

# The Gathered View

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

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

## United by PWS, East met West in Taiwan

by Joan Gardner, PWSA (USA) parent delegate for IPWSO

Chaired by Dr. Li ping Tsai, "East Meets West", the International Prader-Willi Syndrome Organisation's (English spelling) triennial conference held in Taipei, Taiwan, was a spectacular success. It was a privilege to attend as your USA parent delegate with my husband, Jim, along with delegates from all 32 member countries and most of the 83 affiliated countries.

Highlights included the joy of families from countries with no awareness and support for PWS such as China and Cuba, meeting their first parent peers who knew the syndrome; beautiful musical performances by a choir of children who have rare diseases; charming volunteers who guided us every step of the way, even in the subways; fascinating food including two western luncheons provided by Burger King; dozens of enormous pink flower arrangements from sponsoring community businesses and friends;



Children from Taiwan with PWS drumming for the conference.

city tours and a final banquet in the 1500-person dining room which Chiang Kai-shek built at the top of a mountain for his legislative assembly.

Excellent programs were presented in the Scientific, Caregivers, and Parents sessions. PWS knowledge and related research continues to evolve along with the



Janalee Heinemann, Jackie Mallow and Mary K. Ziccardi with families from Taiwan

most effective standards of care and management. Dr. Anthony Holland, UK, captured the importance of these meetings when he stated, "PWS is the best example of where knowledge is critical to be effective." Number one and number two on every presenter's priority list was early diagnosis and weight control.

Dr. Shuan-Pei Lin was honored for his work with the conference, assuming the IPWSO board presidency, and for being a key person in establishing the Taiwan PWS organization.

The four-day IPWSO conference concluded with the election of Dr. Suzanne Cassidy as president and Janalee Heinemann as vice president of the board of directors, both USA! Dr. Cassidy is the first professional delegate to be elected president. (Dr. Shuan-Pei Lin was vice president and took over the presidency after Pam Eisen's

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Volume 35, Number 4 ~ July-August 2010 ~ Our 35th Year of Publication

## East Hosts West in a Grand Way

By Janalee Heinemann, MSW

Director of Research & Medical Affairs

*The face of our future not only comes from research in the USA, but from research around the world.*

Although they had never hosted a national PWS conference let alone an international one, Taiwan, our host country, did a phenomenal job creating a spectacular 7th International Prader-Willi Syndrome Conference. (See Joan Gardner's article.) Having the conference in an Asian country brought in many presenters and attendees that have not had the opportunity to participate before. We also had a strong share of USA involvement as organizers and presenters. The Caregivers program was exceptionally well attended, and Dr. Li Ping Tsai told me afterwards that it has given their families in Taiwan the knowledge and motivation to begin the process of establishing supportive living homes in their country.

Here are glimpses of a few of the 29 oral reports and 36 poster presentations from this conference. The entire report must be heard and/or read to understand the conclusions. This is non-peer reviewed research (a process required by medical journals). The full abstracts, including more complete credits, are currently posted on the PWSA (USA) web site at [www.pwsausa.org](http://www.pwsausa.org) and on the IPWSO Taiwan website at [www.ipwso.org](http://www.ipwso.org).

INTERNATIONAL PRADER-WILLI  
SYNDROME ORGANISATION  
7TH SCIENTIFIC CONFERENCE  
MAY 20-21, 2010, TAIPEI, TAIWAN  
Co-chairs: Suzanne B Cassidy, M.D. and  
Leopold M.G. Curfs, PhD

### **HYPOTONIA IN NEONATES WITH PWS IS NOT ALWAYS SEEN AT BIRTH BUT BECOMES EVIDENT AFTER THE FIRST DAYS**

~ Susanne Blichfeldt -- Denmark

Hypotonia and other typical symptoms in neonates with PWS are not always observed at birth but most often during the first days. A normal Apgar score includes normal muscle tone. Cases with both low and normal Apgar scores in PWS have been published previously. Their data call attention to a possible clinical change during the first days. One question to be considered is if any normal neuronal or hormonal stimuli gradually disappear.

### **FREQUENCY AND RISK FACTORS OF SEVERE SCOLIOSIS IN PWS**

~ Toshiro Nagai -- Japan

They studied 156 patients with PWS - The frequency of scoliosis in Japanese patients was 41% which was lower than that of the Caucasian populations studied. The frequency of severe scoliosis was about 10% of all patients and 25% of the patients with scoliosis. With respect to the shape of scoliosis, lumbar type was the most common and double-curve type had a tendency of rapid progression. All of these patients with severe scoliosis had surgical indication. About half of the double-curve type showed severe scoliosis indicating that this type should be carefully monitored

### **EXENATIDE (BYETTA®) INCREASES POSTPRANDIAL FULLNESS WITHOUT SIDE EFFECTS IN PRADER-WILLI SYNDROME - A PILOT STUDY**

~ Alexander Viardot -- Australia

(Byetta®) is a drug recently developed for the treatment of type 2 diabetes, and it has been demonstrated to have beneficial effects on appetite suppression and weight loss, but it also has significant side effects which limit its use. Eight subjects with PWS and eight obese controls were put on Byetta. The drug significantly increased fullness, but did not reduce appetite, in both groups.

This is the first report on the use of Byetta in PWS that they feel demonstrates that this drug is well tolerated in these subjects. Their observation of suppressed insulin levels and unchanged ghrelin levels challenge previous reports and hypotheses on the mode of action of this drug, suggesting delayed gastric emptying might be an important mechanism (my comment – it might also be a risk factor for PWS due to the high prevalence of gastroparesis) which should be assessed in future studies. Larger prospective studies should follow to investigate whether chronic administration of Byetta will lead to decreased food intake and weight loss in PWS, and if it is a safe drug for use in individuals with PWS.

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

## TWO YEARS OF GROWTH HORMONE THERAPY IMPROVES BODY COMPOSITION IN ADULTS WITH PWS

~ **RASMUS SODE-CARLSEN, Sweden**

In this first large scale, long-term, placebo-controlled study of 46 patients, the improvement in body composition by GH treatment in adults with PWS was confirmed. No side effects were observed.

## BRAIN DEVELOPMENTAL DIFFERENCES IN PRADER-WILLI SYNDROME DETECTED BY DIFFUSION TENSOR IMAGING

~ **Ken-ichi Yamada – Yasuhiro Kido -- Japan**

The study provides objective evidence that individuals who have PWS indeed have developmental differences in specific areas of the brain. The findings provide not only new insights into developmental pathophysiology, but also an opportunity for interventional strategies for the behavioral issues in PWS.

## NOTES FROM INVITED SPEAKERS PRESENTATIONS

### **Daniel J. Driscoll, M.D., Ph.D. FAAP, FACMG – USA** CLINICAL AND GENETIC OVERVIEW OF PRADER-WILLI SYNDROME

Here are a few of the genetic issues Dr. Driscoll discussed.

PWS is a model system for:

- Obesity and nutrition
- Genomic imprinting and epigenetics
- Endocrinology issues

PWS results from the loss of function of several imprinted genes in the 15q11.2 region. One gene cluster called HBII-85 (also called SNORD 116) seems to be particularly important since two rare patients have been found that only have a small deletion of this gene cluster. These two individuals have many (including early-onset obesity), but not all the clinical features of PWS.

There are two main classes of deletions (Type 1 and Type 2). However, about 10% of deletion patients have a unique deletion size which results in a milder or more severe phenotype, depending on the area deleted. Unique deletion subjects will aid scientists in determining the function of the various genes in the PWS region.

### **Dick F. Swaab, M.D., Ph.D. – The Netherlands** PRADER-WILLI SYNDROME: GENE EXPRESSION AND PREMATURE ALZHEIMER DISEASE

Now that more persons with PWS are surviving longer, it seems that we find premature aging and dementia, probably of the Alzheimer Disease (AD) type, as a new challenge. Obese patients might be prone to early-onset AD. Also, lack of sex hormones may add to the risk factors. ■

*Special thanks go to Dr. Shuan-Pei Lin of Taiwan for his leadership and dedication to the families in his country dealing with PWS, and his heart for the families of the world.s*



*Professor Leopold Curfs, co-chair of scientific (Netherlands); Janalee Heinemann (USA); Dr. Loisel (Cuba); Dr. Shuan-pei Lin, conference organizer (Taiwan)*

### **Taiwan, continued from page 1**

death.) This is a true tribute to her international reputation for more than thirty years of commitment as a researcher, clinician and educator in Prader-Willi syndrome.

Mark your calendars for July 11-14, 2013, for the 8<sup>th</sup> IPWSO triennial conference in Cambridge, England. UK Co-chairs Jackie Waters (IPWSO Board Member) and Dr. Holland (IPWSO Scientific Advisory Board) will provide updated information at [www.pwsa.co.uk](http://www.pwsa.co.uk) and also at [www.ipwso.org](http://www.ipwso.org). ■



# Cancer, Cryptorchidism and Small Genitalia in PWS

by Phillip D. K. Lee, MD

former PWSA (USA) Scientific Advisory Board member

## RE: Cryptorchidism

1. There is no reason to think that the cancer risks or treatment of cryptorchidism (undescended testicles) should be any different in PWS as opposed to non-PWS.

2. In Non-PWS, cryptorchidism is thought to be a contributory cause of approximately 10% of all testicular tumors.

3. The vast majority of men with cryptorchidism do not have and never will have testicular cancer. However, cryptorchidism does impart an estimated 2 to 5 fold risk for testicular cancer over the general population risk.

4. Testicular tumors are the most frequent cancer in young adult males (e.g. 15-50 years old), but are still rather infrequent. The incidence is estimated at ~5 in 100,000 males in this age range. Therefore, it is not at all surprising that there are so few reports of testicular cancer in PWS.

5. The old dogma was that cryptorchid testes MUST be brought down into the scrotum (orchiopexy) or removed (orchiectomy) to avoid the risks for cancer. The theory was that the higher internal body tem-

perature might promote cancerous changes. However, more recent data indicate that orchiopexy probably has no influence on the risk for testicular cancer. Some of the older data may have been tainted by the fact the cryptorchid testes are not readily palpable, therefore cancers would be detected late.

6. My recommendations are outlined in the 3<sup>rd</sup> edition 2005 Management textbook and follow traditional guidelines for evaluation and treatment of any cryptorchid male, PWS or non-PWS.

7. In my opinion, cryptorchid testes should be brought down (or removed, if orchiopexy is not possible) not because this will reduce cancer risk, but because the risk of having undetected cancer is higher if the testes are not visible. In addition, the externalized environment does promote better testicular development and function, particularly if the surgery is done before puberty, but this might be a somewhat moot point for most boys with PWS (at least for the moment).

## RE: Genital Size

There is no doubt that male geni-

tal size, regardless of function, is an important element of human self-esteem and social behavior. In addition, there are the functional aspects (e.g. using a stand-up urinal) and, later in life, issues related to somatic virilization (body habitus, facial hair, muscle strength). Therefore, it has been my longtime policy to treat boys with PWS exactly the same as I do non-PWS boys with microgenitalia and testosterone deficiency. This treatment is also outlined in the 2005 text, and essentially consists of (1) neonatal/infant low dose testosterone to achieve normal prepubertal penile length and (2) testosterone replacement therapy beginning in the teenage years.

As I pointed out in a previous E-response, there is absolutely ZERO evidence that testosterone replacement therapy to achieve normal levels of testosterone has any adverse effects on behavior in PWS or non-PWS males. A recently published, well-performed controlled study in hypogonadal non-PWS males also made this point.

A more complete discussion on this topic can be found in the 2005 Management of PWS textbook available through PWSA (USA) . ■

**Please note that there are more articles posted in the medical section of the web, e.g., on skin picking.**

## Help us to help you!

**We need your participation in the Rare Disease Research Network consortium studying Prader-Willi syndrome.**

The purpose of our study is to identify the natural history of PWS and those with EMO or early-onset of childhood morbid obesity and to learn more about the genetic causes and co-morbidities of Prader-Willi syndrome and to compare PWS with other causes of EMO. Eligible participants must have a confirmed genetic diagnosis of Prader-Willi syndrome or those with EMO

have onset of obesity before 4 years of age. Individuals of all ages are eligible. For more information, please contact, Merlin G. Butler, MD, PhD: 913-588-1873, email: mbutler4@kumc.edu, Erin L. Youngs, MS: 913-588-1871, email: eyoungs@kumc.edu or Marilyn Logan, RN: 913-588-1315, email: mlogan@kumc.edu ■

## Election of PWSA (USA) 2010-2013 Board of Directors Approval of 2009 Annual Membership Meeting Minutes Voting Instructions

1. Review the candidates' statements printed on the Slate of Candidates. Read the 2009 Annual Membership Meeting Minutes.
2. Cast your vote on the Official Ballot. Note any corrections necessary to the Annual Membership Meeting Minutes. Insert the ballot into the Official Ballot Envelope.
3. Print and sign your name on the Official Ballot Envelope. Affix postage. Mail it to PWSA (USA) postmarked no later than August 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, 2010. 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:	_____
<small>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.</small>	
<div style="text-align: right;"><small>Please Place Your Stamp Here</small></div> <div style="text-align: right;"><b>Julie Doherty, Secretary</b> <b>Prader-Willi Syndrome Association (USA)</b> 8588 Potter Park Drive, Suite 500 Sarasota, FL 34238-5471</div>	

*sample ballot envelope*

### Approval of 2009 Annual Membership Meeting Minutes OFFICIAL BALLOT

Cast your vote for the 2010-2013 Board of Directors. Vote for five (5) of the candidates listed below.

- ☐ Michael Alterman      ☐ Jamie Bassel, D.C.      ☐ John Heybach      ☐ Stephen Leightman      ☐ Mary K. Ziccardi
- ☐ Corrections to the 2009 Annual Membership Meeting Minutes: \_\_\_\_\_
- ☐ No Corrections Necessary (if neither box is checked, we will assume you have no corrections to the minutes)

## MEET THE SLATE OF CANDIDATES



**John Heybach** has been a member of the board for six years. He has led the strategic planning and research committees and served on the finance and fund development committees. He is currently co-chair of the board and serves on the executive committee. John is president of the Illinois chapter of PWSA (USA). He lives in Chicago

with his wife, Sue, and son Conor, who has PWS and is a member of the Adults with PWS Advisory Board. His daughter, Michelene Bajakian, is an attorney living in Ohio who does consulting advocacy work for PWSA (USA). John is the director of a non-profit supplemental education and character building organization for under-represented boys in Chicago.



**Mary K. Ziccardi** is an Administrator at The MENTOR Network in Cleveland, Ohio, where she has been employed for 22 years. Ms. Ziccardi oversees a region of a national agency which provides services to more than 200 individuals with a variety of intellectual and developmental disabilities and who are supported by greater than 300 employees.

Ms. Ziccardi has been directly involved in providing services to people with Prader-Willi syndrome for nearly 20 years. In addition to the five residential programs specifically for people with PWS in Cleveland, she works with PWSA(USA) to provide trainings and consultations in schools and residential programs throughout the United States. Over the last year Mary K. worked with a small team of professionals who organized, lectured, and facilitated the Providers conference for the IPWSO meeting in May 2010 in Taiwan. Ms. Ziccardi has co-chaired PWSA(USA)'s Providers Day conference on twelve occasions and participates in the leadership of PWSA(USA)'s Advisory Board.



**Dr. Jamie Bassel** became involved with Prader-Willi syndrome 9 days after his son Zakary (age 5) was diagnosed. He is a proud member of the Board of Directors of the Genetic Disease Foundation and a member of their clinical advisory committee. He serves on the Board of Directors of the Prader-Willi Syndrome Association (USA) and is

co-chairman of the Scientific Advisory Committee. He is vice president of the Prader-Willi Alliance of New York. Dr. Bassel has been a practicing chiropractor in Manhattan for 13 years. He specializes in treating spinal injuries, musculoskeletal conditions, scoliosis and assisting in active rehabilitation. He is involved in yearly community activities such as Avon Breast Cancer 3day Walk. After 9/11 he volunteered with the American Red Cross, providing chiropractic care to law enforcement agents, firefighters and relief workers. He is a team physician with the American Basketball Association's Harlem Strongdogs and the United States Basketball's Brooklyn Kings. He and his wife Jacqueline have created **Zak's promise**, that is devoted to fundraising for research and awareness for PWS.



**Michael Alterman** is a native of Atlanta, Georgia where he is the Chief Operating Officer of HT Group, LLC, a Commercial Real Estate Investment company and brokerage and Co-Founder of End Results DMC, a destination management company. Michael has had a lifelong association with PWS and PWSA (USA). Michael is a sibling and legal

guardian of his brother Andrew, 39 with PWS. His family has been extremely active in both the state and national organizations. His father is a previous Board member of PWSA, sister Katie a former Assistant Director of YAP, and mother Pam who spearheaded the annual conference logo merchandise and apparel. Michael's first conference was at age 9 and by age 12 he was serving as a counselor at the annual conference. During the years of 1997-2002 he also served as Assistant Director of the YAP program at each respective annual conference, including the 2002 international conference in Minneapolis/St. Paul. Michael

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has recently completed his first term on the PWSA (USA) Board of Directors, serving as Chair of the newly formed social media committee, Co-Chair of the fund development committee and a member of the 2011 Conference committee.



**Steve Leightman** says: I am a devoted grandfather to an 8-year-old with PWS. Needless to say, our entire family was devastated with the diagnosis eight years ago, and we continue to struggle with the challenges the syndrome presents. I have been privileged to serve on the PWSA (USA) Board for five years and am now Chair of the Finance and Development Committees. I also serve on the Association's Executive Committee. Professionally, I have been a practicing financial consultant for over 30 years. I seek re-election in the hope that I may be able to partially repay the Association for all it has done for me and my family. ■

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## PWSA (USA) Annual Membership Meeting (held telephonically) September 1, 2009

Co-Chair Carol Hearn called the meeting to order at 8:02 p.m., EST.

By reference to the Web site, Carol introduced the board members, officers and staff of PWSA (USA) and members of the Clinical, Scientific, Professional Providers and PWSA (USA) Advisory Boards.

The incoming board members were welcomed: Dr. Greg Cherpes, Jackie Mallow, James Koerber, Lisa Thorn-ton and Michelle Torbert. Our outgoing board members were thanked for their service: Dr. Linda Gourash, Mary K. Ziccardi and Mark Ryan.

Minutes of the July 3, 2008 annual membership meeting were approved by mail-in ballot.

Evan Farrar, Acting Executive Director, provided his report. He noted that the association is holding its own, despite the challenging economic times, a reduction in the number of staff, and a change in Executive Director. The Annual Report is available on the PWSA (USA) Web site, or by calling the office to obtain a printed copy.

Bert Martinez, Treasurer, presented the financial report. He referred to the income statement and pie chart of expenses in the Annual Report. The Audit results and Form 990 will be available for anyone to review. He noted

PWSA (USA) benefited from over \$600,000 in donated services, mostly from our physicians. For 2009 we're closely monitoring our budget and staying within budget.

Evan Farrar read the Development Committee report. The current economic climate has produced challenges. Some of our foundations have had to reduce or eliminate their contributions, and we have also had to reduce our development staff, but we are hard at work and optimistic for our future. An event guide has been prepared which is patterned after the successful Spirit Week fundraiser held last year by Eastside High School, Greenville, South Carolina. Members were encouraged to contact Jodi O'Sullivan or Steve Leightman if they are interested in helping with a fundraising event.

Evan reported on Crisis and Family Support. He noted that despite reduced staff we are continuing to meet the needs of our members in crisis. The Willett Fund donation has helped in providing school staffing assistance and enabling patients to be admitted to the Children's Institute. We are getting earlier referrals which means awareness is spreading. Chapter development is growing, and many support groups are moving to chapter development.

Janalee Heinemann presented the Research Committee Report. She reported on the wide variety of calls received from physicians and parents. The currently-funded grants are listed on the Web site. An update on the 2009 Hyperphagia Conference was provided. She noted our involvement in the UAB-Birmingham Research Conference, spearheaded by Theresa Strong. The research account balance and the funds committed for '09 and '10 were given. She discussed the BIG (Big Idea Grant) which arose out of the hyperphagia conference. Eleven letters of intent have been received. Members were reminded to enter their initial data or update their data in the medical survey. She thanked our members for supporting research.

Evan noted that the 2009 conference broke even financially. He discussed the difficult decision to not hold a conference in 2010. He shared information on the Web site re-design initiative. The dates and topics of the two upcoming webinars were provided. He reminded members of the Go Green initiative and encouraged them to opt to receive their Gathered View in an electronic format.

Evan shared that it was not his intention to be considered for the permanent Executive Director position. He loves being a crisis counselor and looks forward to returning to that role when a new Executive Director is selected.

John Heybach provided an update on the Executive Director search process. Phone interviews have been completed and face-to-face interviews with 10 candidates

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# U.S. Senate Resolution Supports Designation for National Prader-Willi Syndrome Awareness Month

On May 27, 2010, another significant milestone occurred for Prader-Willi syndrome (PWS). Senator Robert Menendez (D-NJ) sponsored and Senators Patrick Leahy (D-VT) and Benjamin Cardin (D-MD) co-sponsored and submitted to the U.S. Senate S. Res. 543 "Expressing support for the designation of a National Prader-Willi Syndrome Awareness Month to raise awareness of and promote research on the disorder." The 111th Congress second session considered and agreed to the resolution without amendment and

with a preamble by unanimous consent. Both houses in U.S. Congress have now recognized a National PWS Awareness Month. In December 2009, the U.S. House of Representatives passed House Resolution 55, introduced in the House of Representatives by Reps. Ed Royce (R-CA) and Jane Harman (D-CA).

Prader-Willi Syndrome Association (USA) gratefully acknowledges Senators Menendez, Leahy and Cardin. Additional special thanks go to grandparent Peter Fleischmann, and Chasseny Lewis of Senator Menen-

dez's office who were instrumental in this latest successful effort.

To read the full resolution text, go to <http://thomas.loc.gov/cgi-bin/query/z?c111:S.RES.543>: ■

## *To contact and thank sponsoring Senators:*

Contact Senator Menendez:  
<http://menendez.senate.gov/contact/>  
Contact Senator Leahy:  
<http://leahy.senate.gov/contact/>  
Contact Senator Cardin:  
<http://cardin.senate.gov/contact/>

## Prader Willi Association of New York Gala Celebration a Smashing Success!

A dinner dance was held on Friday, May 1<sup>st</sup> to celebrate PWANY's 20 years of achievement and success in the PWS community and to honor three of the people who played a critical role in that success. More than 225 people dined and danced with us.

Mr. James Whitehead, Assoc. Comm. of OMRDD gave the keynote talk and highlighted the working relationship between PWANY and OMRDD that has helped to bring about the milestones of the last 20 years.

Our three honorees delighted those present with their humor and humility. Each was serenaded by the duet "The Doc-apellas" (Doctors Foster and Gourash) who wrote special

lyrics about the qualities of each recipient.

Dr. Moris Angulo was honored for his overall contribution to the field, Janalee Heinemann for bringing our national organization, Prader-Willi Association-USA, to national and world prominence, and B.J. Goff for her contributions to the education of people with PWS.

Entertainment was provided gratis by Tom Roberto, father of Sonny and husband to our own Nina Roberto, and his six member band, "Big Daddy". The people with PWS showed up everyone else on the dance floor with their enthusiasm and energy; they out danced anybody and everybody! ■



*B.J. Goff, Dr. Moris Angulo and Janalee Heinemann*

## *Minutes, continued from page 7*

will take place in the next few weeks. Three candidates will be brought before the board in October, with the goal of offering the job to one of them.

Evan noted that no questions were e-mailed in during the meeting.

Carol adjourned the meeting at 8:25 p.m.

Julie L. Doherty, Secretary ■

## Annual PWSA (USA) Membership Meeting

The Annual Membership Meeting for 2010 will be held telephonically on Wednesday, September 1, 2010, at 8:00 p.m., Eastern Standard Time.

To join the call, please dial 1-219-509-8222. The Participant Access Code is 692767.

All members of PWSA (USA) are encouraged to attend. ■



# For the Moment

By *Courtenay del Moral-Beeman*  
St. Paul, Minnesota

How much is too much? When do you decide that you can no longer cope with your child's behavior at home? At what moment in time do you understand that you are not able to care for your child? In other words, when does your child need to be placed in a group home? When do you emotionally wave the white flag and make the decision to walk away?

To walk away, not from the child I love, but from the lifestyle I have become accustomed to. A lifestyle of constant calorie counting, food monitoring, and locks placed strategically on my refrigerator and cabinet doors. How do I walk away from my life spent, in many ways, isolated with my son who is consumed with a never-ending hunger?

My son, Pierce, is 11 and suffers from Prader-Willi syndrome. His brain sends constant signals of starvation to his body. No medication will stop his pangs of hunger. Like many with PWS, Pierce does not have the intellectual capacity to understand what makes his body different from other little boys. He just knows that his stomach is always hungry.

Pierce has a terrible time with transitions; a tantrum can be violent and last for more than an hour. We have several aides for Pierce who help him stay on a schedule of walking, swimming and various activities that he is able to understand. Pierce has good days--and days when he is completely inconsolable. He has endless doctor visits and medication adjustments with his psychiatrist. I find myself alternating between complete and consuming devotion to my child and a state of mental exhaustion.

Tonight, after a violent episode with my son, it occurs to me to dare ask myself the question: when is



enough, enough? Grief stricken, I find my bed in the dark. My mind reels about what will happen to Pierce in the future. Is he too young to be placed in a group home? If he is away from me, who will make sure his feet are warm at night? How will someone different than I handle his tantrums? Will he be safe? Will he feel abandoned? I close my eyes and let the night of "what ifs" take me to sleep.

It is five o'clock in the morning; I hear Pierce's footsteps as he enters my bedroom.

"Mommy," Pierce calls me, then climbs into my bed. "Why did God give me to you?" He crawls under the quilt, then reappears on my pillow.

"God gave me to you because I was the lucky one," I relay this to Pierce as I have many times before.

"Is your M.S. O.K., Mommy? Do you need my help walking?" Pierce's nose crinkles with concern.

"No, I'm alright today, honey." I sit up and stare at my Pierce. My feelings of helplessness dissipate as I study his face. His violent episodes seem less relevant, and I think of the

little boy before me who is kind to animals and loves babies. Pierce is the child who will offer his hand to me before I approach an icy road, or talk to strangers who are in emotional pain. He is amazingly funny and, when he is happy, he actually skips when he walks. I get out of bed and give my hand to Pierce who willingly takes it. As we walk to the kitchen together, I am convinced, once more, that Pierce is more than his tantrums and insatiable appetite. It occurs to me that I will survive another day with my son and PWS.

When is enough, enough? I have no idea. If I avoid the land of "what ifs" and stay in the present, I can cope. I know the point will come when Pierce will no longer live with me, and I will handle this event when the time arrives. For now, I will focus on the present. Now, Pierce crawls into bed with me in the mornings. He has his good days and tantrumy moments. Now, Pierce is my little boy who proudly offers his hand to me before I cross an icy road. ■

# The History and a Tribute of our Crisis Intervention Program

*By Janalee Heinemann, MSW  
Director of Research & Medical Affairs*

I realize that when you call the PWSA (USA) 800 number and ask to speak to a crisis counselor, unless you have been a part of our organization for many years, you do not have an understanding of how this very important program evolved. I would like to give you the history and give a tribute to the many people who made it possible.

**1997:** After working with medical and family crises for over 20 years and raising a son who has PWS, I took over as Executive Director, and quickly realized that the needs for PWS crisis support were far greater than I could ever meet.

**2000:** David Wyatt, who has a master's degree in counseling and 37 years of experience as a retired hospital chaplain and chaplain instructor, began volunteering and rescued me by beginning to take the non-medical crisis. Although he has had many of his own medical crises, David worked harder than most full time paid employees. I remember many times David would be in the hospital bed with his clipboard in his hand, making crisis calls, and coming to work with IV lines in his arm or chest.

**Fall of 2001:** David could not financially afford to continue to volunteer for no pay, yet he had become invaluable to the crisis program. I approached our member and PWS parent, Paul Alterman, and he agreed to provide a grant from the Alterman Family Foundation. This enabled us to pay David a small salary. At that point David had already worked with over 1,900 families. Even after Paul's death, the Alterman funding has continued thanks to his son who is our board member, Michael Alterman. David is now fully retired, but still volunteers.

**Dec 2002:** We were fortunate to be able to expand our crisis services thanks to another "angel" family, the Willetts, who, in honor of their nephew, Brian Schertz, have supported a grant yearly that is for legal and educational crises. Through this support, we were able to develop an educational consulting program that helps with serious school and placement crises.

**March 2006:** Due to the overwhelming demand for services, we hired Kate Beaver (parent of a child with PWS who has a master's in social work) part time to assist with the non-medical crisis calls. We had officially become a team. Kate continues in this role today.

**June 2006:** We hired Barb Dorn, who had 25 years of experience as a registered nurse plus 8 years of experience working with PWS in her state of WI. Barb is also a parent of a child who has PWS. Barb was in her paid part-time position as crisis counselor only for a year, but continues to volunteer with the syndrome and write articles for PWSA (USA).

**Early 2007:** We expanded our medical crisis coverage thanks to a one-year grant from Bill and Connie Devitt in memory of Connie's sister, Colleen. This funding enabled us to hire a nurse, Prentice Lantzer, to respond to after-hours and weekend calls. Although this was a pilot program, we have been able to continue to provide this service thanks to grassroots efforts and individual donations.

**Fall of 2007:** We hired Evan Farrar full time to take David's place and to expand the crisis program. He became the Crisis Team Leader. Evan has a Master's of Divinity degree and currently is completing a Masters of



*David Wyatt passes the torch to Evan Ferrar/*

Mental Health Counseling. He has provided crisis counseling in multiple settings for over a decade. Thanks to Evan, the extensive Non-Medical Crisis Intervention section of the PWSA (USA) web site was formed, and the crisis team continues to expand its services to do earlier intervention by providing more educational materials, webinars, etc., on a variety of subjects.

There are also many volunteers and consultants we need to thank for their role in enabling us to provide these services. For years, Carolyn and Dr. Jim Loker (parents of a child who has PWS) volunteered to cover for me when I was not available to take the medical calls, and both our clinical and scientific advisory board members continue to volunteer their time to provide me with daily advice. Mary K Ziccardi and B.J. Goff, our educational consultants, are often flying around the nation to meet face-to-face with schools and care providers for consultations to avoid an expulsion and diffuse a major crisis.

We get hundreds of calls and e-mails yearly from desperate parents, schoolteachers, and care providers. There is always another mother crying and another child in serious medical crisis, and the calls are often gut wrenching. But if not for PWSA (USA), who would help these families? We cannot turn our back on these urgent needs. Please help us with the financial resources so that no family is ever turned away when they reach out their hand and heart for help. ■

## Chapter View

### *By Barb McManus, Director of Family Support*

Chapters and affiliates around the country are busy with fund-raising, awareness and support for families. PWSA (USA) is working to create more and more chapters in every section of the USA. The newest chapters are in **Texas, Tennessee and the Carolinas.**

**Texas** has created a new website for their new chapter at [www.txpwa.org](http://www.txpwa.org). Do check out this new site! **Tennessee** officially started their chapter in late 2009 with officers and board members. President Dianne Bryden and board member Angel Sims hosted the first fundraiser car wash, earning \$1,200. The **Carolinas** Chapter had an exhibit at the WRAL-Health Fair at the North Carolina State Fairgrounds in Raleigh in May.

Re-establishing **Indiana's** chapter with new goals was the topic of their first official meeting in January. The chapter received their 501©3 charitable-giving status recently. The third annual Guns and Hoses event was held in April. This is modeled after a similar event in St. Louis that pits police officers against firefighters in a series of three-round one-minute boxing bouts. Officer Patrick Phernetton (parent) hatched the idea as a way to raise money for his project to build and fund a group home for people with PWS. To promote PWS awareness month, a "Skip A Lunch" fundraiser was held in May. Next general membership meeting is planned for **October 2** in Indianapolis.

**Wisconsin** is proud to announce these upcoming events: 10th Annual PWSA-WI Golf Benefit on **August 28**; and "Special Tricks on Treating Prader-Willi Syndrome: A Behavioral

Approach" featuring guest speaker Linda Gourash, M.D. on **October 15**, (a joint event between Wisconsin and Illinois). Find more information at <http://www.pwsaofwi.org/>

Prader-Willi **California** Foundation plans a benefit concert on July 16 near San Francisco, continues to provide professional staff training to all PWS residential and vocational settings, is creating a PWS Camp, is completing a new Residential Staff Training DVD, and will host Drs. Linda Gourash and Janice Forster at their annual conference on **November 6** in San Jose.

**Utah** is busy with establishing their next medical clinic, planning their state conference in September, and working hard on fundraising to help complete the national knowledge repository software that outlines care for all families with PWS.

**July 31-August 1** will find PWSA of **Pennsylvania** presenting a Behavior Workshop with Linda Gourash, M.D. and Janice Forster, M.D. in State College. Contact Debbie Fabio for more information at [debwpwsapa@yahoo.com](mailto:debwpwsapa@yahoo.com).

In June the chapter hosted its 11th annual fundraising golf scramble. Attending were 122 golfers, 12 volunteers, six individuals with PWS and two siblings.

Thanks to members Stacy and Ryan Kramer, the **Iowa** Chapter hosted its 4th Annual fundraiser, the Anneke Kramer Softball Tournament and Silent Auction, in June. The event is a community awareness and fundraising event hosted by Anneke and her family.

On **Sept. 18 Michigan** is having a one-day conference. Guest

speakers: Linda Gourash, M.D., Greg Cherpes, M.D., and Mary K. Ziccardi. The Michigan Chapter is extending this invitation to anyone in any state who would like to attend. Please see Michigan's website at [www.pwsausa.org/MI](http://www.pwsausa.org/MI).

In May the chapter held its annual walk to promote awareness of PWS—a huge success this year. Before the walk Jessica Belanger was shopping in Wal-Mart and noticed an adult woman being pushed in a wheelchair who looked like her son. She decided to approach the woman pushing the chair and asked about what the woman in the chair had. The reply: "You've never heard of it." Jessica started to walk away, then turned back and said, "Try me." The reply: "Prader-Willi syndrome!" Jessica explained that her son, age 9, has PWS and the next day was an Awareness Walk. The woman pushing the chair and her adult daughter in the chair attended. They were thrilled and want to become more involved. Plus, Jessica has an 11-year-old, and the woman has a 12-year-old daughter who was looking for someone to connect with who understood.

To find support or a chapter near you, please go to [www.pwsausa.org/links/chapter.htm](http://www.pwsausa.org/links/chapter.htm) or call Barbara McManus at 800-926-4797. ■



Our son Andrew, age 9, was looking at a model of the Solar System. He remarked to us that if he lived on Saturn he could walk around the "rings" every day to get his stomach "down".

~ The Ward Family  
Jacksonville, Florida



*“Unless someone  
like you cares  
a whole awful  
lot, nothing  
is going to  
get better.  
It’s not.”*

~ Dr. Seuss, from *The Lorax*

### Wearing Awareness

**Jennifer Cheshire**, mom to **Ethan**, almost 2 with PWS, decided she wanted to help with fundraising and awareness. She contacted PWSA (USA) and her state chapter PWFA (Florida), and explained her idea to create awareness shirts for Valentine’s Day and PWS Awareness Month in May. The shirts she envisioned would be designed general enough to wear all year round. With the help of PWSA, two new shirt designs were born: “I (heart) Someone with PWS” and “Prader-WHAT?” The shirts were announced, including in a previous newsletter (see March-April GV, page 10), and Jennifer took in orders from around the country. From those sales, she donated \$2,000 to PWSA (USA). Shirts are still available and can be ordered by contacting Jennifer at

Jennifer\_Cheshire@comcast.net. They make great awareness tools.

### It’s Madness!

**Jim Kane** from MD, father to 29-year-old **Kate** who has PWS, conducted his annual PWS March Madness Pool 2010. His effort was no dribble. The fundraiser ‘netted’ \$2,210 for PWSA (USA). Can you hear the ‘swish?’

### Years of Thought

**John Lens**, Massachusetts father to **Hunter**, age 12 who has PWS, said he had been thinking for a long time about how to raise funds for PWSA (USA). He finally settled on a golf event, promptly named it “1st Annual Hunter Lens Golf Tournament for PWS,” and scheduled the event date for May 1, 2010. Then he went about all the details of planning. His first event netted over \$12,900. It just goes to show what years of thinking can accomplish in one event.

### Pounding the Pavement

Not one, not two, but eighteen runners in four events netted over \$14,000 for PWSA (USA).

**Kelli Parker**, Texas mom to 1-year-old **Emerson** who has PWS, tied up her shoelaces to run two half marathons: The Cowtown Half Marathon in February and the Dallas Rock and Roll Half Marathon in March.

On her donation page she wrote, “As many of you know, I train for and run half marathons. I have always wondered why, but now I know why. I am running for a reason, Emerson Lynn.” With love and support of her friends, she surpassed her fundraising goal of \$1,000, instead raising \$2,525 for research.

**Karen and Brian Gill’s** friends, **Billy Parlon and Monica Jacobo**, ran the Boston Marathon in April in honor of the Gills’ 5-year-old son **Gavin** who has PWS. It is the second time friends of theirs have entered this prestigious marathon to raise funds for PWSA (USA). The group raised over \$1,200.

**Teri Roach** from Georgia and her team (**Jim Reese, Ashley & Oliver Jones, Kathy Corchis, Jody Brown, Jenny Schneider, Andy Cobb, Melissa Emerich, Allyssa & Chandler Yount, Jaime & Eric Perez, Andrew Hodge, & Brian Connolly**) decided to take a “work together” approach to raising funds for PWSA (USA) toward research. On April 24<sup>th</sup>, they all ran the Nashville, TN Half Marathon in honor of Roach’s 2-year-old daughter, **Connolly**, who has PWS. Together, they raised over \$10,200. Teri and her husband, Andy, wrote, “If we all work together...if we all give what we can... it’s POSSIBLE!” ■

## The Obesity Society includes PWS

The Obesity Society has special interest sections which members sign up for when they join the society and which meet at their annual conference. One such section now is on Prader-Willi syndrome! Their 28th Annual Scientific meeting will be held in San Diego, October 8-12. Awareness about Prader-Willi syndrome continues to grow! ■

### Update

PWSA’s former Executive Director, **Craig Polhemus**, advises us that he is now Vice President of StatPoint Technologies, Inc. Craig served as Executive Director of Prader-Willi Syndrome Association (USA) from June 2007 through April 2009 before his resignation.

During Craig’s tenure, PWSA (USA) expanded its federal advocacy initiatives, formed the Crisis Support Teams, and strengthened ties with other organizations. In a severe financial environment, Craig worked with the Board to reduce non-research costs while preserving critical services.

According to Craig, before joining

PWSA (USA)’s staff, he had helped StatPoint launch the earlier version of its flagship statistical analysis product, Stratgraphics Centurion XV. Craig tells us that, last fall, he helped spearhead the launch of its newest version, Stratgraphics Centurion XVI.

Craig remains a member of and frequent contributor to PWSA (USA). ■



## WE REMEMBER

Dorothy Thompson died on April 9, 2010 at the age of 91. She provided the guidance, leadership and expertise to help establish one of the first designated homes for PWS in the country. She became a valued member of the Board of Directors of PWSA (USA).



Over the course of her life she was a teacher; a school social worker, assistant principal and counselor; held a job in the Detective Division of the Minneapolis Police Department; and was a director with several social service agencies. She held a Master's degree in Personnel and Guidance. She survived two husbands, one MIA in the Korean War and the other killed in an auto accident.

Karen Virnig, Minnesota, remembers:

*Oakwood Residence [in Minnesota] became a reality because of Dorothy Thompson. Back in 1980, parents of children with PWS met to discuss problems and solutions and to support one another. We often discussed building a dedicated PWS home and finally decided we would do it. We passed the hat, collected \$17.00 and we were on our way --but without a road map. And then Dorothy, the Director of Clara Doerr Residence, offered to help us. Dorothy had experience with two PWS clients and knew the problems we faced and had long advocated for a dedicated home. She assured us that opening a home was a simple task, one we could easily complete.*

*We did open the home, and because of Dorothy's insight and leadership, Oakwood became home to 15 people with PWS for twenty years. Dorothy and her son Jon Thompson located a building and helped negotiate leasing terms; Dorothy found used furniture, funding for the project and staff. Dorothy led us down the long path of opening the ICF-MR facility,*

**continued on page 14**

## Counselors Corner

### Still Answering the Call!

From its creation, a core mission of PWSA (USA) has been to answer the crisis calls of people and families living with PWS. In the early days of the Crisis Intervention program we literally answered crisis phone calls. Today crisis calls arrive as e-mails, faxes, texts and messages via Facebook and other social media sites around the country and even the world.

This growth in communication technology, along with a dramatic increase PWS awareness, changing economic circumstances, and a reputation for effectiveness contributed to a decade of dramatic growth for PWSA's Crisis Intervention Program. Since 2000, for example, requests for help from the Crisis Intervention Program have grown by 374%! Over the past 4 years crisis cases have grown by 121%. The Crisis Intervention Program now handles over 1000 crisis cases per year.

Within this overall growth, specific types of cases have increased as well including:

Type of Case	% increase since 2006
Medical	88%
Behavior	5%
Advocacy	44%
Legal	235%
Placement	17%
School Issues	139%

In response to this growth, PWSA (USA) has continued to answer crisis calls by:

- Providing trained Master's-level Crisis Counselors skilled in crisis management and knowledgeable about PWS.
- Utilizing medical, educational and behavioral consultants to assist with cases as needed.
- Creating an Extended Crisis Team to coordinate crisis response across the agency.
- Developing and updating web and written resources to prevent and respond to crisis situations.

As we move into the future, the Crisis Intervention Program remains dedicated to continuing to provide the highest level of professional crisis assistance to people and families living with PWS.

See you next time in the Counselors Corner! ■

~ Evan Farrar  
Crisis Counselor

one step at a time. She would say, "We have one more thing to do" and we would dig in and get it done. Again and again, she would say, "And we have one more thing to do." When we opened the home, Dorothy remained involved, giving advice, loving our PWS children and cheering us on. When we were in a financial position to purchase a building, Dorothy again found the perfect

building in a great location.

Dorothy's understanding of PWS was the backbone of Oakwood. Our staffing reflected the nutritional and medical needs of our children. Her experience with PWS helped in organizing a home (not a facility) for our Oakwood family. The Oakwood family loved Dorothy; they knew how much she loved them and that love was returned. Her

sense of humor was special. She would laugh at being outmaneuvered by the PWS clients – and then she would figure out ways to outmaneuver the client, always with kindness and understanding of the individual. Dorothy could give a client that 'special look' – sometimes the look was all that was needed for a wayward client to reform (at least for the moment!). ■

## Contributions

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

### Major Benefactors (\$500 and more)

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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)

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

# USA PRADER-WILLI SYNDROME ASSOCIATION

*Still hungry  
for a cure.*

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**Our Mission:** PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support 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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Medical information published in *The Gathered View* is not a substitute for individual care by a licensed medical professional.

**Deadlines to submit items  
to *The Gathered View* are:**  
**Dec. 1; Feb. 1; Apr. 1;**  
**June 1; Aug. 1; Oct. 1**

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