

The *Gathered View*

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

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

The Children's Institute Expands Its PWS Footprint

By *Lota Mitchell, Editor*

Thirty years after the program for Prader-Willi syndrome began at The Children's Institute in Pittsburgh, Pennsylvania, construction has been completed on a \$500,000 expansion of the PWS unit. This doubles the square footage, increases capacity to housing 20-22 patients, and will help to decrease the long waiting list (recently up to 100).

In 1981 I wanted to start a support group for parents connected to a medical facility in Pittsburgh. A call to the Institute was answered by a very nice British-sounding lady who suggested the possibility of a "camp" for Prader-Willi like the "camp" they had for spina bifida. A few weeks later I found my surprised self at a lunch in the private dining room with the medical and other staff to discuss just that.

I recall saying something that incredible day like "you give me the services and I'll give you the people". I was on the PWSA board of directors so I had national connections in addition to the local support group that would meet soon. Bea Maier arrived at the meeting—the amazing person who would design, develop, and oversee the program for many years. Then I remember thinking in awe, "This is really going to happen!"

That first summer saw seven kids with PWS, ages 8-12, in a four-week "camp". This went so well that the next summer another session was added for ages 13-18. The focus gradually changed to crisis, as some in need were admitted outside the summer program. By the early 1990s the program was year-round, and the term "camp" was dropped. The average patient stay is about 46-47 days, although some stay longer and return visits may happen occasionally.



Obtaining insurance coverage has been a challenge and is becoming even more so.

Over 1600 patients with PWS have been treated at the Institute, including from countries like South Africa, Canada, Saudi Arabia and France. Most come in crisis because of weight or behavior or both. The unit now can be divided into two sections: one for under 21 and the other for over 21. It is the only program in the Institute which accepts adults.

During their stay patients receive occupational therapy, physical therapy, speech therapy, nutrition services, psychological and psychiatric services, 24-hour nursing care, medical supervision, and intensive individualized exercise along with a recreational component.

The program is overseen now by Ken Smith, Case Manager, and Lucy Krut, R.N., Unit Manager. At the Prader-Willi program at The Children's Institute, lives are being changed—and sometimes saved. ■

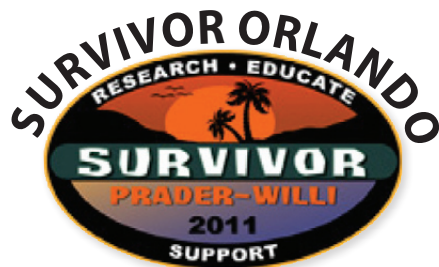


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Volume 36, Number 4 ~ July-August 2011 ~ Our 36th Year of Publication

November 11-13, 2011 Conference



contact the hotel reservations department at 1-866-397-6516 - mention PWSA (USA) - or use this link to directly make reservations: https://reservations.ihotelier.com/crs/g_reservation.cfm?groupID=465089&hotelID=6579

REGISTRATION for the CONFERENCE WILL OPEN on AUGUST 15, 2011.

After that date you (1) can register online at www.pwsausa.org/conference/2011

or (2) you can get the information on our home page at www.pwsausa.org or

(3) you can register by mail by calling 800-926-4797 to request a registration packet.

Dates of conference - Friday-Sunday, November 11-13, 2011

Scientific Conference, Professional Providers, and Chapter Leaders will meet Friday, November 11.

General programming for parents, children and young adults (with and without PWS) will be provided for two full days, Saturday, November 12, and

Speakers (*inspiration and information!*) for our **November 11-13, 2011 Conference** have been confirmed, the hotel (*comfort and beauty!*) is ready to accept your room reservation under our room block, and we have discounted Walt Disney World Resort (*lots of fun!*) tickets available for our attendees (*convenience!*) (<http://www.pwsausa.org/conference/2011/>). These tickets can be picked up in the hotel – no waiting in long lines at the Will-Call booth at the park (*easy!*)! Our room block will be held until October 23, 2011, which means that all reservations requested after that time will be made on a space-available basis. Guests may either

Sunday, November 13.

The Gala Dinner will be held Saturday evening, November 12.

NOTE: Friday, November 11, 2011 is Veteran's Day and a holiday for most students and workers.

How much will it cost?

The room rate at the Buena Vista Palace Hotel & Spa, Lake Buena Vista, Florida, is just \$119 a night, plus tax and resort fee, for a single or double room, \$139 for a triple and \$159 for a quad room. These rates are available for the 3 days before conference begins and 3 days after conference ends if you would like to extend your stay in Orlando.

Conference registration is \$225 per person until 9/30 and \$250 after 9/30. This fee includes breakfast and lunch Saturday and Sunday. Companion

registration fee, which includes the two days of meals, is \$100, for those not attending the lectures.

YIP Infants (under age 2) \$100

YIP Children (ages 2-6) \$125

YAP Participants - \$175. This fee has remained the same since 2003.

Siblings - \$125

LIMITED ENROLLMENT:

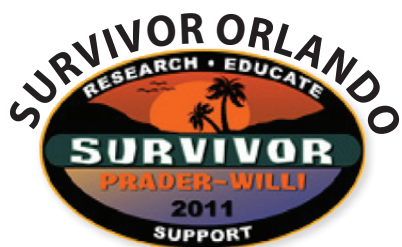
Enrollment in all three programs will be **CAPPED**, on a first-come, first-served basis, once conference registration begins, as follows:

YIP: 20 babies (birth-2), 50 children (ages 2-6)

YAP: 60 individuals ages 7+

SIBLINGS: 30 siblings ages 7-15

Watch all through the *Gathered View* for comments from people who have attended previous conferences. ■

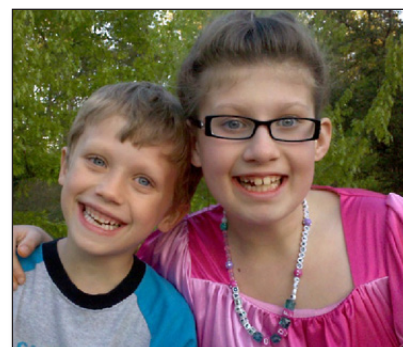


We Have a Winner! 2011 National Conference Tagline and Logo Contest...

In April 2011 we ran a contest via the Yahoo Groups to challenge our talented membership to come up with a tagline and logo for the 2011 National Conference. We're a little behind in announcing that winner but (drumroll please)...

It's Lori DiCola, proud mom of Danielle (11 with PWS) and David (7). Lori is a talented graphic artist originally from Oregon, now living in North Carolina for the past four years. Her design complemented the "Survivor" theme we selected for our youth programming in a simple, straight-forward way.

Danielle is a constant source of inspiration for Lori. Danielle, challenged by her nutritionist to lose 20 pounds in 10 months, has already lost 10 pounds in 4 months! Danielle is also growing her hair out to donate it to kids that are going through chemo and have lost their hair. Congratulations, Lori and Danielle, on your accomplishments! ■



Danielle, 11, with brother David, 7

Medication News

Keeping our members updated on the latest medical information on PWS is our priority. We had planned to update our readers on the five hyperphagia grants being sponsored by PWSA (USA), but will hold that section for the next edition due to the need to provide the following information on medical issues.

Janalee Heinemann, MSW

*Director of Research & Medical Affairs
PWSA (USA)*

Vice President, IPWSO

Efficacy of modafinil (Provigil) on excessive daytime sleepiness in Prader-Willi syndrome

By De Cock VC; Diene G; Molinas C; Masson VD-L; Kieffer I; Mimoun E; Tiberge M; Tauber M. 2011.

American Journal of Medical Genetics Part A

Excessive daytime sleepiness is a frequent and a highly disruptive symptom to the daily routine of children with Prader-Willi syndrome (PWS) and their families. The objective of the study was to evaluate the efficacy of modafinil (brand name Provigil), a central stimulant, on excessive daytime sleepiness in children and adolescents with PWS. The efficacy of modafinil was evaluated in this open label pilot study comparing the Epworth sleepiness scale before and after treatment. Ten patients with molecularly confirmed PWS and a complaint of excessive daytime sleepiness underwent a nighttime

sleep recording and multiple sleep latency tests. One patient was excluded because of severe obstructive sleep apnea syndrome. Nine patients (4 males) with median age of 16 years (8-21) received modafinil at a starting dose of 100 mg/day. We found that all patients had excessive daytime sleepiness with an Epworth sleepiness scale at 14 (11-20) and mean sleep latency on multiple sleep latency tests at 5 (3-6) minutes. Moreover, six patients had at least two sleep-onset rapid eye movement periods showing a narcolepsy-like phenotype. Modafinil significantly improved sleepiness in all patients on the Epworth sleepiness scale from 14 (11-20) to 4 (3-12), ($P=0.007$). Body mass index of the patients did not change significantly under treatment. No side effects were reported, and the drug was well-tolerated. We posit that this open label case series shows good efficacy of modafinil in nine children and adolescents with PWS.

(Note: The French researchers of this study sent Janalee a copy of the full grant report. If anyone needs the full grant report for an insurance appeal, call PWSA (USA) for a copy.) ■

Q & A re: NORDITROPIN

Q We recently received a note from our insurance plan that they would like us to try Norditropin as an alternative to Genotropin for our son's Prader-Willi management. Is this a good alternative?

A Although growth hormone medication is sold by a number of companies in the United States under different product names, the basic protein ingredient is the same in nearly all GH products for injection. Because it is based on the human gene for growth hormone, manufactured GH is identical in structure and chemistry to the growth hormone produced in the body. The generic name for the major GH products now in use is somatropin, rDNA origin, for injection. The "rDNA" (recombinant DNA) means that it is produced by combining DNA material from

continued on page 4

Did you Know?

That in April of 2010, Omnitrope was given FDA approval to treat children with growth failure due to PWS? They are the second growth hormone product (Genotropin being the first in 2000) to get the indication specifically for Prader-Willi syndrome. Omnitrope's FDA approval is worded as being "*indicated for the treatment of pediatric patients who have growth failure due to PWS.*"

Omnitrope is owned by Sandoz which is a generics company.

Special product features

Omnitrope® - liquid GH injection pen available in 5 and 10 mg.

Omnitrope® - 5.8 mg vial for reconstitution for use with syringe.

Patient support program

OmniSource – provides insurance assistance, injection training, and the Sandoz Patient Assistance Program – assists in obtaining Omnitrope to uninsured and underinsured patients 877-456-6784 ■

Norditropin, continued from page 3

different sources through genetic engineering.

While the GH protein molecule itself is the same from product to product, there is an increasing variety of medication forms and injection methods available. In its basic manufactured form, GH is a freeze-dried white powder that must be mixed with liquid, called a *diluent*. Some manufacturers now have pre-mixed forms of GH and/or pens that simplify the mixing process. As with other types of medicines, GH products may contain inactive ingredients as preservatives. These additives vary among the different products, and some might cause minor reactions in some people. Most GH products require refrigeration before mixing and use, but a few can be left at room temperature until the powder is reconstituted.

FDA approval of one GH product for PWS opened the door for doctors to prescribe all equivalent products for that use as well. Doctors might recommend a particular medication based on any of the following: the doctor's familiarity or experience with different GH products or delivery systems, requirements or preferences of the patient's insurance company or managed care organization, cost differences, ability of the family to learn and use a particular medication mixing and injection method, or the child's history or sensitivities. Families should discuss their concerns and needs with the doctor to ensure that the best treatment is chosen for their child's situation. (Our updated booklet on GH to be released this fall will contain information on the various GH manufacturers and their products.) ■

Formula Thickening Agents Alert for PWS

The following was on the web:

Health Canada is strongly advising Canadians to speak to their healthcare practitioner with any questions or concerns regarding "Simply Thick" if this product is being used.

"Simply Thick" is a product that can be added to liquids, such as breast milk and infant formula, to thicken them to make them easier to swallow. It is sometimes used for premature infants to help with swallowing difficulties.

The US FDA has reported 15 cases of necrotizing enterocolitis (NEC) including two deaths, involving infants who were fed "Simply Thick" for varying amounts of time. NEC is a serious and sometimes fatal condition where the tissue of the intestine is damaged. It mostly affects premature newborn infants.

A response on this issue from Norma Terrazas, the registered dietician on our PWSA (USA) Clinical Advisory Board was:

They should contact their healthcare provider if they are on a thickening agent and their child is < (less than) 3 months corrected gestational age.

Below are some guidelines instituted here at Texas Children's Hospital. I am sure every major hospital institution should have some guidelines also made available to their staff.

1. External thickening agents, including Simply Thick, Thick It, and several other similar products should not be used under any circumstances for any infants < 44 week postmenstrual age* (gestational age plus chronological age). At present the cases of NEC and similar illnesses are

limited to those born < 37 weeks who developed illness at < 43 weeks PMA. This puts a small boundary around it.

2. It is not recommended to use these products for any infants < 3 months corrected age to provide a further safety margin while the investigation is underway and cases collected.

3. Alternative thickening approaches including rice cereal are not recommended as they are nutritionally inadequate, do not often work with human milk and have little if any evidence of efficacy in our patient population. However, in an individual circumstance, on a risk:benefit consideration in which no alternative was deemed available, a practitioner could use rice cereal for a formula-fed infant. We do not believe this is the correct solution, however, to any feeding related problem in newborns.

4. Use of specialized anti-reflux infant formulas is also not recommended for our preterm infant population, although these formulas are probably safe and can be considered in special circumstances. Again, we do not believe this is the correct solution to feeding related problems, especially in preterm infants.

5. Any infant discharged in the last 4 weeks on any thickening agents who was born at < 37 weeks gestation should immediately have the product stopped.

* Postmenstrual age is the time elapsed between the first day of the last menstrual period and birth (gestational age) plus the time elapsed after birth (chronological age). Postmenstrual age is usually described in number of weeks and is most frequently applied during the perinatal period beginning after the day of birth. Therefore, a preterm infant born at a gestational age of 33 weeks who is currently 10 weeks old (chronological age) would have a postmenstrual age of 43 weeks. ■



Evan Farrar

Thinking Differently

An ongoing challenge for PWSA (USA) is to continue thinking differently about how we communicate with the PWS community. Many traditional communication paradigms are long gone in an era of Facebook and other collaborative online communication tools. This is especially true in the PWS community where a thriving and spirited online community of parents and professionals are interacting with each other in many different communities and forums. In order to engage more vigorously in this conversation, we have created some new online communication tools to help more people participate in a conversation with us about our programs and services and, most important, the needs of the PWS community. So I am happy to invite you to join us online in any of the following ways:

We now have a “Fan” page where members of Facebook can “like” us and – by doing so – regularly receive updates on their individual Facebook page about communications from PWSA (USA) and others in the PWS community because folks connected with our page can freely post items of interest for others to see on our page. This provides a dynamic place of interaction. To sign up for our Facebook

page visit this link: <http://www.facebook.com/pages/Prader-Willi-Syndrome-Association-USA/145662662172371>

We now have an official PWSA (USA) blog at <http://pwsatoday.wordpress.com/> In this ongoing blog, we will share with you what’s happening at PWSA (USA) today, including ideas for spreading awareness, important information on resources and strategies for supporting people living with PWS, encouragement for families raising a child with PWS, updates on advocacy issues, work we are doing in partnership with others, and more. After reading a blog post, you can join the conversation by leaving a comment and you can advance the conversation by e-mailing the blog to friends or posting it on your Facebook page!

PWSA (USA) is back on Twitter! Follow us @PWSAUSA to hear timely updates about events, resources and more.

We now have a weekly PWSA (USA) e-Bulletin which provides announcements about grassroots fundraising events and other opportunities to support the PWS cause in a succinct and easy-to-read format. We try to make sure there is also medical or research information, or other items of interest. You can sign up to receive the e-Bulletin on the homepage of our website at <http://www.pwsausa.org/>

We look forward to hearing from you!

Evan Farrar

Chapter View

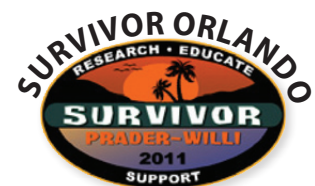
New York Alliance has received good news twice—first, that **Gov. Cuomo personally restored the money to the OPWDD budget for Camp Wilton this year, 2011** (many letters and phone calls do have an impact), and second, that the state has declared the month of May to be official Awareness Month for PWS in New York.

Pennsylvania held its 12th annual golf outing in June. Clint Hurdle, national spokesperson for PWSA (USA) and manager of the Pittsburgh Pirates baseball team (Go, Bucs!) was one of the 137 golfers. At the dinner afterwards he shared his story of his daughter, Madison, 8, who has PWS.

Cathleen Morrison reports that a very special family friend, recently ran the Boston Marathon and asked that donations of \$1 per mile (so \$26.20) be made in honor of their daughter Julia, aged 10, with PWS. Her run raised over \$500 for the **New England Chapter**. ■



Clint Hurdle, national spokesperson for PWSA (USA) and manager of the Pittsburgh Pirates baseball team, telling about his daughter, Madison, 8, who has PWS.



A Parent Comments about: YIP (Young Child and Infant Program for those with PWS and their siblings)

I was extremely impressed with YIP. This was our first time at a PWS conference and both our 4-year-old (PWS) and 2-year-old daughters were in the program. Wonderfully organized and fabulous caretakers... [which] allowed us to really take full advantage of the conference.

Election of PWSA (USA) 2011-2014 Board of Directors

Voting Instructions

1. Review the candidates' statements printed on the Slate of Candidates.
2. Cast your vote on the Official Ballot. 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 20, 2010.
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, place 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.** (See sample ballot envelope below.)

Deadlines: The deadline for voting is August 20, 2011. Ballots postmarked after August 20 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.

PWSA (USA) OFFICIAL BALLOT ENVELOPE	
I am/We are a PWSA (USA) Member in Good Standing Eligible to Vote	
Printed Name:	_____
Address	_____
City, State, Zip	_____
Signature:	_____
Mark your Ballot and insert into Ballot Envelope. Ballot Envelope must be signed to be counted. To ensure confidentiality, Ballot will be separated from Ballot Envelope before being counted.	
Julie Doherty, Secretary Prader-Willi Syndrome Association (USA) 8588 Potter Park Drive, Suite 500 Sarasota, FL 34238-5471	
<small>Please Place Your Stamp Here</small>	

sample ballot envelope

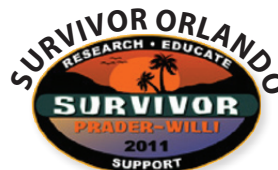


2011 OFFICIAL BALLOT

Cast your vote for the 2011-2014 Board of Directors. Vote for four (4) of the candidates listed below.

- | | |
|--|---|
| <input type="checkbox"/> David Agarwal, M.D. | <input type="checkbox"/> Dan Driscoll, M.D. |
| <input type="checkbox"/> Ken Smith | <input type="checkbox"/> Michelle Holbrook |

Election of PWSA (USA) 2011-2014 Board of Directors



A Parent Shares a Sibling's Comment about YAP (Youth and Adult Program for those with PWS and their siblings)

[A sibling] told his dad that he was always angry and feeling left out before YAP, but being there helped him realize the important role he could play in his brother's life and that he counted, too.

MEET THE SLATE OF CANDIDATES



David M. Agarwal, M.D., has 10- and 11-year-old sons, Sam and Alex. Alex just returned from his first weeklong PWS camp and loves telling stories about Wonderland in Missouri. David has been the Director of the Vascular and Interventional Radiology Fellowship Program at the Indiana University School of Medicine in Indianapolis, Indiana, since 2001, spends most of his days performing minimally-invasive image

guided arterial, liver, and cancer procedures, is board certified in both Interventional and Diagnostic Radiology, and just finished chairing his national society's Student and Resident Committee. Within PWSA(USA), David has served on the Research Advisory Team and remains on the Clinical Advisory Board. Together with his wife Janice, a current PWSA (USA) board member, David has participated in PWSA (USA) since Alex was 9 months old and looks forward to many more years to come. ■



Daniel J. Driscoll, M.D., Ph.D., is a Professor of Pediatrics and Genetics at the University of Florida College of Medicine where he is the John T. and Winifred M. Hayward Professor of Genetics Research. 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 has received board certification in Pediatrics, Clinical Genetics, Molecular Genetics, and Cytogenetics. He is a member of the Board of Directors and Chair of the Clinical Advisory Board for the Prader-Willi Syndrome Association (PWSA) USA. In addition, he is a member of the Medical and Scientific Advisory Board of the International Prader-Willi Syndrome Organization (IPWSO). ■



Michelle Sorensen Holbrook, Lehi, Utah, is a special education teacher at Lehi High School, working with students with severe disabilities. She has been a special education teacher for 10 years in secondary education, 7 years in elementary education. She is currently finishing her Master of Science Degree at Brigham Young University, anticipating graduation in August 2011 with an emphasis in special education.

Eight years ago she formed a not-for-profit organization, Just For Kids of Utah County, Inc., to assist kids with disabilities. This parent-based group has developed a summer school program, adult day program, and purchased a bus for transportation for people with disabilities in her community. She jump-started the Special Olympics programs of basketball, volleyball, bowling,

track and field, soccer, and swimming with over 92 Special Olympians and Unified Partners participating in the last Utah state games. She has served on the Utah Prader-Willi Syndrome Association board and also was president for four years. She has directed the YIP program for the national Prader-Willi Syndrome Association for three conferences. She and her husband Scott have been married for 32 years and have a son Curtis, 17 with PWS.

I have worked with people with disabilities in many facets. I believe I can be an asset to the board with my educational background working with students' parents and the legal issues of IDEA. I also bring a wealth of knowledge in formation and vision of programs that benefits those with disabilities. I am a hard worker, visionary, and love serving others. ■



I have worked in various administrative roles including the treatment team's manager. The Children's Institute established its program for children and adults with Prader-Willi syndrome and related disorders in 1981. Since then, we have served over 1600 individuals in our inpatient and outpatient programs. ■

Ken Smith: I have been employed at The Children's Institute since 1985. During this time, I have worked in several different capacities within the organization. I have served on the board of directors for the Prader-Willi Syndrome Association (USA) for 15 years, plus one year as Vice-President. I am now currently serving as Co-Board Chair.

My first exposure to Prader-Willi syndrome was as a college student working directly with children admitted to the Institute's summer inpatient program. For the past 23 years

Aedan's Story



By David Crump,
Development Coordinator

When I tell people that I am a fundraiser for a nonprofit organization, the first response is often something like this: "Oh, that is wonderful! Such important work." Pause. Then, "Wow. That must be hard, though, asking people for money."

Many of you who have organized fundraising events for PWSA (USA) can identify with this short exchange. If we imagined ourselves simply asking for money, it might be a rather frightening proposition.

But I have learned that fundraising is not so much about asking, as about sharing and inviting. We share the story that inspires and motivates us, and we invite people to become a part of that story. I was reminded of this again recently when Amy Tenbrunsel shared the story of her own family and her son Aedan:

"Our son, Aedan was born on January 13th, 2009. After delivery via C-section and great APGAR scores, our families were overjoyed with the birth of their first grandchild. However, very shortly we realized that something was wrong. Aedan was extremely sleepy, never waking or crying even to eat. After two days he was placed on a feeding tube and was sent to the University of Connecticut's Neonatal Intensive Care Unit. After three weeks Aedan was ready to come home, but without a clear diagnosis. We were given instructions on



how to feed him using a special bottle and were immediately set up with Birth To Three services. After eight months, Aedan was diagnosed with Prader-Willi syndrome.

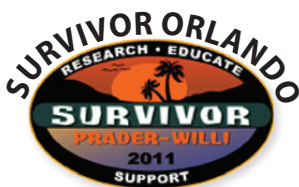
The last 19 months have been filled with millions of questions, thousands of phone calls, numerous trips around the country to see specialists, and weekly therapies. They have also brought bright and shining moments like we could never have imagined when Aedan's diagnosis was first made clear.

We are deeply thankful for all of Aedan's doctors and nurses, who have worked with him since his birth.

We are also deeply thankful for the support we have received from PWSA (USA). From the very first day Aedan was diagnosed, the Association's staff has been there to help our family. They began by sending us the Package of Hope, a packet filled with information on PWS, medical alert booklets, and the next steps to take. We also received phone numbers of families within the PWS community and venues to begin to have many of our questions answered. With a membership to PWSA (USA) and their publication "The Gathered View" we have remained abreast of all that is happening in the world of PWS.

We were given information on research opportunities that will benefit Aedan and all who suffer from PWS. We have been able to order informational DVDs for Aedan's physicians and therapists. By sending important documents to anesthesiologists who would be overseeing surgery, or giving phone numbers of specialists to help local doctors make the most appropriate decisions for Aedan's care, PWSA (USA) helped make difficult times on Aedan's journey easier. Even during our scariest moments, when Aedan has had medical emergencies, they were only a phone call away."

In July, Amy and family sponsored a Prader-Willi Syndrome *On The Move* walk, to help raise funds for PWSA (USA) and to invite people to be part of Aedan's story, which represents the stories of other children and adults with PWS across the country. It is these stories and connections that inspire people to support all that the Association does, so that Aedan and others living with PWS can live fuller, happier, and healthier lives. Their stories demand the unswerving determination and provide the nonnegotiable reason for all that we do in the PWS community to advance our cause. And it is through the Association's campaigns as well as the grassroots fundraisers organized and carried out by so many of you all across this country that we have the privilege and honor of inviting others to join the story, too! ■



Be a Sponsor and help defray the costs of Conference 2011

As one sponsor said: "...this is such a great cause, as it drives so much awareness and education for so many."

You, too, can be a part of the awareness and education! If you or someone you know is interested in supporting this event, please learn how by going to <http://www.pwsausa.org/conference/2011/exhibitors-sponsors.htm>

Here are Recent Grassroots Events!

By Jodi O'Sullivan

Hooked on another fishing tournament, **Michelle Torbert** and Prader-Willi Florida Association reeled in \$40,000 for PWSA (USA) and more for the Florida chapter with their 3rd **Annual Casting for a Cause** in March.

Jim Kane and **The Private Foundation of Maryland** scored \$125 in their March **PWS March Madness Pool 2011**.

Kerry Sexton and **Robin Grey**, mom to **Chase Grey, 6** with PWS, teamed up for the **Kerry Sexton 1st Annual Charity Tennis Tournament** in California in March. The event raised \$5,000 for crisis and research. Sexton lives in California and is godparent to Chase, who lives in Colorado with his parents. After aceing her first fundraiser for PWSA she wrote, "It was such a blessing to be part of raising the awareness and money for PWS. The community I live in was amazing with their contributions and love for Chase."

Also from California, **Eileen and Drew Higgins** held a fundraiser at a pizza place on April 6. **Round Table Pizza** donated over \$300 in honor of the Higgins' son, **Donovan, 1** with PWS. Eileen and Drew wrote "Thank you for all the support from PWSA!!!"

The **Richard G. Rosenthal JCC of N. Rochester** in New York donated

\$240 in honor of **Brandon Dahan, 4**, in June. A special boy is especially loved.

A group of students in **Ms. Susan J. Kirkham's Fundamentals of Speech Class at University of Wisconsin-Oshkosh** chose PWSA as their class charity. In a final persuasive speech contest, sibling **Brett Danelski** convinced the class to donate \$50 to PWSA (USA).

Grandparent **Maureen O'Neil** from New Jersey used the month of May to support the **On The Move** effort at a Clifton IHOP with a **PWS Donations Display Wall**. Patrons purchased a sticker on which they could write their names and then place it on the wall. They raised \$300 for research.

Another grandparent, **Barb McManus** from Florida (who is PWSA (USA)'s Director of Family Support) collected over \$160 in May in her **Losing Weight for PWS** self-challenge. She writes, "**Jessika**, my granddaughter, is 19 now... Yes, she would love to go to an all-you-can-eat buffet, but she can't. So why should I?" That is support!

Students at **Palmer Trinity Private School** in Florida selected PWSA (USA) and contributed \$450 from their

Shed Your Threads program in May. They did not have to wear uniforms on select days if they made a donation. The siblings of **Leslie Torbert, 13** with PWS, attend the school.

North Carolina Aunt **Emily Sprague** set up a **Dress Down Day** on May 6 at her child's school, **St. Paul Catholic School**, in honor of her nephew **Phillip Fusco, 19** with PWS. The school donated \$240 for research.

On May 21, employee **Matt Greenan** of **Navigon Financial** in North Carolina set up an **On The Move 5K/10K Charity Run and Walk**. His boss, grandparent **Graham Self**, and parent **Josh Self**, who also works there, didn't hesitate to agree so long as it supported PWSA (USA). **Lauren**

Horst, an employee instrumental in producing the event, wrote, "Thank you so much for all your help! This has been one of the most rewarding events of my entire life." The event raised \$5,765.

Parent **Cindy Szapacs** also supported **On The Move** with a **Dine and Donate Night at PJ Whelihan's** on May 25 in Pennsylvania. Ten percent of profits from diners were donated to PWSA (USA), raising \$773 for research. ■



Merlin Butler, M.D., Ph.D.

An Outstanding Physician and Volunteer for PWS
By Denise Servais

The PWSA organization is extremely fortunate to have many physicians and researchers who volunteer countless hours of their time and expertise to advance the further understanding of PWS. Through their efforts, they help improve the quality of lives with those living with PWS. One of these individuals is Dr. Merlin Butler.

Dr. Butler is a clinical geneticist and physician at the Kansas University Medical Center in the Department of Psychiatry and Behavioral Sciences and Pediatrics, in Kansas

City, Kansas. He also is the current Chairperson of the Scientific Advisory Board for PWSA. Dr. Butler has given tremendous support to PWSA both through his research and through donating many hours of his time. In 2010, Dr. Butler logged 410 volunteer hours to the PWSA organization.

Since 2010 alone, Dr. Butler has published over 30 research articles, with the majority of them focusing on issues related to PWS. He has been invited to speak all over the world on PWS. Dr. Butler has received numerous awards and honors for his work in the area of genetics. Sincere thanks to Dr. Butler, and to all the other professionals, who have donated their time and talents to help make the world a better place for our loved ones with PWS. ■

Physical Health Issues and the Aging Adult with Prader-Willi Syndrome

By Barb Dorn, R.N., B.S.N. Nurse Clinician,

University of Wisconsin Hospital and Clinics, Verona, Wisconsin

(second in a series of 3 articles that share information about aging in adults with PWS with a focus on health.)

Many physical aspects of Prader-Willi syndrome impact body systems that can result in chronic health problems with increased risk of complications as a person ages. Obesity impacts most (if not all) aspects of health. Low muscle tone and spine deformities can contribute to respiratory and mobility issues. Hormonal abnormalities, low activity levels and nutritional deficiencies can result in low bone density and an increased risk of fractures. Sedentary lifestyle may contribute to lower extremity swelling and poor circulation. Diabetes is common, contributing to problems with eyesight, wound healing and other vascular issues. Constipation and other bowel problems may result from diet and low fluid intake as well as poor bowel habits.

The following are five of the most common health concerns being seen in adults with PWS as they age.

Prevention and management suggestions are also included.

Respiratory Insufficiency is the major cause of death in adults with

PWS, triggered by acute or chronic lung infections – not cardiopulmonary disease as originally believed (Eiholzer and Lee 2006). Spine deformities including scoliosis and kyphosis (“hunchback” deformity) can impact lung expansion and put a person at greater risk for respiratory compromise. Evaluation and treatment of sleep apnea, which can increase morbidity and mortality, is important, especially when an adult is undergoing a surgical procedure. Aggressive measures should be taken to prevent and manage lung infections and chronic lung conditions. Prompt evaluation of upper respiratory infections may necessitate initiation of antibiotics, encouragement of fluids, and/or assurance that the adult is kept moving and expanding their lungs. Follow-up with medical specialists is important. Discussions with health care professionals should take place on the administration of annual influenza immunization as well as the pneumonia vaccine.

Low Bone Density, Degenerative Changes and Mobility

Issues can affect the aging population in general, with those with PWS at greater risk. The normal aging process results in decreased hormone production, arthritic changes and a combination of other risk factors that contribute to mobility issues and increase the risk of falling. Today, the use of growth hormone and supplementation of estrogen and testosterone in adults with PWS is more common,

along with calcium and Vitamin D supplements and a greater focus on proper nutrition in an effort to prevent osteoporosis. Closer monitoring of bone density and the use of appropriate treatment is becoming more prevalent. Weight-bearing activities as well as medications are being tried to treat osteoporosis. Osteoporosis should be documented before initiating these medications, many of which have significant side effects. An increasing number of adults with PWS are undergoing orthopedic surgeries to treat degenerative joint problems. Keeping a person mobile is critical. When an adult with PWS becomes dependent upon a wheelchair, their risk of developing other medical emergencies (blood clots in legs and/or pulmonary emboli) is greatly increased.



Back Row: Kate (43 yrs), Jeff (48 yrs)
Front Row: Cindy (53 yrs), Jim (44 yrs)

It is important to create environments that reduce the risk of falls, such as guardrails installed in bathrooms and other areas, removal of throw rugs and proper lighting (especially at night). Canes and walkers may be needed to stabilize balance. Proper fitting shoes with a good tread can also help. All medications should be assessed for their impact on balance. Vision should be checked, and because bifocal lenses can alter depth perception and increase the risk of falling, two pairs of

continued on page 11



My daughter is REALLY easy to get along with, and quite charming until/unless a) you ask her TO do something or b) ask her NOT to do something...

~Anonymous

glasses may be preferable. A one-story home or home with ramps and other measures to assist with mobility should be considered.

Peripheral Vascular Problems, including ankle and lower extremity swelling and problems with blood pressure, are being reported in many aging adults with PWS. These types of circulation problems are often seen in diabetes. Vascular problems also impact wound healing and can result in leg ulcers and cellulitis. Skin picking problems can become very severe. Preventing circulation problems is optimal. Walking is one of the best activities to promote lower extremity circulation. Prolonged sitting should be avoided. When sitting, make sure feet are resting on the floor or stool – avoid “dangling legs”. In severe cases, special stockings may be prescribed. However, caution must be used to make sure these stockings do not impair circulation further or cause problems with wound healing. In some cases, these stockings have been used as a barrier to skin picking. Prompt attention to any cuts or sores in lower extremities and feet should take place. Avoid open-toe shoes-- especially thong-type sandals--to prevent injury to skin. These types of shoes may also cause balance and stability problems. Nail care is imperative and should be done by a health care provider if the adult has diabetes. Hydration is important to assist with maintenance of blood pressure. Weight loss, exercise, lower salt intake, frequent monitoring of BP measurements are all important. Medication to lower elevated BP may be needed.

Complications of Diabetes can often be severe and impact every body system. According to the American Diabetes Association (ADA), the aging population, especially those who are overweight, may develop Type 2 diabetes. High levels of glucose in the bloodstream damages blood vessels throughout the entire body—resulting in vision problems, kidney disease, and heart and vascular problems including stroke, high blood pressure and heart disease. Diabetes also impacts circulation and impairs healing – especially in lower extremities. Adults with PWS can be at increased risk to develop diabetes, especially if they are overweight. Many persons with PWS are diagnosed with diabetes at a young age. This can add years of damage to blood vessels. Screening, early diagnosis and treatment are important. The ADA recommends screening with a blood

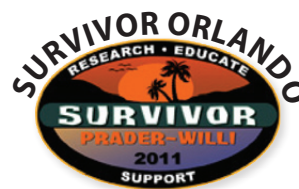
test called Hemoglobin (Hgb) A-1C. This should be done 1-2 times a year depending on risk factors. Annual blood lipid and cholesterol testing is suggested. Diet and weight management is imperative. An active lifestyle including exercise is also important. Once diagnosed with diabetes, the adult with PWS should adhere to any diet and/or medication regime that is prescribed.

Changes in Bowel Habits – Constipation is another health problem that many adults face as they grow older. Persons with PWS of all ages seem to struggle with gastrointestinal issues; constipation is common. Many of the same interventions used to manage other health issues also help this problem. Exercise, an increased activity level, adequate fluid intake, high fiber foods are just a few suggestions. Probiotic foods and supplements have also been beneficial. In many cases, daily fiber and/or laxative supplementation may be needed. Staff may need to monitor the frequency and consistency of a resident’s stool. Higher incidences of intestinal obstruction and ileus (slowing or stoppage of the intestine) have also been reported. Caution should also be used when using medications that slow the intestine – especially medicines used to treat diarrhea. Diarrhea can be a symptom of intestinal blockage.

Many of the issues are the same as all of us age. The goal is to minimize problems so aging adults can maintain a higher quality of life. ■

e-Bulletin...

Reminder – stay informed and stay current with PWSA (USA)’s free weekly e-Bulletin. Sign up today at www.pwsausa.org!



Attention OLDTIMERS!

This means YOU, who went to many of the early conferences, developed friendships with other parents, shared laughter and tears, and whose children have maybe grown up. A special session is planned, just for you. So come and see old friends and share those memories. ■

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

A Dad Speaks Out

My son Luke turned two yesterday. The most difficult part for me was the three-month period after he was born and before we knew he had PWS. The uncertainty was very stressful - what is wrong with my son? Will he be OK? Does he have a chance to be 'normal'? I remember that I was willing to give up just about anything in the world at that point in time just for my son to have a CHANCE at a normal life. By the time we got his diagnosis, I think I was more relieved than upset. At least I knew what we were dealing with. I also remember times of sadness in those first couple of months - I think I was mostly sad for the loss of the boy and the man that Luke will likely never become - the star athlete, the popular kid in school, the husband and father, the accomplished professional. That still makes me sad sometimes when I spend too much time thinking about it.

Finally, I was sad for myself because I would not be able to do many of the things that I always envisioned doing with my son. Thinking back now, I can't even remember what specifically I thought I would be missing out on - I just had some self-pity that my relationship with my son would not be 'normal'.

I remember talking to my brother (who has a 12-year old autistic son) about being worried that Luke's condition would change our family's lives forever. He told me that many things would NOT change. He told me that I would still love my son, and that I would still be proud of my son. The things that make me proud may not be the things I envisioned, but the pride I felt would be just as real.

I have thought about that a lot in the past two years. I know our hardest days are ahead of us. But I am trying to think of it like this: My son will do things that make me proud (like when he began walking a few months ago), that make me laugh, that make me angry, and that make me sad. But isn't that true for every father?

We may think that our anger or sadness will be greater than that of other fathers, or greater than it would be if our sons were 'normal'. I am not sure that is true. My anger and my sadness are for the most part controlled by me. Not by my son. So if I am angry and sad, it is MY problem and my responsibility. My son is who he is, and right now he is an adorable loving little Tsunami that likes to hug and play with his daddy and make messes. ■

*-Pete Pomeroy, New Fairfield, Connecticut
proud father of Luke (2, PWS),
Samantha (6) and Rayna (4)*

A Very Special Accomplishment



In her speech to her son, Aaron Fisher Carvajal at his Bar Mitzvah in April, Susan Fisher said, "It is truly an honor and privilege to be your mother... In your short 13 years, you have taught me more than I could ever have learned in a lifetime with you... When you

were a baby, I cried every time I went to a Bar Mitzvah... because I thought you would never be able to have a Bar Mitzvah. I was so very wrong."

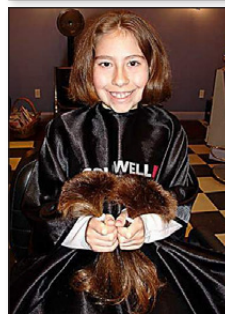
Aaron, a seventh grader, had to learn to read Hebrew and was able, Susan says, to make the blessings over the Torah before and after the readings. Also, he got a new suit and was chosen for the store's advertising in the paper, he collected 800 pounds of dog food for a no-kill animal shelter for his mitzvah project, and he contributed a portion of his Bar Mitzvah gifts to PWSA (USA).

In his speech Aaron said, "I love being Jewish because we pray a lot, and when I pray, God listens to me." ■



From Rebecca with "Lots of Love"

Rebecca Baird, 9, with PWS, had 12 inches of her hair cut for Locks of Love on April 20. This is the third time she has donated her hair, for a total of 40 1/2 inches. Rebecca has had her hair cut every two years for Locks of Love, beginning at the age of 5. Rebecca is always so happy to donate her hair to help kids in need of hairpieces. She is the daughter of David and Ann Baird of Clinton, Massachusetts. ■



We Remember

Born prematurely at 26 weeks, **Lee Michael Wigger** (9/1/1986 – 3/18/2011) was not expected to leave the hospital. He was diagnosed with Prader-Willi at two by a doctor that recognized him as a mirror image of the pictures in medical textbooks for PWS.

Lee beat all the odds through his lifetime. I truly believe it was his zeal for life, his love for others and his love for God. Lee had a special relationship with God as all of His “special children” do. Lee’s disability gave him strength to deal with people who could not handle any imperfections. He accepted all without judging, which seems the opposite of those who are “not disabled” or “handicapped” or “labeled”.

He was undoubtedly the most social person you could ever meet, even though he could not speak, had a trach, and needed 24-hour oxygen and 24-hour supervision. He was a true example of the saying – “You eat life or life eats you.” Lee loved all the basic normal things of life, but he had his favorites: Disney, trains, girls,

cows, music, Sunday Mass at church or watching the Pope on TV and Santa Claus! He was the life of a party; a true host, he could Wii-bowl a perfect score. When you’d visit him, he would welcome you, offer you a snack or refreshments and sit with you as if he could hold the best of conversations. He would clap for you to cheer you up, kiss you when he thought you were down and, always, he would make a chapel sign with his hands inviting you to go to church.

Lee went to special schools and lived with special needs, but his parents dedicated themselves to him and taught him to be as normal as possible. He went everywhere that they went, together with friends and family. Lee is a reflection of his parents’ and brother’s love and dedication. Not only was he special in every sense of the word, but he was a gentleman and a true friend. His symptoms did not affect his emotional or spiritual life because he was the happiest person anyone could ever meet. Without a doubt, so many have learned from Lee Wigger. He will be



missed beyond measure, but his spirit lives on in each one of us as he taught us all how life is what you make of it, no matter what the circumstances may be.

We do not say goodbye to Lee, but “until we meet again.” At his service the memory passage printed in his honor was a very comforting and fitting one. “Come to Me.... God saw you were getting tired and a cure was not to be. So He put His arms around you and whispered, Come to Me. A golden heart stopped beating, hard working hands at rest. God broke our hearts to prove to us He only takes the best.” AND THE BEST HE IS! ■

Brant Wigger (Lee’s father) and Janie Guirola (a close friend)

Friday May 20th, 2011

Dear Family and Friends,

This note is to thank you for standing with us at the most difficult time of our life.

Samia (born: 9/10/1979) passed away on 5/5/2011 at 4:15 PM without any pain or discomfort. She is resting peacefully in Totowa, New Jersey, her beloved state.

She lived an exemplary life, with purpose and determination. Despite her limitations due to Prader-Willi syndrome and several other medical conditions, she accepted her limitations without resentment or self pity. She showed extreme courage in the face of adversity. She lived life on her terms.

She seized every moment given to her and lived life to the fullest. She

taught us how to live with grace and how to smile in the face of heaviest of odds.

Samia collected angels. She made sure that she wore angel pins ALL the time and found peace in knowing that she was in their company. Indeed she was, and is.

The support of friends and family has been overwhelming. We want to thank her grandmother, her cousins, uncles and aunts who treated her like a princess. We want to thank her teachers, her doctors, and her caregivers who enriched her life. We want to thank all of you for being the angels that we needed. Your support provided us the greatest possible comfort and gave us the strength to endure the loss.

Losing a child is very tough, but



we draw strength in knowing that she served her purpose in life. **Samia taught us the greatest lesson in giving, by donating her brain and tissue for Prader-Willi research.** She is going to be with us forever. ■

Zafar, Ghazala, Saif, and Beenish Nomani

Contributions

Thank you for Contributions in February and March 2011. We try to be accurate in recognizing contributions above \$25, and apologize for any errors or omissions. If you notice an error, please tell us.

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Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers.

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

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Still hungry for a cure.

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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)

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Parent Comment after attending Conference

It was not doom and gloom. It was uplifting and I felt empowered.

I got reassurance that we were on the right track with our son's therapies and I got information about how to continue to improve them. Lots of ideas! I didn't think my husband would get as much out of it, but he did. What great information and positive people. I came away feeling invigorated and enthusiastic.



Getting Ready for School

By Labor Day most children with PWS are beginning a new school year. This can cause parents and their child to have a lot of anxiety and nervousness. Common thoughts are "Will the other kids accept and understand my child and the struggles my kid has with PWS?" or "Will the school understand the needs of my child?" Here are some ways to help your child start the new school year.

A few months ago a parent called us to discuss ways to help her son's peers at school understand PWS. After a few conversations, this parent created a fabulous resource, making a simple story of her son and his personal struggles with PWS. This resource was specifically written in language her son's peers could understand. At first she created a power point presentation and later created a PDF file for distribution for other parents to use, entitled "Parent Resource – Nolan". The link to access it on our website is <http://www.pwsausa.org/awareness/tools.htm>.

To help your child's peers understand PWS, you can also make your own story. Here are some suggestions on how to create your own resource:

- Include several pictures of your child that go along with the story.

- Introduction with name, age, grade, and teacher.
- Include what your child likes to do that is similar to other kids his age.
- Include how your child is different and introduce PWS.
- Explain how PWS always makes your child hungry, special diets, and foods your child should not eat. May also include the purpose of food security.
- Physical and/or emotional challenges your child has with PWS.
- Learning challenges and the supports your child needs.
- A positive conclusion that is supportive of the friends and teachers at school.

In addition, you can help your child by creating a school portfolio. The instructions on developing a portfolio are now on our website under the Support section. We also have a school portfolio packet that can be purchased.

You can contact a crisis counselor for more information and support as your child starts on a new school year adventure.

See you next time in the Counselors Corner. ■

-Jeremy Johnson

Counselors Corner