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

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

This issue of **The Gathered View** *is focused on the history of our organization, what we as a community with the leadership of some key individuals, have built and accomplished since our inception, not all that long ago. PWSA (USA)* ***today*** *is a vibrant and growing organization that through extensive research and support and collaboration has very positively impacted the lives of so many. But* ***past*** *is always prologue, and this history best serves to highlight the exciting nature of what PWSA (USA) is today and where we can be as we look to and work toward the* ***future****.*

~ John Heybach, Ph.D.
Chair, Board of Directors, PWSA (USA)

Dr. Andrea Prader

Dr. Andrea Prader attended our 6th National Conference in Minnesota in 1984. All who met him commented on what a kind and charming person he was.

While there, he visited what was then one of the first group homes in the nation, Oakwood Residence. Our young adults with PWS did not hold him in awe like everyone else did, so they took him by the arm and insisted he come with them and see each of their bedrooms.

At the time a big debate was how to pronounce the name "Prader." Dr Prader said it was Prah-der, so it became official.

A true pioneer in pediatric endocrinology, Professor Prader died on June 3, 2001, at the age of 81.

Dr. Andrea Prader's Presentation at the Banquet, 1984

(edited due to space limitations)

I am delighted to be with you…It is impressive to see how much progress in medical knowledge and in practical management has occurred in the 28 years since my colleagues Dr. Alex Labhart, Dr. Heinrich Willi and I have given the first short description of this syndrome. On the other hand, we realize painfully how much we do not yet know and how little we can do.

I am deeply impressed by the successful activity of your association. You were the first Prader-Willi Syndrome Association in the world which has brought together parents, doctors, other health workers and teachers... It is one of the most admirable qualities of American people to develop very powerful private initiative; to have a strong will to help each other, not to be ashamed to have a so-called abnormal child and to go public in support of these children. It is a great experience for me to see what you are doing, how you advise and help each other, how you bring together experts from various fields who can contribute to help these children, and how you have founded and organized special residences which is probably the ideal solution for many adult patients… As a pediatrician, I know how much we can learn from the observations and the experiences of parents and we hope that parents can also learn from us.



Left to right: Hans Zellweger, M.D., Gene Deterling, Vanja Holm, Fausta Deterling, Dr. Prader, Delphin (Sam) Beltran, M.D.

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Our Angel, Opal

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Prader, *continued from page 1*

Let me tell you now the history of our first observations. This takes me back to my own pediatric training and to my colleagues and friends in Zurich in the late forties and early fifties.

In 1947 I started my pediatric training in the Children's Hospital in Zurich. Guido Fanconi was chairman of the department…a famous clinician… He taught us, by his personal example, that progress in medicine depends to a large degree on precise observations. The second man in the department was Hans Zellweger…The training of the residents was mostly in his hands, and it is from him that I have learned general pediatrics during these early years. One of his main interests was muscular hypotonia in babies. If I remember correctly, we have seen together Albert, our first patient with the syndrome, when his age was about 10-15 years. In 1950, I went to New York to continue my training in Bellevue Hospital…[and] at John Hopkins Hospital in Baltimore. When I came back to the Children's Hospital in Zurich… My main efforts were to develop pediatric endocrinology and to initiate studies on normal and abnormal growth.

Heinrich Willi was nearly 20 years older than I was… in charge of the newborn nursery… a neonatologist. My friend Alex Labhart was an internist who shared my interest in endocrinology and metabolism. Our first patient, Albert, had been seen as a newborn by …Willi, later by us…when he was an adolescent, and a young adult by Alex Labhart… We recalled other obese and mentally retarded patients who because of severe hypotonia had been in the newborn nursery for prolonged periods. We began to realize that there was a group of children with identical symptoms…and a typical developmental pattern forming a syndrome which had not been described previously. We presented …at the 8th International Congress of Pediatrics in Copenhagen in 1956, where we discussed it at length with Hans Zellweger… We also presented it as a short paper at the annual meeting of the Swiss Society of Endocrinology in the same year. This paper was published in the German language in the Swiss Journal of Medicine.

[Here he gave their description of the syndrome.]

At first our paper did not stimulate interest in the medical profession. In 1961, Dr. Willi and I reported again on the syndrome at the 2nd International Congress of Mental Retardation in Vienna. In the same year and in the two following years, the first observations from this country were published by Hans Zellweger, and other publications appeared in the United Kingdom and in France. They were followed by reports from most western countries as well as Japan. I am flattered that the syndrome carries my name, but for unknown reasons, the name of Alex Labhart was dropped, and the name Willi has been frequently mistaken as my Christian name.

I have continued to see many patients with this syndrome. Usually they are referred to me for confirmation of the diagnosis…My associates and I felt frustrated over these many years because we were unable to find a clue for the cause of the syndrome and for the development of the various symptoms. Already in 1956 we were aware that even in large families there is never more than one affected child. This was a strong argument against inheritance, and it helped me to convince parents that there was hardly any risk for the occurrence of this syndrome in their future children. But, of course, the parents…wanted me to explain the cause and wanted treatment which would make these children completely normal. I always had to disappoint them. The only thing I could do was to tell them about my own experience and about what I had learned from patients.

I would like to discuss very briefly my original thoughts about the cause of the syndrome. …Since it is not a familial disorder, I considered two possibilities: One was a chromosomal defect which could not be found until 1981 when Ledbetter published his paper on the deletion of a part of the chromosome #15. The other was dominant inheritance with the assumption that each patient is a spontaneous mutation and that subsequent dominant inheritance could not be observed because the patients do not reproduce… Today, it is evident that…the great majority or possibly all of the typical patients have a partial defect of the chromosome 15. Thus a chromosomal defect appears to be the definite cause of the syndrome. This fully explains why familial occurrence is extremely rare.

I would like to conclude with some speculation about future developments… I hope, and I strongly feel, that…a substance or a neurotransmitter inhibitor will be found which will… control the appetite of our patients. I do not have to tell you that such a substance would be of tremendous help in the management of these children. It will remove the most formidable problem and would reduce the situation to mild mental deficiency with behavior problems and incomplete puberty, which are much easier to manage than the voracious appetite, which is so destructive for the patient and his family.

Finally, let me thank you again for your kind invitation, and for the stimulating experience which you have given me. ■



Left to right: Lisa Wett and Dr. Prader with others

Beneficial Effects of Growth Hormone Treatment on Cognition in Children with Prader-Willi Syndrome: A Randomized Controlled Trial and Longitudinal Study

By Elbrich P.C. Siemensma, Roderick F.A. Tummers-de Lind van Wijngaarden, Dederieke A.M. Festen, Zyrhea C.E. Troeman, A.A.E.M. (Janielle) van Alfen-van der Velden, Barto J. Otten, Joost Rotteveel, Roelof J.H. Odink, G.C.B. (Karen) Bindels-de Heus, Mariette van Leeuwen, Danny A.J.P. Haring, Wilma Oostdijk, Gianni Bocca, E.C.A. Mieke Houdijk, A.S. Paul van Trotsenburg, J.J. Gera Hoorweg-Nijman, Hester van Wieringen, René C.F.M. Vreuls, Petr E. Jira, Eelco J. Schroor, Evelyn van Pinxteren-Nagler, Jan Willem Pilon, L. (Bert) Lunshof, and Anita C.S. Hokken-Koelega

Methods: In this Dutch study, fifty prepubertal children aged 3.5 to 14 years were studied in a randomized controlled growth hormone (GH) trial during 2 years, followed by a longitudinal study during 4 years of GH treatment. Cognitive functioning was measured biennially by short forms of the WPPSI-R or WISC-R, depending on age. Total IQ (TIQ) score was estimated based on two subtest scores.

Results: During the randomized controlled trial, mean SD scores of all subtests and mean TIQ score remained similar compared to baseline in GH-treated children with PWS, whereas in untreated controls mean subtest SD scores and mean TIQ score decreased and became lower compared to baseline. This decline was significant for the Similarities and Vocabulary subtests. After 4 years of GH treatment, mean SD scores on the Similarities and Block design subtests were significantly higher than at baseline and scores on Vocabulary and TIQ remained similar compared to baseline. At baseline, children with a maternal uniparental disomy (UPD) had a significantly lower score on the Block design subtest but a larger increment on this subtest during 4 years of GH treatment than children with a deletion. Lower baseline scores correlated significantly with higher increases in Similarities and Block design SD scores.

Conclusions: Their study shows that GH treatment prevents deterioration of certain cognitive skills in children with PWS on the short term and significantly improves abstract reasoning and visuospatial skills during 4 years of GH treatment. Furthermore, children with a greater deficit had more benefit from GH treatment. ■

(J Clin Endocrinol Metab 97: 0000–0000, 2012)

PWSA (USA) International Hyperphagia Conference Jumps Research Forward

By Janalee Heinemann, Director of Research & Medical Affairs

Our international conference focused on the collaboration of renowned researchers with expertise in the study of hunger, obesity, and the uncontrollable drive to eat. This conference in Baton Rouge, Louisiana, was the product of a 1½ year collaboration with Pennington Biomedical Research Center, the world's largest obesity research center. It is not possible to give enough praise that expresses our gratitude to our hosts at Pennington for making this challenging conference possible. We had 22 national and international invited speakers and many more experts in the audience of 102 people. We also had representatives from five pharmaceutical companies attending. Many of these stayed over for our PWSA (USA) 26th Scientific Conference. **I cannot say enough about the potential for the knowledge and connections made at this conference to advance the field of research for years to come that will benefit our children and adults who have Prader-Willi syndrome!**

More details to come once we get our heads above water, but I will end with one of the positive emails we received right after the conference:

"Now that the meeting is over, I wanted to write to express my appreciation for the amazing work that the leadership of PWSA (USA) did to organize and run the Hyperphagia conference, in conjunction with the Scientific, Service Providers, and State Leaders conferences, this year. I am really hoping the conferences stimulate the scientists who attended for the first time to think more about how to study and treat hyperphagia. Let's hope now you all get some well-deserved rest - PWS-USA is fortunate to have such wonderful folks as you are helping to keep it running!"

Best wishes,
Jack A. Yanovski, M.D., Ph.D.
Chief, Section on Growth and Obesity, PDEGEN
Eunice Kennedy Shriver National Institute of Child Health and Human Development
National Institutes of Health ■

Thankful for the Past, Giving Today, Volunteering for the Future, And Getting Stronger along the way

In **November** our thoughts turn to the **PAST** and giving thanks for the blessings our family and friends have received. That goes for our PWS family, too. In this edition of the GV, you will find reflections of our past and a sense of how far PWSA (USA) has come in our 37 years of existence. Imagine a world not so long ago where parents knew of no one else in the world who was experiencing or could understand the challenges of PWS. We are so grateful to those brave parents who found each other (how did they do it?) and were so heroic and open in a time when that was not the norm.

Over the many years that followed, we bonded and attended annual conferences, where we learned about behavior management and emerging medical considerations and anxiously followed new genetics information and growth hormone trials. Because of the efforts and pioneering spirit of our researchers on PWS, the quality of life for our loved ones with the syndrome was enhanced, and **we got stronger**.

In **December**, our thoughts turn to the **PRESENT**– giving praise and giving gifts. Having the opportunity to work in the National Office has really given us a new understanding and deeper appreciation of the many people and organizations that contribute to the quality of life for our loved ones with PWS. Did you know that, like Santa's elves, the PWSA (USA) National Office staff works tirelessly for us every single day? We have researchers and medical clinicians who apply their learning, expertise, and understanding to PWS--and providers and caregivers who "get it" and help our loved ones with PWS to understand and navigate their abilities and limitations--and educators and employers who teach, support, and build self-esteem. What beautiful gifts they all are to our families.

We also have volunteers, who give so much. We owe a deep debt of gratitude to the national Board of Directors, whose members contribute an inordinate amount of time and money year after year, traveling to Board meetings and addressing issues to support our national PWSA (USA) and State Chapters. The *Gathered View* and Publications Committees are populated by volunteers and supported by countless other volunteers from around the country who contribute countless hours, writing and editing. The amazing State Leaders Team and leaders from each of the states give so much of themselves. Thank you all for the gifts of your service, time, talent, and energy.

We cannot overstate how appreciated the financial gifts are that PWSA (USA) receives throughout the year and how important they are to its mission. We thank you for your gift to our Angel Fund this year. From the fundraisers at the states, to donors and grants, to honorariums and memorial gifts–because of all who have contributed financially to support our national efforts, today **we are even stronger.**



Dale and Dottie Cooper

Approaching **January**, our thoughts turn to the **FUTURE** and New Year's resolutions. We are inspired by the gifts of today and am optimistic of even better things to come, in particular driven by the excitement and energy emanating from the state leaders. But we have to help our state leaders. My resolution for 2013 is to volunteer in my state– to stand shoulder-to-shoulder with my state leader and help propel our state in supporting the needs of the families we serve. If each of us is active in at least one state activity next year, **our states will grow stronger**. Please see http://pwsausa.org/help.

The future is bright, and we eagerly anticipate the next discovery which will emerge to positively impact the lives of persons with PWS. As our families support our states, our states support our National programs, our National programs support our families, the circle closes and the quality of life for our persons living with PWS will be further enhanced. And, **we will be stronger** still. ■

Quotation contributed by Clint Hurdle:

"Learn from the **past**, set vivid, detailed goals for the **future**, and live in the only moment of time of which you have any control: **now**."

Denis Waitley, Author and Speaker

CHUCKLE CORNER

When my four-year-old son and I took my daughter (11 months, PWS/UPD) to daycare for the first time when she was three months old, he had not had much experience with babies. He saw all the babies in the room and asked, "Where are all of their tubes?"

~Penni Grant
Huntsville, Alabama

Thank you, Jodi, for all your hard work, and good luck!

By Denise Servais



For the last seven years until recently when she felt that she needs more time with her small children, Jodi O'Sullivan was our Volunteer Fundraiser Coordinator. A great deal of the success of fundraising was due to her tireless efforts in the development of the programs. Jodi's responsibilities mainly focused on grassroots fundraising but also included helping with the development of the Angel Fund, PWS On the Move campaign and many other special projects.

One volunteer who had gotten to know Jodi well is Julie Doherty. "Jodi came in and developed how-to-guides on a myriad of fundraising events. Jodi has been there to mentor fundraisers and encourage them at each step of the process. She has a compassion for the individuals with the syndrome and for the organization, coupled with her professionalism, that has made the program the success that it is now."

Aunt to Josi, 10, born with PWS, Jodi says, "When I learned that there was an opening for a part-time fundraising position, I knew I wanted it. I wanted to give back my time and expertise to the organization that was there for me and those I loved. I was paid as a part-time position, but I worked more than full-time hours as I quickly realized the need to grow this area of support for PWSA (USA). Individuals were calling, asking for direction on how to conduct fundraisers to help the organization so it was just a matter of making sure we could assist them skillfully in the process." Jodi reported that working with members, families and chapter leaders had been truly rewarding.

When asked for any advice she could give others on fundraising or being a relative to a person with PWS, she replied, "I would say that anyone can fundraise. I watched those with significant apprehension execute incredibly successful first-time fundraisers or grow an annual fundraiser because they did not give up and they overcame their fears. We're all in this together.

"Extended family and friends have a unique role. I've said that aunts/uncles and other family tend to be silent sufferers in this life of PWS. Many times they are not in direct care of the person they care about who has PWS, but they still have potential to make a large impact in that person's life by supporting an organization like PWSA (USA). Parents can play a role by communicating what they wish extended family would do to help."

Jodi lives in Dublin, Ohio, with her husband Ryan and their three children Alec (5), Mara (3), and Rory (2). She is looking forward to spending more time with her family. ■

PWSA Bulletin Board

PHOTOS NEEDED

PWSA (USA) would like to include pictures of those with PWS in various publications and Web sites. Please send quality photos with clear facial shots to alogan@pwsausa.org along with a signed copy of the photo release. **All photos must be submitted electronically by email. Questions?** Contact Amy Logan at 800-926-4797 or at the email address.

DATABASE UPDATES

Report healthcare professionals who "get it" https://www103.ssldomain.com/pwsausa/HealthProf/input.asp

Are the professional providers in your area listed? If not, tell them they can submit their agency information here. https://www103.ssldomain.com/pwsausa/Providers/StateLookup.asp

Help us, help research! We have 1,914 people with PWS in our database. The statistical information we get from this data collection tells our researchers what research needs to be done. Are you registered? http://www.pwsausa.org/population/index.htm

WANTED - FOR *The Gathered View*

Submissions for editorial consideration: articles, stories, Chuckle Corner material, pieces by persons with PWS/siblings/grandparents/relatives/friends, pictures. Email to alogan@pwsausa.org. ■

Did You Know There Are Angels Among Us?

By Dale Cooper, Interim Executive Director

The World is full of angels--in many shapes, colors, nationalities, races and creeds. The wonder of this is that each Angel is special, has a purpose and reason in life and touches others in special ways. Occasionally, say one in 12 to 15 thousand births, we are presented with a "Special Angel" who is born with Prader-Willi syndrome. Like all Angels, they are loved and cherished by their families. Unlike most Angels, they have very special needs that must be addressed to aid in their progress, development and yes, survival.

Our "Special Angels" sometimes need the support of our "Guardian Angels" of PWSA (USA). Meet a few of our "Guardian Angels" and the services they provide.

PWSA (USA) FAMILY SUPPORT TEAM



From left to right: Mary Kay Aide, Dale Cooper, Dottie Cooper, Amy Logan, Nerely Palomino, Lin Sherman, Evan Farrar, Debi Applebee (in front of Evan), Cindy Beles, Kate Beaver. Not pictured: Janalee Heinemann, Barb McManus, Nina Roberto.

- Counseling with trained staff with advanced degrees
- Support for medical, behavioral, legal, school and placement crises
- Information and referral services

Amy Logan

(Admin/Triage Advocate) will direct your phone call or email to the person best equipped to assist you, take your order for any of our many publications and have them shipped.

Cindy Beles

(Family Support Advocate) will speak with you if your child has been recently diagnosed with PWS. Cindy is the kind, soft-spoken person who often offers new parents their first ray of hope. She will send you a "newcomer packet" and can assist you to obtain the following:

- Parent to Parent support with a trained parent mentor
- Extensive age-appropriate materials provided at no cost
- Free packet for physicians which includes a medical overview of PWS (DVD) and a Growth Hormone booklet.

CRISIS SUPPORT:

Once your needs are determined, you will be directed to a member of a world-class consulting team dealing with family and crisis support.

Janalee Heinemann

(Director, Research/Medical Affairs) is a conduit of information from the vast medical community dealing with PWS to provide support and information to our PWS families regarding medical questions and treatments. She directs the research projects PWSA (USA) supports nationally and internationally and is vice-president of the International Prader-Willi Syndrome Organisation. Parent of an adult son with PWS, she has a Master's in Social Work.

Evan Farrar

(Crisis Counselor) has worked with PWSA (USA)'s crisis program since 2007, helping parents and professionals address a variety of crisis situations including at school, home, and in residential placements. He also develops new resources and handouts to prevent crisis situations from developing and to spread awareness about the support needs of people and families living with PWS. He has a Master's in Mental Health Counseling.

Kate Beaver

(Alterman Crisis Counselor) has served as the Alterman Crisis Intervention Counselor (CIC) for PWSA (USA) since 2006 and is Crisis Team Leader, helping to coordinate and develop PWSA (USA)'s crisis program and services. Kate has worked with hundreds of school-related crisis cases as well as many other types of situations. Kate has a Master's in Social Work and a daughter with PWS.

Nina Roberto

(Family Support Counselor – Spanish) handles calls from our national and international Spanish-speaking population. She provides support to our Hispanic PWS community, using our extensive publications available in Spanish and communicating the broad spectrum of what services PWSA (USA) offers. Her son has PWS.

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Angels, *continued from page 6*

ADVOCACY

Advocacy is provided on behalf of students with PWS including: information about IEPs and PWS-specific school strategies; a DVD for educators; help for those living with PWS to connect with needed benefits and services including SSI and essential therapies; support for public policies that increase services/opportunities for people with PWS & their families; and research.

DID YOU KNOW WHAT THE PWSA (USA) OFFICE PROVIDES?

Did you know –

The National PWSA (USA) Web site is used by medical professionals worldwide for the most comprehensive and up-to-date database of medical information?

Did you know –

The National Office receives over **600** communications per month seeking assistance and hundreds more requests for information about PWS?

Did you know –

The National Family Support Team receives calls from about **15 to 20** families each month that have just received the diagnosis?

Did you know –

The PWSA (USA) Library has **30**-plus up-to-date PWS publications available on such topics as growth hormone, early childhood, education, work setting, physical therapy, to name only a few?

The office also has important behind the scenes "Angels". Without **Debi Applebee** (Business Manager) and **Lin Sherman** (Accounting & Systems Assistant), how could the National Office operate?

DID YOU KNOW HOW ALL THESE WONDERFUL THINGS ARE FUNDED?



The Angel Fund Campaign!

By now you should have received an important piece of mail from PWSA (USA), the Angel Fund campaign card. On your Angel Fund card, you will see outlined some of the many ways PWSA (USA) works to make your life easier. Having a healthy and strong organization is essential to the well-being of those who have and are affected by PWS.

The Angel Fund campaign is the national Association's largest single fundraiser. Donations from this campaign help to meet the growing needs of our families and the professionals who want help in caring for those who have PWS. For so many, this lifeline of an organization has been an anchor in a storm and a significant part of their life story. We ask you to support it.

As PWSA (USA) works to meet your needs regarding PWS, please realize how vital you are in the equation and make a tax-deductible contribution to the Angel Fund campaign. So many families need our help; PWSA (USA) needs yours. If you have not received your Angel Fund card, please visit our Web site to donate at www.pwsausa.org. ■

Gracie Blue Eyes

On September 7, 2001, Grace Elaine Todd was born in Lexington, Kentucky. Right away the parents, Jonathan (J.T.) and Joy, knew there was a problem. But what? A few days later Troy, Grace's dad's best friend, died at age 26 of an undiagnosed genetic disorder. And then came 9/11. It was a turbulent, emotional time.

Baby Grace didn't cry, was lethargic, and didn't have either normal muscle tone or sucking reflex. The tests for Prader-Willi in the first few weeks of Grace's life came back negative. When she was two, J.T. and Joy moved back to Ohio, and she was re-tested. This time the diagnosis of Prader-Willi was positive.



Now 11, Grace loves horses and has been riding for the past six years to build strength. She likes playing with American Girl dolls, putting puzzles together, swimming, and playing with the dogs in her neighborhood. And she loves her younger brother, named Troy. Her favorite TV show is The Biggest Loser. She understands the food implications of her syndrome, but the refrigerator is kept locked to avoid temptation.

J.T. is a guitar player. He wrote and recorded the song "Gracie Blue Eyes" in tribute to his daughter and to tell her how much he loves her, just as she is. He also wanted to be able to help other kids like her.

The song was released this past summer to iTunes and Amazon.com. It can be downloaded for 99 cents, and all the proceeds will go to PWSA (USA). He hopes for 10,000 downloads in the next twelve months. The song may also be purchased through his Web site www.graciebluеeyes.com for 99 cents. You can help reach that 10,000 goal!

Visit his Web site, too, for the ten Todd House Rules. ■

Imagine

IMAGINE –
There are no PWS educational materials for schools, medical staff, parents, supportive living staff, and relatives

IMAGINE –
There is no program of support for new parents of a child with PWS, and they have to hang on the edge of despair of the unknown for years

IMAGINE –
There are no specialized supportive living homes for PWS

IMAGINE –
There is no one to call when you have a medical emergency or have specialized PWS medical questions

IMAGINE –
There is no counselor to call when you and your child need help with school, SSI, insurance denials, placement, the law, etc.

IMAGINE –
There is no one you know who has a child with PWS, and there are no state support groups, no conferences, and no email groups where you can meet other parents to share your hopes, fears and questions

IMAGINE –
There is no growth hormone nor psychotropic medications to help your child, and no one to educate and advocate for their safe and effective use

IMAGINE –
There was no one educating large numbers of professionals on PWS at medical conferences

I CAN IMAGINE –
Because that was our world 30 years ago – before the growth of PWSA (USA) and state chapters.

~Janalee

Historical Dates for Prader-Willi Syndrome Association (USA) and PWS: 1956-1980

1956 Drs. Andrea Prader, Heinrich Willi and Alex Labhart in Switzerland notice a grouping of symptoms in clinic patients and publish their findings in a journal.

1975 "Prader-Willi Syndrome Parents and Friends", soon renamed "Prader-Willi Syndrome Association", was established by Gene and Fausta Deterling, parents of a son with PWS, with the support of Dr. Vanja Holm, of the Child Development and Retardation Center in Seattle, Washington.

1977 PWSA officially incorporates, with Gene Deterling as first President, and Delfin Beltran as first Chairman of the Board.

1978 The newsletter, *The Gathered View*, PWSA's first publication, was followed by a booklet entitled "Prader-Willi Syndrome, A Handbook for Parents", by Shirley Neason (also editor of the GV).

1979 The first annual National Conference was held in **Minneapolis, Minnesota.** 165 adults, 15 with PWS, and 15 siblings attended.

1980 Marge Wett appointed as first Executive Director, office in her house. Delfin Beltran, M.D. becomes second national President, and Richard Wett, M.D. second Chairman of the Board. National Conference at **Hyannis Port, Massachusetts.**

Janalee Heinemann 15 years of employment, 30 years of service



By Dottie Cooper

September 15, 2012, marked Janalee Heinemann's 15th anniversary of employment with PWSA (USA), plus another 15+ years of volunteering – over 30 years of service to our families.

Janalee represents herself as "an ordinary person, who was able to accomplish extraordinary things out of need and passion." Indeed she has. Janalee completed high school after having three kids, worked part time while going to Junior College, then College, and eventually earning a Master's degree in Social Work. Her career before PWS included ten years as an oncology medical social worker, five as a hospice social worker, and six as a child abuse and neglect social worker; she received numerous humanitarian and service awards. For the past 14 years Janalee has been the volunteer leader of the Homicide Bereavement Support Group in Sarasota.

When Janalee met Al Heinemann, who had custody of Sara, 6, and Matt, 7, and they decided to blend their families, she also met PWS. Dr. Hans Zellweger, one of the pioneers in PWS research, had diagnosed Matt at three months. Matt had typical symptoms – hard-to-feed floppy baby who then ate too much and went from chubby to extremely obese. Janalee recalls, "*We had no clue what to do.*"

At that time there was almost nothing published on PWS--a few paragraphs in medical libraries. The first conference they attended was the third national conference in Boca Raton, Florida. "*I was in school then and we had little money, but we were so desperate for any crumb of knowledge that we stayed in a tent. We realized that when we came home we needed to lock up the food. This made us sad, but I still remember Matt thanking us and saying* ***'I try and try, but my hand reaches in the refrigerator and I can't stop it.'*** "

Janalee and Al then established the Missouri chapter with meetings initially in their home. Over time, the need for supportive living for adults with PWS in Missouri led them to fight to get such homes started. Their group went to the state capitol to testify. Only one person on the bus where they rehearsed had ever been to the capitol before–in eighth grade. When it was time for the PWS presentation, the families poured out their stories. The panel was so moved that PWS was the only funding request of this type approved that year.

As part of her Master's study, Janalee and daughter Sarah wrote the sibling book, "*Sometimes I'm Mad – Sometimes I'm Glad*", still in circulation today. At the second conference they attended, Lota Mitchell encouraged her to allow PWSA (USA) to publish it. She began writing personal stories for the Missouri newsletter she and Al published for years. No one else then was writing on a personal level about PWS and its impact on the family. Those writings brought national attention. From 1986-1991 she was on the PWSA (USA) Board of Directors; in 1991 she became President of PWSA. In 1993 Janalee was asked to be an international (IPWSO) delegate and board member.

In 1994, she stepped down as national president and from the IPWSO board, as well as from the Missouri

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Historical Dates for Prader-Willi Syndrome Association (USA) and PWS: 1981-1989

1981 Deletion in long arm of chromosome 15 was identified by David Ledbetter, M.D. as the cause of many cases of PWS. National Conference at **Boca Raton, Florida.**

1982 National Conference at **Overland Park, Kansas.**

1983 Deletion in long arm of chromosome 15 was determined by Merlin Butler, M.D. and colleagues to come from the contribution of the father to the chromosome pair. National Conference at **San Diego, California.**

1984 First salaried staff in addition to the Executive Director is hired. National Conference at **Minneapolis, Minnesota.** Dr. Andrea Prader himself attended.

1985 First Scientific Conference held, in conjunction with the annual national conference. National Conference at **Windsor Locks, Connecticut.**

1986 National Conference at **Sacramento, California.**

1987 National Conference at **Houston, Texas.**

1988 PWSA gets its first official office in Minneapolis, Minnesota. (Until then it had been in the Wetts' house.) National Conference at **Louisville, Kentucky.**

1989 Maternal uniparental disomy, or UPD (meaning both of the 15th chromosome pair came from the mother) was identified by Rob Nicholls, Ph.D. and colleagues, accounting for the cause of most of the non-deletion PWS cases. National Conference at **Calgary, Alberta, Canada.**

Janalee, *continued from page 9*

chapter. Janalee and Al were moving to Florida–sailing off into the sunset. By then Matt was established in a good PWS supportive living home, Sarah was in college, and their other kids were grown and married. They felt they had done their time.

Their respite was short. When Janalee found that the Florida chapter needed help with the 1997 conference, she felt compelled to volunteer as co-chair. In the meantime, the national office of PWSA (USA) was struggling. Janalee was about to accept the offer of a job she wanted when she received a call from Jim Kane, chair of the PWSA (USA) board: would she accept the position of Executive Director? Certain she would not leave her new home, the board voted to move the national office from St. Louis to Sarasota. Janalee accepted because of her personal passion for families struggling with the syndrome.

Janalee started the office with only one other employee. As Executive Director she did it all–helping families in crisis, working with medical professionals, writing. There was one brochure on PWS. Janalee's vision was that "one day" they could have a packet with various brochures and articles that could be sent out.

Janalee served as PWSA (USA) Executive Director from 1997-2007 and grew the organization tremendously over those 11 years, working to find funding and volunteers. *"PWSA (USA) was built on the backs of volunteers – we made it happen, one day at a time."* Eventually David Wyatt came to help with crisis counseling. Al was always supportive through the many long hours, son Tad Tomaseski took over the Youth program for three national conferences and created the PWS rap songs, daughter Sarah led sibling programs at national conferences, and all did whatever needed to be done.

When I asked Janalee what she thought the greatest accomplishments were during her tenure as Executive Director, she said:

• Literature – the library of information that we now have in booklets, brochures, other publications and DVDs, and the vast amount of information available on our Web site. We have more information on PWS than any other source in the world, and much has been translated into many different languages to help families and professionals all over the world.

• The Crisis program which has saved so many lives.

• Getting Growth Hormone approved and then accepted by physicians.

• Our strong relationship with researchers and physicians.

Eventually Janalee began to think about transition – growing the leadership and stewardship of the organization. In 2007 Janalee stepped into her current role as Director of Research and Medical Affairs, working with the PWSA (USA) Clinical and Scientific Advisory boards on a daily basis. She coordinates and often co-writes with physicians the medical information distributed and collaborates with researchers.

She has presented at many national conferences, state meetings, and other conferences and has traveled extensively to so many countries–presenting at conferences in Italy, New Zealand, Israel, Taiwan, China, Japan, Mexico, Chile, Brazil, France, Romania, and Armenia. She was called back into service at IPWSO, serving as Vice-President since 2009. One vivid memory for her was a last-minute scramble for her and our dear deceased Pam Eisen to get materials and make a presentation to top government officials in Taiwan to get growth hormone approved for their country – and they were successful! Today PWS organizations are in over 90 countries, and Janalee continues to receive messages from people she helped 20 or more years ago.

As an integral part of the management team at PWSA (USA), Janalee continues to support our growth as an organization while we experience another period of transitional leadership. She remembers going through this before.

"There was no map, no one charting the course. We created our own vision and direction and forged ahead. A good thing was as a freestanding non-profit organization we were free (and still are) to do whatever we thought was right and what we needed to do to help our families.

"Life happens. We all have brick walls – you either let them stop you or find ways to climb over them or break them down. In the early days, we just had to climb higher on each other's shoulders or carry a bigger hammer to break down those walls."

Obviously, they did not stop Janalee. ■

Historical Dates for Prader-Willi Syndrome Association (USA) and PWS: 1990-1999

1990 National Conference at **Salt Lake City, Utah.**

1991 "800" line service begins. First International Conference held in Holland. First report on growth hormone therapy for PWS was made by Moris Angulo, M.D. DNA methylation analysis was developed by Dan Driscoll, M.D. National conference at **Lincolnwood, Illinois.**

1992 Mission statement formalized. PWSA becomes PWSA (USA). National Conference at **Philadelphia, Pennsylvania.**

1993 National Conference at **Scottsdale, Arizona.**

1994 National office relocates to St. Louis, MO. National Conference at **Atlanta, Georgia.**

1995 National Conference at **Seattle, Washington.**

1996 National Conference at **St. Louis, Missouri.**

1997 National office relocates to Sarasota, Florida. National Conference at **Orlando, Florida.**

1998 National Conference at **Columbus, Ohio.**

1999 National Conference at **San Diego, California.**

The Swim Coach and the Silent Waltz

by Lisa Peters

"Hello, er yes," I said rather nervously over the telephone, "I am looking for some swimming lessons for my son this summer."

"Okayyyy," said Beth, our local swim coach, who owns a pool and for many years has taught all of the neighborhood children how to swim. I closed my eyes and waited for the next inevitable question.

"How old is your son?"

"Well, um, er..." I replied uncomfortably.

How do I do this? I wondered to myself. *How do I explain why it took so long for me to consider swimming lessons for Nicholas? How do I explain about Nicholas? How do I tell her about his diagnosis? But more importantly, will she be willing to teach him how to swim?*

"He, um, has very low muscle tone and struggles with issues related to coordination." My pathetic attempt to try to educate her on some of Nick's challenges.

"Okayyyy, how old is he?" she asks again patiently.

"He's ten," I replied and felt my cheeks start to redden.

"No problem," she said, "we will probably need to place him in a class with younger children."

Oh no, I thought to myself, she does not understand. Inside my head, I pictured a school of flopping, screaming children splashing her pool into a seething whirlpool of doom and destruction. I could see the slow moving Nicholas overcome by a monstrous wave of blackened pool water.

"Perhaps this isn't going to work," I answered, frustrated with my inability to explain what Nicholas needed.

"I have taught several children diagnosed with special needs to swim," she replied trying to assure me she had done this before. I started to breathe a little easier.

How many children will be in the class?" I asked.

"About 6 or 7, but I would need to take a look at him in the water first."

More images of a floundering Nicholas gulping mouthfuls of chlorinated water.

"I don't know," I said, "I am not sure this would be a suitable class for Nicholas."

Again my fear and inability to communicate.

"Once I see him in the water, I will have a better idea of what he needs," she reassured.

"Oh," I said feeling a little better but still picturing Nicholas and Beth floating out of the pool on a giant kid-made tsunami.

"Why don't you just bring him by on Monday," she said. I could sense she was getting frustrated with me.

I hung up the phone and questioned the value of my degree in communications.

As the days passed, Nicholas looked forward to his first swimming lesson.

We all tried to prepare him for the arrival of the big day.

"Nicholas, you're going to love swimming in the pool, it's so much fun," Weston said, anxious to reassure his younger brother.

"I am?" Nicholas asked.

"You are!" Weston answered.

"Beth is soooo nice!" I told him enthusiastically.

"She is?" Nicholas asked.

"She is!" I answered.

Monday finally arrived and Nicholas awoke. He donned an old pair of Weston's "surfer dude" swim trunks, anxious to begin his new adventure.

We arrived at Beth's pool. A mass of tiny, wet children was exiting the churning pool, laughing and shivering. What was I *thinking?* I thought to myself as they clamored around me and Nicholas looking for their towels. It wasn't long before each chilly child found their mother and headed home. The pool and surrounding area became quiet, the water stilled. A tanned, gray-haired woman walked up to Nicholas and extended her hand.

"Are you ready, Nicholas?" she asked.

"I am!" he replied enthusiastically.

continued on page 12

Historical Dates for Prader-Willi Syndrome Association (USA) and PWS: 2000-2012

2000 Growth hormone has now become a standard treatment for PWS, and FDA approves its use for PWS. National Conference at **Pittsburgh, Pennsylvania.**

2001 National/International Conference at **Minneapolis, Minnesota.**

2002 National Conference at **Salt Lake City, Utah** (first "mini-conference", providing child care only up through the age of eight).

2003 National Conference at **Orlando, Florida.**

2004 National Conference at **Huron, Ohio.**

2005 30 year Anniversary of Prader-Willi Syndrome Association (USA). National Conference at **Orlando, Florida.**

2006 National Conference on **Grand Island, New York.**

2007 National Conference in **Dallas, Texas.**

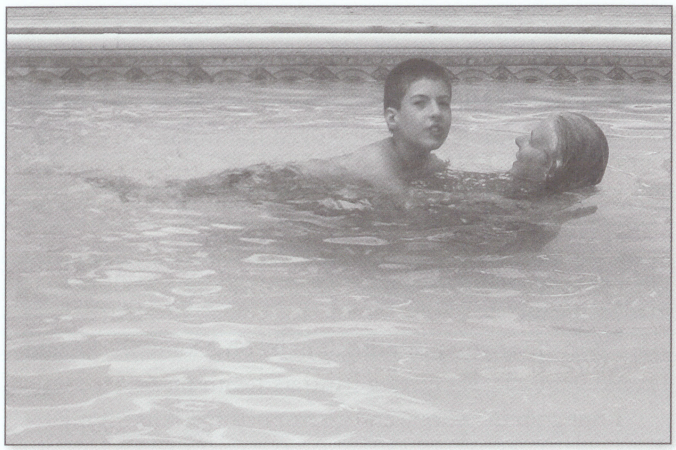
2008 National Conference in **Milwaukee, Wisconsin.**

2009 First International Hyperphagia Conference, held in **Washington, D.C.**

2011 National Conference in **Orlando, Florida.**

2012 Second International Hyperphagia Conference, held in **Baton Rouge, Louisiana.**

Swim Coach, *continued from page 11*



A tranquil waltz in water performed by Nicholas, age 10 and his coach Beth.

She held his hand and led him to the edge of the pool. They did not speak.

Within minutes, Beth had the sensory-sensitive Nicholas in the pool and smiling. I sat stunned on the side of the pool. I watched as these two strangers silently connected. They glided through the water in an effortless motion of trust and mutual respect.

Beth pulled Nicholas slowly around the pool. He let her gently guide his body.

"Ok, now try to put your legs behind you," she instructed softly, and the compliant Nicholas allowed his body to float. They swirled silently together through the water from one side of the pool to the other, softly, gently, quietly. Nicholas bonded easily with this patient woman. There were no dangerous waves or whirlpools. There was no fear or anxiousness, no difficulties communicating; submerged in the clear, tranquil water of the pool, they were dancing. As I watched their graceful movements together, I could almost hear the music.

This calm, silent scene was a sharp contrast to the loud, nervous noise inside my head. My needless worry seemed silly to me now, and I wondered if perhaps the word "disabled" was a more accurate description of me. I was the one who was awkward and afraid. I was the one who had trouble trusting.

I was the one who couldn't dance.

It is my son, not me, who hears this inner music, a song that connects him silently and fluidly to others in this world who also vibrate to that beautiful sound.

As I watched my son dance to this silent music, I realized I have a lot to learn. ■

Chapter View

Conferences, Conferences!

Michigan invited all to its one-day conference on September 15. Featured speakers were Janice Forster, M.D., Developmental Neuropsychiatrist, and Linda Gourash, M.D., Developmental and Behavioral Pediatrician.

Florida held its Fall Conference October 12-14. Speakers included Evan Farrar, PWSA (USA) Crisis Counselor, Mark Kamleiter, Esq., Education Law and Advocacy, and John Adelinis, who discussed managing behaviors.

Prader-Willi **California** Foundation's 2012 Annual Educational Conference *Putting the Pieces Together* was on November 3. Topics included medical management, menus, research on PWS and teaching social thinking skills. Suzanne Cassidy, M.D., from the PWSA (USA) Scientific Advisory Board, was a speaker.

Ohio planned a mini-conference on November 10. First session was "Creating the PWS IEP", with speakers Mary K. Ziccardi, Regional Director, REM Ohio, and Joshua Mason, Inpatient Teacher at The Children's Institute. Second session was specific to Ohio and its waiver system.

TEXAS PWS ROUND-UP: Annual Conference will be held on Saturday, February 9, 2013 from 8:00 AM to 5:30 PM (CST). ■

¡HOLA!

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

¡Hola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi. Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que nececitan informacion y ayuda. Les quiero directar a www.pwsausa.org donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718)846-6606 o email, ninaroberto@verizon.net. ¡Hablamos pronto! ■

Write it, Share it, Post it, and Use it: Tips for Creating a Positive Behavioral Plan



By Evan Farrar and Mary K. Ziccardi

Challenging behaviors are a feature of Prader-Willi syndrome (PWS). When responding to these behaviors, it is important to remember that negative consequences (which include responses such as shaming, threatening to take things away, etc.) are not typically effective in helping a person with PWS to manage their behavior more appropriately. The cognitive and impulse control deficits caused by PWS inhibit the ability to understand what a negative consequence is trying to teach so it does not alter future behavior. Most often it leads to a power struggle which rarely helps to improve a challenging behavior. So what does work?

People with PWS are successful behaviorally when a positive behavioral strategy is developed and consistently employed. This is a tried and true strategy that is effective for people with PWS of all ages.

A positive behavioral strategy uses incentives and rewards to move a person successfully through the day by mixing preferred and non-preferred activities. For example:

> If Tommy, who has had a problem getting up and ready for school in the morning, is able to accomplish this task in the designated half-hour time period, he will receive a sticker. If he earns 10 stickers during the week, he will be able to pick a movie he wants to watch.
>
> In this example, Tommy's desire to watch a movie of his choice is used to motivate him to successfully accomplish a non-preferred activity – getting ready for school on time.

How to get started?

1. **Create a list of challenging behaviors**–the behaviors you want your plan to help change.
2. **Prioritize the list** by identifying one or two behaviors to be addressed first. Behaviors that are most disruptive could be at the top of the list. Or you could start with behaviors that will improve more quickly so the person begins to earn rewards and feel successful more quickly, which can increase ongoing commitment to the plan.
3. **Create a list of rewards or incentives** that will motivate the person. When possible, invite the person with PWS to help you create this list. This offers a good opportunity also for you to begin to explain the purpose of the new plan you are creating in a positive way.
4. **Create the plan** for the initial behaviors you want to target. As with the example above, create a strategy for each challenging behavior that includes the preferred behavior you want to encourage and how and when the reward will be applied to motivate the behavioral change you want to help create. Pay attention to how often the reward is applied. For some people a weekly reward works well, but for others the positive reinforcement might need to be daily or even hourly. Find what works for the person you are supporting!

Tip: Before beginning step three, do some research. You can find many helpful resources on positive behavioral strategies by searching online. If you are working with a counselor, social worker, or school professional, they also might be able to assist you with ideas. And don't forget to contact PWSA (USA) for helpful behavioral resources (video and written) for supporting people with PWS. The more you know, the better your plan will be!

Once you have a **written plan** designed, **share it** with the person with PWS and others involved in their life so they understand the expectations of the plan and how it works, **post it** where you both can see it every day, and **use it** consistently. A good positive behavioral plan is an essential foundation for diminishing challenging behaviors experienced by a person with PWS. ■

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The Gathered View Survey Results

Special thanks go to all who took the time to complete our recent *Gathered View* survey. To summarize the results, most respondents were parents, women to be specific, from the USA. The overwhelming majority of those surveyed felt the length of the newsletter, as well as the frequency of delivery, were just right. Research reports, personal stories, medical features, and advice and information articles were rated as the most valuable topics.

We appreciate your feedback on suggested improvements. We are implementing one in this issue – information about the resources available for our Spanish-speaking families. Another suggestion, to regularly feature an article written by an adult with PWS, will be seen in upcoming issues. **Thank you for letting us know how much *The Gathered View* means to you.** ■

USA
PRADER-WILLI SYNDROME ASSOCIATION
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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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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see page 7...

PWS: Yesterday, Today and Tomorrow

In the beginning was darkness and drear.
No one had heard of Prader-Willi.
If you had described a syndrome like this,
People would say you were silly.

Then came along Swiss doctors observant
Named Prader, Labhart and Willi.
They knew the symptoms they saw in some kids
Had just not occurred willy-nilly.

They wrote up their findings in careful detail
To publish in nineteen hundred fifty and six.
Their article described the characteristics so well
But the problem no one knew how to fix.

Children kept dying of obesity so great.
Help was nowhere in sight
Until from University of Washington at Seattle
There came a glimmer of light.

Vanja Holm, our "Mother Superior" and tiny M.D.,
A big job was put in her hand,
To run an interdisciplinary clinic for PWS,
The very first one in the land.

Next on the PWS history channel we find
The Deterlings—Fausta and Gene.
Curtis, their son, was diagnosed Prader-Willi.
Their confusion and grief were keen.

Across the continent Shirley Neason
Heard the same about Daniel, her son.
Their forces they joined to help other parents.
The formation of PWSA had begun.

Years have gone by, and we learned of the cause
Long questioned by husbands and wives.
Deletion, disomy, imprinting—all three—
Genetic culprits that disrupted our lives.

Our focus has changed to the **Present** now,
To the folks who are making it work,
To those who toil day after day
And never their duty do shirk.

Group homes especially for folks with PW
And growth hormone have appeared on the scene.
Many grew slimmer, or never got fat,
And a few are really quite lean.

Psychotropic meds and management techniques
Now help stop behavioral fits.
Behavior's much better than ever before
But still there are tantrums and snits.

Doctors and parents and researchers, too,
The national office of PWSA,
Chapter leaders and group home providers—
All helping to find the way.

Winning the fight against hunger and fat
Are the goals of the **Future**, it's true.
Who will the leaders of that **Future** be?
Will it be you, or you, or you?