to the Coromega website. Calories are 20 kcals/packet, 850mg fish oil. There is a \$5 printable coupon also available online. The company is pretty reputable.

How much to give is the bigger question.

I would try 1 packet every 2-3 days for starters and see how the Coromega sits with him.

[http://www.coromega.com/coromega/html/product\\_childsqueeze.html](http://www.coromega.com/coromega/html/product_childsqueeze.html)

This is just a suggestion. Definitely let his pediatrician know if you put him on fish oil.

*Norma Terrazas, R.D., L.D., Pediatric Clinical Dietitian  
Dept of Gastroenterology, Hepatology, and Nutrition  
Texas Children's Hospital*

**A 2)** There are a few things I would add. We typically recommend starting the fish oil when the child is over 1 year of age and on milk rather than formula or breast milk or if they are 6-12 months of age and taking less than 20 oz per day of formula or breast milk, because both formula and breast milk contain the essential fatty acids found in fish oil supplements.

Coromega has a product that is a mixture of fish oil and CoQ10 which a lot of parents like because that way they only have to give the one packet and not both fish oil and CoQ10 (the less meds they have to give, the better). It is called "Coromega Healthy Heart" and is the same price as the regular Coromega. Coromega is palatable for most children and easy to mix with yogurt or applesauce if the child doesn't like the taste of the product alone.

Many families like the Nordic Naturals brand of fish oil and they have an infant formulation. The website for Nordic Naturals is [www.nordicnaturals.com](http://www.nordicnaturals.com). Also, both Nordic Naturals and Coromega will send parents samples to try before they order a big supply so they can make sure the kids will tolerate the product - parents just have to call the company (phone numbers are available on the websites) and ask.

Lastly, there is a prescription grade fish oil (Lovaza) that some parents like because some prescription drug plans will cover the cost of it. It is a capsule, but the parent can puncture it and put it with yogurt or something. If the insurance won't cover the cost, it is definitely not worth spending the money for as it is much more expensive than Coromega or Nordic Naturals, but if it is covered, then it is worth it for some families. ■

*Jennifer Miller, M.D., Pediatric Endocrinology  
University of Florida*

### Lower BDNF Conclusions

A research study by Joan C. Han, Michael J. Muehlbauer, Huaxia N. Cui, Christopher B. Newgard and Andrea M. Haqq which was published in the July 2010 Journal of Clinical Endocrinology & Metabolism produced the following conclusions:

Lower Brain-derived neurotrophic factor (BDNF) in PWS suggests insufficient central BDNF production because BDNF in peripheral circulation is believed to reflect cerebral BDNF output. Decreased BDNF may be a potential cause for the disordered satiety and morbid obesity associated with PWS. Further studies are needed to confirm this preliminary pilot study in a larger cohort of patients with PWS. ■

continued on page 4



## Volunteers Needed for Research Study on Behavioral Features of PWS

This new NICHD funded study is a continuation of the current Elisabeth Dykens PWS study to characterize and accurately describe the behavioral features of Prader-Willi syndrome (PWS) and how these can be different based on age, gender, family history and genetic subtype of PWS. The study looks at key psychiatric features of PWS, like rigid and repetitive behaviors, insistence on sameness, tantrums, aggression and depression and how these change over a lifespan. We want to see if intervention timing is related to successful outcomes and effectiveness. We hope to see 170 families with children aged 5 and up through adulthood with PWS for a one-day visit at Vanderbilt Kennedy Center in Nashville, Tennessee, over the next 5 years. We want to see how children with PWS change, and we will follow them every other year to track changes. Parents will receive a written feedback report of all results and behavioral management tips during the visit. There are travel funds to help with expenses. Parents who are

interested should contact Elizabeth Roof at [elizabeth.roof@vanderbilt.edu](mailto:elizabeth.roof@vanderbilt.edu) or 615-343-3330 to get more information about the study. ■

## Two Years of Growth Hormone Therapy Improves Body Composition in Adults with Prader-Willi Syndrome

*as reported on at the International Prader-Willi Syndrome Organization 7th Scientific Conference, May 20-21, 2010, Taipei, Taiwan*  
*By Rasmus Sode-Carlsen<sup>1</sup>, Jens Bollerslev<sup>2</sup>, Thomas Schreiner<sup>2</sup>, Jens Sandahl Christiansen<sup>3</sup>, Stense Farholt<sup>1</sup>, Kai Fr. Rabben<sup>4</sup>, Charlotte Höybye<sup>5</sup>*

**INTRODUCTION:** Prader-Willi syndrome (PWS) presents clinically with a multitude of findings, including abnormal body composition and partial growth hormone (GH) deficiency. Until now three studies have reported beneficial effects upon body composition of GH treatment in adults with PWS. However, only one of these studies had the optimal randomised

controlled design.

**AIM:** The aim of this study was to confirm and substantiate the results from previous studies.

### **PATIENTS AND METHODS:**

46 patients, 25 women, 21 men, age 29 years (16-41) (median and range) with genetically verified PWS participated in a multinational Scandinavian study. The patients were randomised to treatment with GH or placebo for 12 months, the following 12 months all patients were treated with GH according to their IGF-I value. Body composition was measured yearly by dual x-ray absorptiometry. The study was approved by the local Ethical Committees.

**CONCLUSION:** In this first large-scale, long-term, placebo-controlled study the improvement in body composition by GH treatment in adults with PWS was confirmed. No side effects were observed. Based on our two years results, findings persist during long-term therapy.

**For a more complete report on this research and other research presented at the international conference in Taiwan, go to the research section of the PWSA (USA) web site:** [www.pwsausa.org](http://www.pwsausa.org) ■

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## Are You a Stressed-Out Parent?

PWSA (USA), Angelman Syndrome Foundation, Inc., and the International Rett Syndrome Foundation collaborated to present "Parental Stress When Your Child Has a Developmental Disorder: Helpful Tips and Coping Strategies". The presentation is done by M. Paige Power, Ph.D., from Texas Children's Hospital and Baylor College of Medicine. You can view it by using the following link: <http://www.bioedonline.org//workshops/evening-genetics.cfm>, or clicking on the announcement on PWSA (USA)'s web site home page. We want to thank the Gerald J. and Dorothy R. Friedman, New York Foundation for grant funding to PWSA (USA) that helped make this project possible. ■

## SPOTLIGHT ON... *The Care Notebook*

The Care Notebook is an organizing tool for families to keep track of important information about your child's health and care, developed just for you as parents of a child or adult with PWS. It can serve as a guide in organizing and keeping track of your child's records, appointments, and other important information. Create your own sections; remove and rearrange pages to fit your needs; and personalize it with drawings, stickers, photographs, and special articles and resources you've found helpful.

Go the PWSA (USA) web site [www.pwsausa.org](http://www.pwsausa.org). In Members Only, click on the Publications button. Scroll down to the bottom to access the resources for The Care Notebook. The Care Notebook pages may be downloaded from the Members Only section. ■



Evan Farrar

## Executive Director View

### Hungry for Support

I want to address in this column an issue that is close to my heart: providing support for people with PWS and their families. The PWSA (USA) logo is “Hungry for a Cure”, which appropriately identifies the urgent need to continue to support cutting edge and creative research into the causes of PWS, important new treatments, and hopefully someday a cure. Yet, as important as research is for all of us in the PWS community, people with PWS and their families have an equally strong hunger for support.

The need for support often receives less focus perhaps because it is not as glamorous as research. It doesn't promise a cure, and its definition is unique and specific to each person and family living with PWS. Yet, as I've had an opportunity to continue talking with people with PWS and their families in my new role as Executive Director, **again and again I've heard people say that increased support is their number one need:**

■ **Support** in how to manage PWS at home, including how to provide better behavioral support and food security for children and adults living with family members.

■ **Support** for training staff at residential programs that serve adults with PWS.

■ **Support** for students with PWS in school settings where their needs are too frequently mishandled by school professionals.

■ **Support** for people with PWS who want to enjoy the sense of purpose that comes in finding appropriate and meaningful vocational opportunities.

■ **Support** for people with PWS who are denied basic services such as essential therapies and insurance coverage.

■ **Support** for people with PWS who find themselves in trouble with the law due to disability-related behavior.

■ **Support** for people with PWS – and their families – who feel isolated and need a sense of connection with the community around them through social and other opportunities to share life with others.

■ **Support** for people with PWS who are experiencing a behavioral, medical, or health crisis.

■ **Support** for families of people with PWS who are struggling with questions about the future.

I am thankful that PWSA (USA), through its Crisis Intervention Program, the New Parent Mentoring program, various publications and video resources, and other services, is addressing in very meaningful and effective ways all of these issues.

In fact, if you spent time with us in our Sarasota office, you would quickly realize that providing support is what we spend most of our day doing. Whether it is a Crisis Intervention Counselor on the phone with an IEP team at a local school, a staff person signing up a parent for the New

Parent Mentoring program, a counselor talking with a parent about a medical concern, or important behavioral or medical resources being mailed out to a family or professional, support is like the air we breathe. It is all around us. But, as families tell me consistently, we need to do more. And I agree.

So, in 2011, without diminishing the critical importance of continuing to fund research, I intend to highlight the support services provided here at PWSA (USA), to ensure that everyone in the PWS community is aware of the full array of services offered, as well as the impact these services are having. It is also my goal to help people understand

how each dollar given to PWSA (USA) translates into a life-changing – and in some cases a life-saving – difference for people with PWS. And, as we tell that story in a variety of ways (see page 11, as an example), we also hope to inspire chapters, and families, and individuals to participate in our new national campaign (see page 6) which is designed to increase both awareness and financial support locally as well as nationally.

An important part of our mission at PWSA (USA) is to discover ways to strengthen and enhance support and services while at the same time creating a world that better understands the needs of those living with PWS. Together, we can continue making this mission a reality in 2011. ■

Evan Farrar

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## Fundraising

By David Crump  
Development  
Coordinator

*"Prader-Willi Syndrome Association was my salvation, the lifeline that enabled me to maintain my sanity and to persevere. Never have I been connected to a community of people so dedicated to their cause. I thought to myself, if my son was going to be disabled, I wanted him to have PWS; I wanted to be related to this group of wonderful, caring individuals that have so compassionately guided me through the apprehensions and challenges I have had to face."*

This is a recent testimonial from Hope, mother to 9-year-old Hayden who has PWS--just one of the many families whom we have the privilege of working with every day at PWSA (USA). They are an example of the impact your gifts and the proceeds of the many local fundraisers across the country have on the real lives of real people!

*"By creating channels for it to flow through our lives, money can become a conduit for expressing our closest held intentions and deepest values."*

Lynne Twist – *The Soul of Money*

After many failed attempts to work with Hayden's IEP team at school, Hope was left feeling alone and helpless. But then she reached out

to PWSA (USA) for help. Our crisis counselors were able to advocate with the school and provide documentation and letters that enabled Hope to finally get the much-needed services for her son. Soon after, she learned that Hayden would need to undergo scoliosis surgery. Again, because of the resources and contacts that PWSA (USA) has developed over the years, we could connect Hope with a surgeon who specializes in both PWS and scoliosis, thus helping to alleviate many of Hope's concerns and allowing her to place her focus where it was most needed – on Hayden. ■

The following fundraisers and the many individual gifts received each year make it possible for PWSA (USA) to address the critically important needs and emergencies that families like Hope and Hayden are facing today, while at the same time funding equally important research projects in search of a cure. In the past six years PWSA (USA) has committed over \$1,200,000 to research! At the same time our professional, experienced staff, available almost every day of the year, are walking with our families through times of crisis, ensuring that parents with a newly diagnosed child have the information they need and are linked to a parent mentor, and providing ongoing support for persons with PWS in schools, in residential settings, and in emergency rooms or with their local

physician. Additionally, PWSA (USA)'s online, print, and video materials are recognized worldwide as the most comprehensive bank of resources on PWS.

So as we begin a new year, I take this opportunity on behalf of Hope and Hayden, all of our PWS families and friends, and all of us here at PWSA (USA) to say THANK YOU! Thank you for your caring and support. I look forward to the hope and victories – the value – our ongoing partnership will create in 2011! ■

### Create Your Own Fundraising Web page! It's Easy! It's Fun!

Through PWSA (USA)'s **FirstGiving** connection, anyone can easily create a personal fundraising web page. You tell your family and friends the address of your page, and they go there to make donations online. For more information and to sign up, go to <http://www.firstgiving.com/pwsausa>

**Fabien Modoux** - In November, Fabien used **FirstGiving** to receive sponsorships for his participation in the New York City Marathon, and surpassed his goal of raising \$1,000 **"for Baby Liam and his family."**

**Sara Shipley**- After months of training, Sara Shipley took part in the Dallas Whiterock Marathon on December 5. Using **FirstGiving**, she raised \$2,000 in sponsorships **in honor of her boyfriend's brother, Whit**, who was born with PWS and, as Sara says, "has grown into a loveable and high-functioning young man." ■

Congratulations and thanks to **Valerie Jornlid** and The Little Farm, in Goulds, Florida, for their successful **2<sup>nd</sup> annual Pumpkin Patch fundraiser**, that raised \$700. ■

The **7th Annual Jack Martin Bevacqua Dinner Dance and Auction** took place on October 17, 2010, with over 170 people in attendance. Special guests included Jack, the honoree, and Sybil Cohen, President of PWSA New

*continued on next page*

## Make sure we are on your Radar Screen! National Awareness and Fundraising Campaign



PWSA (USA) is rolling out a National Awareness and Fundraising campaign to take place in May 2011. The campaign is being designed to benefit state chapters and other local groups as well as to support work at the national level. For more information, go to <http://pwsausa.org/fundraising/PWS-move.htm> or contact David Crump at 941-312-0400 or at [dcrump@pwsausa.org](mailto:dcrump@pwsausa.org) ■



# PWS Advisory Board Meets



Front row seated L to R: Brooke Fuller, Abbott Philson, Shawn Cooper. Back row L to R: Janalee Heinemann, Evan Farrar, Lauren Lange, Andy Maurer, Conor Heybach, Kate Kane, David Wyatt, Mary K. Ziccardi

The Adults with Prader-Willi Syndrome Advisory Board of PWSA (USA) held their annual meeting in Sarasota on October 30-31, 2010. The meeting focused on developing video and written materials for the upcoming PWSA awareness and

fundraising campaign being developed by PWSA (USA) for May of 2011. While the agenda was full, Advisory Board members did take a brief break to visit the world famous Mote Marine Aquarium in Sarasota on Saturday afternoon. ■



Advisory Board taking a well-deserved and fun break at the beach



Advisory Board working with PWS leaders at annual meeting

## Fundraising, continued from page 6

Jersey chapter. The evening's festivities included great music, wonderful food, and a silent auction. Food and auction items were 100% donated, which meant that proceeds from these items were 100% profit. The local VFW also donated the hall, and proceeds for the evening topped \$17,000! "We hope next year that other local families will be able to participate," said event organizer, Christie Bevacqua, "as it is a very fun and uplifting evening." ■

*Correction:* Revenue from the 6th Annual Clyde's Run was \$16,000, not \$3,000 as printed in the November-December 2010 issue of *The Gathered View*.

**If you are  
a Federal  
Employee, you can  
help!**



### PWSA (USA) CFC ID Number is 10088

PWSA (USA) qualified for membership and is part of the Combined Federal Campaign (CFC). If you work for the federal government and its agencies, you can make a donation via the CFC to PWSA (USA)! Funds derived from the CFC offer essential support for programs and research supported by PWSA (USA) and, with the help of

those who can participate, will continue to do so. The CFC holds activities during their campaign in different local areas around the nation. You can participate by selecting PWSA (USA) to receive donations, and spreading awareness of PWSA (USA) so others can learn about PWS and make donations, too! The PWSA (USA) CFC identification number is 10088. Thank you to all those who support PWSA (USA) this way! Your contributions are greatly appreciated and help ensure our loved ones with PWS have the best futures possible! Questions? Please call PWSA (USA) at (800) 926-4797 and ask for Debi Applebee. ■

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## Believe – In Angels!

Suppose you wanted your child to get a certain treatment or participate in an important research study, but it was quite distant and you didn't have the financial resources to get there. What could you do?

One possibility would be to contact Marita Eddy at [meddy@mail.nih.gov](mailto:meddy@mail.nih.gov). She is the travel coordinator for Angel Flight, a non-profit organization that helps to ensure that needy patients can travel to distant medical appointments. It began over 30 years ago with one six-seat single-engine plane. Today it is providing service for thousands. Angel Flight is supported by donations of services and money from individuals, corporations, foundations and trusts.

Angel Flight is the umbrella term for the many missions carrying patients needing to travel more than 1,000 miles. The flights may be done by volunteer pilots using their own planes or on a commercial aircraft. Many of the missions are for patients participating in clinical research trials. This is



encouraged, especially for patients with rare diseases to increase knowledge about these conditions.

Criteria to use Angel Flight's services include financial need. Patients must be able to walk and capable of sitting upright during flight. They must require medical treatment, evaluation, rehabilitation or testing that is only available at a distant facility, or be in a clinical research study. Travel is offered for one patient accompanied by one escort, although in certain cases both parents may be included.

Angels can be found not only in the sky but also on the ground. In Bethesda, Maryland, an "Earth Angel" volunteer will go to the airport, meet the patient and take him or her to the National Institutes of Health Clinical Center.

To help with the mission of Angel Flight, people can donate unused air miles by going to <http://www.donate-frequentflyermiles.org/>. For USAirways, donate to Mercy Medical Airlift. For United Airlines and Delta Airlines, donate to the American Cancer Society. ■

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## PWS Goes to the Special Olympics World Games

*By Denise Servais*

Alexandra Pope has been selected to represent the US in the Equestrian Division at the Special Olympics World Games in Athens, Greece in 2011. Alexandra is a 25 year-old woman with Prader-Willi Syndrome. Nine other riders from across the country will also be participating. In Athens, she will be joined by 7,500 other athletes who will compete in 22 different sports.

Per Alexandra's mother, Martha, Alexandra (nicknamed Zanders) began riding horses when she was 12 years old with Heather Johnson at Lee's Riding Stable in Connecticut. Alexandra refused to participate in Special Olympics and insisted on riding in a regular program. Martha found a program that was supportive of Alexandra's needs and Alexandra began learning to ride, groom and show horses. As Alexandra grew older, her riding became more limited due to weight gain. In the summer of 2008, she was admitted into the program at The Children's Institute of Pittsburgh and lost weight. After six weeks in the program, Alexandra moved into a group home run

by Latham Centers in Cape Cod, MA where she continued to lose weight.

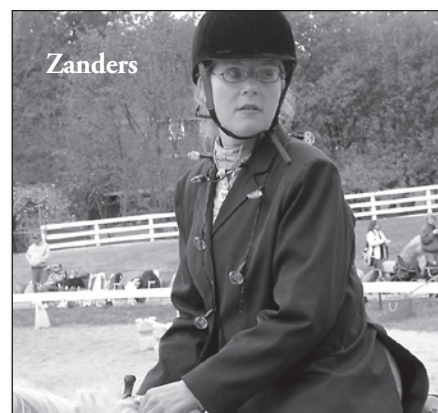
Last year, Alexandra starting riding horses again with coach Brenda Tri from the Diamondsedge Farm. Brenda encouraged Alexandra to try Special Olympics and compete on the equestrian team. Given Alexandra's skill in riding, Brenda nominated Alexandra to compete at the World Games in 2011. The Special Olympics organization takes those nominations and randomly selects the athletes who will attend the World Games. The Pope family is very excited and proud of Alexandra's accomplishments. Martha added, "it really takes the support of the whole community...I have many people to thank." Martha noted that horse riding has given Alexandra an important skill where she could excel and enjoy. "It (horse riding) has made Zanders feel competent and capable." Martha stressed the importance of encouraging young children to be active so exercise becomes a normal part of their routine and lifestyle.

The event takes place on June 25-July 4, 2011. Special Olympics,

Alexandra, and her family are currently raising funds to cover the cost of her trip. Donations can be made online at Special Olympics Massachusetts in the name of Alexandra Pope or at [www.diamondsedgefarm.com](http://www.diamondsedgefarm.com). Her Facebook page can be viewed at Alexandra Pope-Special Olympics Equestrian.

The last known athlete with Prader-Willi syndrome to participate in the Special Olympics World Games was Andy Maurer in 2003 in Ireland. He won a bronze medal in one of three equestrian events.

Good luck to Alexandra and the other athletes competing in this amazing event. ■





## Pay it Back to Move it Forward

By **Barb McManus** and  
**Dottie Cooper**

Over the years we have been so fortunate to have each other in PWSA. We are also fortunate to have medical and technological advances not available when our organization was first formed. One of the newest tools is the eSupport groups that Barbara McManus has been able to initiate for each state. What a wonderful opportunity for families impacted by PWS to get to know each other and work through challenges in their own state.

Like any new tool, the challenge is to get it going – to get people aware of and comfortable with the magic of this communication tool. Sometimes a group just needs a jump start – someone to initiate the communicating, getting together, and sharing. Those of us who have been helped by someone reaching out can use this tool as a way to Pay Back the help they have received and build new connections to move our cause to a greater awareness and understanding. Those of us who have been in PWSA for a while, have attended conferences, and/or are just naturally comfortable reaching out can really make a difference in the lives of families more recently impacted by Prader-Willi syndrome.

*Louisiana get-together December 5*



### Pay it Forward Challenge (New Year's Resolution)

The challenge is for every person reading this article to make a difference in our PWS community. Can you find a way to reach out and connect with someone else who is dealing with the syndrome? Just think how much we can help each other by just putting a hand out in friendship and support. Go to an area meeting—or host one, join your state chapter—or help start one, be a parent mentor or volunteer. All are ways you can join us in this challenge.

During the 2010 holiday season, many parents of children with PWS united during parties and get-togethers all around the USA.

**Dottie Cooper** traveled from her home in Georgia to spend Christmas in Louisiana. She called PWSA (USA) for names on the sharing list in Baton Rouge so that she could host a get-together with the families there on December 5. Six families gathered in the Cooper family home



*San Antonio, TX group meets November 22*

for a “Meet and Greet”. Dottie stated, “What a wonderful experience! It was an opportunity to meet others dealing with Prader-Willi syndrome in another state! The families were so responsive, and my family was able to meet some new very special friends. We plan to stay in touch and meet other families in Louisiana through the LA Yahoo Sharing Group.”



*December 11 gathering in Oregon*

**Barbara McManus** traveled from her Florida home to San Antonio, Texas, for the Thanksgiving week to be with distant relatives in that area. She asked Jennifer Dean, board member of PWSA of Texas, if she could arrange a meeting of some of the families on November 22. Six family members joined Barbara and her mother for an evening at a Tex-Mex restaurant, sharing stories and experiences while dining on local cuisine.

Another gathering took place December 11 at **Vonnie Sheadel's** home near Portland, Oregon. Thirty-seven

*continued on next page*

people attended the annual Christmas Party, enjoying a visit from Santa with gifts for the guests of honor with PWS, singing songs, making ornaments, and joining in other fun activities. Many had been coming to this event for years; some were new guests who made new friends and will hopefully have long-lasting connections.

Such meetings renew and create friendships, and offer assurance to participants that they are not alone. Dotie and Barbara took an opportunity to make the connection with others. We hope that others will do the same: call PWSA (USA) to get the sharing list of families in a given location so that you can set up a meeting with families.

Another way to connect and give back is by becoming a parent mentor. This program gives a family with a newly diagnosed child someone to talk with in their area. Ideally, it is a parent of a young child so that the sharing of information is helpful for both the mentor and the person being mentored. Several new mentors are **Donnita Evans** in Nebraska, **Sarah Pedon** in Indiana, **Carrie Holliday** in Kansas, **Deana Wells** of Idaho and **Lynne Baughman** of Ohio. Lynne can help with Spanish families and has translated the Growth Hormone Consensus statement into Spanish (*click Espanol button on the PWSA web site*). ■

## Welcome, Gathered View Volunteers!

**Andrea Glass**, from Foxboro, Massachusetts, and **Denise Servais**, from Lake Elmo, Minnesota, have joined the team who brings *The Gathered View* to PWSA members. We are delighted to have them! Thank you, Andrea and Denise, for answering the call to be volunteers. ■

~Lota Mitchell, Editor

## Thank You, Don!

Meet **Don Goranson**, from Bristol, Connecticut, a volunteer who has paid it both Backwards and Forwards!

When the PWSA national office moved from St. Louis to Sarasota in 1997, Don, then a member of the board of directors, began his oversight of the printing and distribution of *The Gathered View*. He continued faithfully every issue until the Connecticut printing company went out of business in November 2010, and the job moved to Sarasota.

Uniquely suited to take on this task, Don spent 42 years in the communication business, starting in radio, then newspapers (reporter to city editor to managing editor), and finally for 22 years in the Publications Department of the Connecticut State Department of Education until his recent retirement.

Son David, 41, who has PWS, lives in a group home 40 minutes away. Don is delighted that David has a life of his own. He is custodian at a building in Hartford and has been a proud member of the fire department for 17 years.

Don was a single parent for 15 years, raising David alone from the time he was three. He considers PWSA his lifeline during those difficult years and says he will never quit the association. He says, "Everyone who has received help from PWSA should give something back in their field." He is now going to be Editor of the second edition of the growth hormone booklet. ■



Jessika says to her father, "Daddy, Big Fat Loser!"

Her father replies, "What? Are you calling me a Big Fat Loser?"

Jessika shouts to her mother, "Yes, Mom tell him!"

Her mother replies, "No, no, Jessika, You watched The Biggest Loser. Not daddy is a Big Fat Loser!"

~from Grandma Barbara McManus  
The Villages, Florida

## With Thanks to All PWSA (USA) Volunteers!

*Many will be shocked to find  
When the day of judgment nears  
That there is a special place in  
heaven*

*Set aside for volunteers.  
Furnished with big recliners  
Satin couches and footstools  
Where there is no  
committee chairman  
No group leaders or car pools.  
No eager team that needs a coach  
No bazaar and no bake sale.*

*There will be nothing  
to stamp or staple  
Not one thing to fold or mail  
Telephone lists will be outlawed  
But a finger snap will bring  
Cool drinks and gourmet dinners  
Rare feasts for a queen or king  
You asked "who will serve  
these privileged few  
And work for all they're worth?"*

*Why, all those who  
reaped the benefits  
And not once  
volunteered on Earth.*

*This poem, author unknown and untitled  
was found in Norma Rupe's desk after her death.*

*Norma was our longtime volunteer  
Bereavement Coordinator.*



# Two Families with PWS Meet in Israel

By Yael Putney  
Zichron Yaacov, Israel

What happens when two families from different parts of the world meet? Lori Moline, of Faribault, Minnesota, and I found out last week when she and her daughter Sophie visited us in our home in Israel.

Lori and I have been corresponding with one another since our daughters, just a couple of weeks' difference in age, were infants. We "met" on the PWSA 0-5 group, and realized right away that we had a lot in common. We compared notes, gave each other suggestions, and became Internet friends. We both remember how much our girls looked alike as babies. Truly, Sophie's pictures could have been Naomi's!

Thanks to the realities of the new media, Lori and I were able to feel like we knew each other long before our meeting. Drawn together by the common denominator of PWS, we "talked" freely about physical and emotional issues as they came up over the years. We experienced the difficulties of feeding our little girls, starting growth hormones, discussing supplements, and illnesses. Whenever I had an issue, I compared notes with Lori and began to think of her as a friend. She was so easy to talk to, and I loved that she called her daughter Princess Sophie!

When my family moved to Israel four years ago, I truly thought Lori and I would never meet in person. Oddly enough, Lori has a sister and brother-in-law who live in Jerusalem, and she and Sophie came for an extended visit to the Holy Land this November.

Within minutes of their arrival in our home, Naomi took Sophie's hand and led her up to her bedroom. Sophie charmed my other daughter,



Ahuva Dina (6), Sophie (9), Naomi (9), Twins, Becky and Abby (8)

ters, Becky, Abby, and Ahuva Dina who also has PWS. They introduced Sophie to "Clics," Israel's answer to Legos—much easier for little hands to put together. Sophie liked our Miniature Schnauzer, Shula, and she told us about her two dogs. We all enjoyed a meal together and talked about food strategies, supplements, and even had some regular adult dinner conversation!

It was interesting to note the similarities and differences between Naomi and Sophie. Sophie is much taller than Naomi, but then Lori is tall, too! The evening was pretty exciting for Naomi, and she wound up asleep in my lap before the visit ended. Lori noted that she has many pictures of Sophie in the same "pose."

The importance of our connection was underscored a couple of weeks after our visit. Lori called me from Jerusalem to say that Sophie had a fever, stomach pains, and a distended stomach. Here she was in a strange

country without Hebrew speaking skills, and she needed help figuring out what to do.

At first, I suggested that she try to reach the Prader-Willi Clinic at Shaarey Zedek Hospital in Jerusalem (nearly all of Israel's 90 people with

PWS are treated there). However, it became clear that this was a potential emergency, so Lori and Sophie headed to the ER at Shaarey Zedek. Meanwhile, I called the Prader-Willi Clinic and let Dr. Varda Gros, head of the clinic, know that Sophie was there.

In the end, thank God, it was determined that Sophie had a stomach virus, and she was sent home after a long day at the hospital. Their trip back to Minnesota was delayed by over a

week, but all is well. Lori was very impressed with the care they got and extremely happy that the pediatrician there was very familiar with PWS. ■

*Drawn together  
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over the years.*

**Thank you to the RGK Foundation  
for a grant of \$10,000 to  
support staffing and publication  
costs for PWSA (USA)'s  
New Parent Mentoring program.**



*This month we asked Micheline Bajakian, an attorney and a consultant for the PWSA (USA) Crisis Intervention Program, to write about the important issues of public guardianship and life planning. We hope you find this information helpful as you consider the future of your loved one with PWS.*

### **Thoughts on Your Child's Future: Public Guardianship and Life Planning**

The worst fear of most parents of individuals with PWS is thinking about who will care for their child after they are gone. To deal with this fear, plan, plan and plan. Decide who will be your child's guardian and who will actually care for your child. In planning for these future needs, it is prudent to envision the "worst case scenario" where no siblings, relatives or next of kin are available or suited to serve in any of these capacities after your death. In this worst case scenario, a public guardian is available.

#### **Public Guardians:**

The laws of guardianship vary from state to state, but each state has some version of a public guardian. A public guardian is a professional guardian, appointed and supervised by the court to serve as your child's guardian. A professional guardian may not benefit beyond compensation specifically authorized by the court; a public or private agency that financially benefits from directly providing housing, medical, mental health, or social services may not be appointed as guardian. PWSA strongly urges parents to explore guardianship when their child reaches adulthood as an important step in helping to keep their child safe and in maintaining the parents' role in important life and health decisions for their child. Once guardianship is established, the court continually supervises this legal relationship. Existing guardianships can be modified if such modification is determined by the court to be in the best interest of the ward.

Guardianships allow for the listing of successor guardians. Once you have exhausted the list of those who may serve as guardian after your death, you may identify a specific public guardian to serve this capacity. You may want to meet different public guardians to identify which you are most impressed with. If you are having trouble locating a public guardian, try calling the probate register at your local county court to ask who they recommend.

Also, be aware that if you execute a health care proxy or power of attorney, naming a specific individual who can make medical decisions on behalf of the individual with PWS, this power trumps that of guardianship, and the guardian must consult the health care power of attorney when making medical decisions. This is a good way to provide a check and balance to a future public guardian by an individual who may be close to your child, but not willing to undertake full responsibility for your child. To explore and pursue guardianship in your state, contact a local estate planning attorney.

#### **Giving Direction to a Public Guardian: The Life Plan**

A public guardian will want as much information about how to care for your child as possible. The more information you provide, the less the guardian has to guess or rely on other family members who may not know, when making decisions regarding the ward's best interests. A Life Plan is a non-legal, non-binding document that you can draft, detailing all the pertinent care information from doctors, to religious preference, to hobbies, to the best ways to communicate with your child. To receive a sample Life Plan to complete and include with your child's documents as well as with your estate planning documents, contact a PWSA Crisis Intervention Counselor. If a guardianship is established, you may want to file a copy with the court as well, to ensure it is always part of your child's court file. ■

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**Thank you for Contributions in October and November 2010** We try to be accurate in recognizing contributions, and apologize for any errors or omissions. If you notice an error, please tell us.

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PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to

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

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*Still hungry for a cure.*



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

**Deadlines to submit items  
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Be a Valentine! See page 2...

dashed line = fold; will NOT print!



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tax-deductible donations

your own to request

can use or you can create

been prepared that you

A Valentine letter has

through February 28.

Campaign – January 1

Valentine Research Fund

Support the

Be a sweetheart!



*Mark your calendar and plan ahead!*

November 11, 2011

Scientific and Providers Conferences

November 11-13, 2011

Orlando, Florida

Buena Vista Palace Hotel

Conference 2011

PWSA (USA)

**SAVE THE DATE!**

**see more on page 7...**

*Never have I been connected to a community*

*to maintain my sanity and to persevere.*

*my salvation, the lifeline that enabled me*

*"Prader-Willi Syndrome Association was*