PWSA (USA) Has a New Executive Director!

The Board of Directors of PWSA (USA) is pleased to report the selection of a new Executive Director for the organization. Her name is Kim Weinberg, and she comes to us with twenty years of experience in non-profit administration and a high level of compassion for individuals with special needs and their caregivers and families. This appointment, effective October 26, 2009, follows a comprehensive national search to identify a leader to guide the Association into the future.

When asked to tell about herself, this is what Kim wrote:

My roots are in the suburbs of Philadelphia, but I transplanted to Sarasota three years ago.

I have a long history of working in the non-profit sector. After graduating from the University of Hartford, I started as a Director of Volunteers with the American Red Cross and quickly knew that working in social services was my true calling. I continued my education at Eastern University to complete a Masters of Science in Non-Profit Administration. My career path led me to the Association for Developmental Disabilities as Executive Director for almost nine years; this was a most meaningful and life-shaping time for me. I look forward to bringing the experiences and knowledge that I have gained to PWSA.

It doesn’t surprise anyone who knows me that I have stayed working with those who have special needs or challenges all of my professional life because I have been involved since my youth with volunteering and service organizations. This aligns closely to my personal mission and is reflected in my two favorite quotes: “You and I can change the world and the rest will then follow” (Einstein) and “If you have a chance to accomplish something that will make things better for people coming behind you, and you don’t do that, you are wasting your time on Earth.” (Roberto Clemente).

In my free time, you can find me working on my golf game and enjoying all that makes Sarasota so unique. I am a diehard Eagles fan who has learned to cheer quietly in Florida.

Deserving the gratitude of all is Evan Farrar, who assumed the role of Acting Executive Director during the search for a dynamic and well-qualified individual to fill the role permanently. Well-deserved thanks also go to the rest of the staff who have been handling the added demands of this difficult period with the best interests of PWSA (USA) at heart.

Kim joins a dedicated professional staff, committed to the mission of serving those affected by Prader-Willi syndrome.

Volume 34, Number 6 ~ November-December 2009 ~ Our 34th Year of Publication

Please welcome Kim to the Prader-Willi syndrome family!

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**Ask The Experts – Those Living With The Syndrome**

Our PWSA (USA) Advisory Board (adults who have Prader-Willi syndrome) met October 17-18th in Sarasota, Florida. They went high tech this time and used Skype so Abbott Philson could attend virtually. Here are some of their reflections on questions asked.

**What makes you happy?**
- Work, family life, personal life
- Talking to my family on the phone and when I earn my program
- To have friends, my work, my own place to live, and family visits with parents. Lots of Special Olympic sports and riding horses
- Quitting smoking, work, and having the third floor (of the family's home) to myself. My dogs and family
- Having a regular job that is going well. Living in a supported living arrangement and having my three pets
- My dad being sober, losing weight, having a puppy, and my staff
- Riding horses, playing music/playing sports, animals and having structure

What are the issues in your life where you need better control?
- Spending money
- Time management
- More exercise and losing weight
- Eating right and exercising more
- Being able to cope better with going off the "norm"/change/flexibility
- With my "stuckness", difficulty with transitions/letting go of my rigid routines
- Staying on my diet/not slipping or sneaking

Here are a few of my personal goals:
- Concentrate on controlling my weight while I am on home visits.
- To do more exercising and to do well with weight loss
- Continue not to smoke. Keep my weight down. Spread awareness.
- Keep my weight management under control and continue my support with the local chapter. Improve time management skills.
- To get my own house, losing more weight, getting a new job. Getting a new roommate

**What do you want others to know about living with Prader-Willi syndrome?**
- We are always thinking about food. The thought never goes away.
- Learn to keep the refrigerator and cabinets under lock and key and keep the key with them/you at all times.
- Keep food out of my reach and keep me healthy.
- I am always feeling hungry. I will never be able to control my food intake.
- I want to keep weight under control—it is very hard but possible.
- I want to be gainfully employed.
- Be open to different living situations.
- Keep us safe from harm to our bodies.
- My (group) home is like a family. My own family is very close.
- I wanted to be treated with respect, like a person, not a zoo animal.

Best wishes to all the members of the Prader-Willi syndrome family, near and far, for a Merry Christmas, a Happy Hannukah, and a safe holiday filled with the joy of family and friends.

Kate Kane, Brook Fuller, Andy Maurer, Lauren Lange, Conor Heybach, Shawn Cooper, and Abbott Philson on the computer screen.
Medical and Research View
New Alert regarding Prader-Willi Syndrome and the H1N1 Influenza (Swine Flu)

The symptoms of both the novel H1N1 and seasonal influenza viruses are basically the same, but we have seen in PWS more sudden and serious respiratory complications and two deaths due to the H1N1. Because in PWS: 1) we cannot always use fever and pain as an indicator of severity of illness; 2) there is a higher incidence of respiratory problems due to asthma, obesity, weak muscle tone, etc; and 3) the possibility exists of central adrenal insufficiency (CAI), a parent should have their child or adult with PWS evaluated by their primary care provider if there are concerns about breathing, hydration, or appearance. An extra concern with PWS is that H1N1 can have a very rapid onset of serious respiratory complications, so the best protection for the child/adult who has PWS is to get vaccinated as soon as possible!

Flu symptoms for both types can include
fever*    cough
sore throat    runny or stuffy nose
body aches    headache
chills    fatigue
sometimes diarrhea    and vomiting

*It’s important to note that not everyone with the flu (especially if they have PWS) will have a fever.

Emergency Warning Signs
In Children:
Fast breathing or trouble breathing
Bluish skin color
Not drinking enough fluids
Not waking up or not interacting
Being so irritable that the child does not want to be held
Flu-like symptoms improve but then return with fever and worse cough
Fever (less likely with PWS) with a rash

In Adults:
Difficulty breathing or shortness of breath
Pain or pressure in the chest or abdomen
Sudden dizziness
Confusion
Severe or persistent vomiting (less likely with PWS)

Keep the PWSA (USA) Medical Alert booklet and this article with you or your child’s caregiver at all times. For the full article on what to do for the H1N1 virus, go to www.pwsausa.org or call 800-926-4797 for a copy.

Janalee Heinemann
Director of Research & Medical Affairs

Results of the Skin Picking Survey
“A Comprehensive Analysis of Skin-picking in Prader-Willi Syndrome”

By Jessica Morgan, B.A., Research Assistant, Department of Pediatrics at the University of South Florida with Eric Storch, Ph.D., University of South Florida

The survey results are in, and the results have been analyzed! Thanks to those who participated in the survey!

Sixty-seven parents completed the survey, and their responses were used in data analysis. The survey showed that about 96% of parents who participated in the survey said that their child showed skin-picking behavior. Of these, approximately 42% were picking at levels that would be considered clinically significant, according to the Skin Picking Scale which was included as part of the survey.

Many different locations were targeted, most commonly the hands, legs, and face. Although scabs, itchy skin, and insect bites were frequent targets of skin-picking, approximately 60% of participants noted that their child picked at healthy skin as well. Parents most commonly reported that their child used the fingernails or fingers to pick the skin.

More than half of the sample reported antecedents of being at school, waiting, watching television, being in the car, and lying in bed. Consistent with previous findings (Didden, Kozlilius, & Curfs, 2007), skin-picking may serve as self-stimulation during times of relative inactivity. Skin-picking most often caused minor sores and bleeding. Infections and scarring were also common consequences of skin-picking, and 10-15% reported deep craters or disfigurement due to skin-picking.

Severity of skin-picking behavior correlated with overall severity of anxiety. Although this link doesn't show cause and effect, reducing anxiety may be associated with reduced skin-picking. Skin-picking severity also showed positive correlations with impulsivity, inattention, and opposition. Youth with more severe skin-picking behavior also showed greater deficits in developmental functioning in general, as well as greater problems in health-related quality of life.

Our research group is currently examining a modified behavioral intervention targeting compulsive behaviors among youth with PWS. Preliminary results indicate that Habit Reversal Training and exposure components paired with contingency management

Skin-Picking, continued on page 4
Medical and Research View

Skin Picking, continued from page 3

strategies (i.e., rewards for good behavior) are useful in addressing compulsive skin-picking and obsessive-compulsive symptoms. This modified behavioral intervention may be useful for youth with clinically significant skin-picking.

Our study shows that skin-picking is associated with a number of consequences for many individuals with PWS, and that addressing skin-picking behaviors, and reducing them, could be associated with greater quality of life overall. Further research is needed to understand more about how skin-picking impacts the lives of individuals with PWS.

National Institutes of Health Awards $117 Million for Rare Disorders Grant Including Prader-Willi Syndrome Research

Dear members,

I just came back from presenting at the first meeting of the renewal and expansion of Rare Diseases Clinical Research Network (RDCRN). Under this grant, the Prader-Willi, Rett and Angelman syndromes consortium is only one of five renewed from the ten consortiums that were part of the first five/six year grant. There are now 19 consortiums in the RDCRN representing 95 rare diseases. There are approximately 6,500 rare diseases known, so we are very fortunate to be involved with this major rare disease research grant. Dr. Dan Driscoll (PWSA-USA Clinical Advisory Chairperson) is the coordinator of the PWS section of our consortium; I am the co-chair of the Coalition of Patient Advocacy groups for the grant which now includes 58 advocacy groups. PWSA (USA) has committed to financially supporting two research trainees who will participate in the grant.

I want to take this opportunity to thank the Prader-Willi syndrome community and parents, as well as the PWS staff, for your hard work and effort in making the RDCRN renewal a reality. Thank you!

~ Janalee Heinemann

The following is excerpted from the official announcement:

NIH announced ... “a second phase of the Rare Diseases Clinical Research Network (RDCRN) including funds for 19 research consortia...The Rare Diseases Clinical Research Consortia and a Data Management Coordinating Center (DMCC) will be awarded a total of just over $117 million over the next five years. The research conducted with the new funding will explore the natural history, epidemiology, diagnosis, and treatment of more than 95 rare diseases.

“A rare disease is defined as a disease or condition affecting fewer than 200,000 persons in the United States. Approximately 6,500 such disorders have been identified, affecting an estimated 25 million Americans.

“Initially created in 2003, the RDCRN is unique in its approach to addressing rare diseases as a group. Previously, the NIH’s institutes and centers funded research on individual rare diseases in their respective disease-type or organ domains...

“Since its creation, the RDCRN has enrolled over 5,000 patients in 37 clinical studies in rare diseases. Patient recruitment for clinical studies is a fundamental challenge in rare diseases research because there are typically so few affected patients in any one area. The RDCRN was designed to address this problem by fostering collaboration among scientists and shared access to geographically distributed research resources...

“The direct involvement of patient advocacy groups in network operations, activities, and strategy is a major feature of the RDCRN. Each consortium in the network includes relevant patient advocacy groups in the consortium membership and activities...Collectively, the Coalition of Patient Advocacy Groups (CPAG) represents the perspective and interests of all patient advocacy organizations associated with the RDCRN. The CPAG participants meet frequently throughout the year via teleconference and face-to-face meetings. The CPAG chairperson is a voting member of the RDCRN Steering Committee.

“In the RDCRN’s first phase, the network’s Data and Technology Coordinating Center (DTCC) developed a management system for the collection, storage, and analysis of RDCRN data, and additional systems to address needs of individual studies...The DTCC also created RDCRN’s central public Web site...to provide information on rare disease research, consortium activities, RDCRN-approved protocols, disease information, and practice guidelines. Located at http://rarediseasesnetwork.epi.usf.edu/>, the Web site had over 3.4 million visits in 2008. The RDCRN DTCC also developed a unique voluntary patient registry that provides ongoing contact with approximately 5,000 individuals from over 60
countries representing 42 diseases, alerting them when new studies are opened in the network or when ongoing studies expand to new sites.

“In this second phase of the RDCRN, the University of South Florida will continue these data management efforts, under a new name and with a slightly different charge, as the Data Management Coordinating Center (DMCC).”

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### Educating Endocrinologists Around the World About PWS

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

PWSA (USA) co-sponsored an awareness booth with International Prader-Willi Syndrome (IPWSO) at the world’s largest endocrinology conference in New York in September. It was a combination ESPE (largest European endocrinology organization) & LWPES (largest USA) endocrinology meeting. There were over 6,000 endocrinologists in attendance. Our own Dr. Dan Driscoll gave a presentation on PWS at the meeting. There were also several posters on PWS.

IPWSO paid the expenses through a grant Giorgio Fornasier, Executive Director of IPWSO, was able to obtain. Due to an unexpected Visa problem, Giorgio and his son Daniele were prohibited from getting on the plane to come to the USA, so we had to do a quick revision on plans, and David Wyatt came to my rescue. (There is no such thing as retiring from PWS!) We ran out of the 220 full packets we put together at our office half way through the conference, but had other materials and I rented a name tag scanner. Giorgio has already followed up with sending approximately 170 emails with the articles attached to those who did not get the packets and to those who also needed the information in Spanish. He was also able to inform the less developed nations about endocrinologists from their country who stopped by our booth. We had 208 leads for him to follow up. Our collaborative efforts with our PWS international organization, IPWSO, continue to benefit both the USA and people dealing with Prader-Willi syndrome around the world.

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### Acting Executive Director’s View

**“IT IS GRATEFULNESS WHICH MAKES THE SOUL GREAT.”**  
- Abraham Joshua Heschel

When I became Acting Executive Director, I had two simple goals:  
1. To maintain our day-to-day operations and support services for people and families living with PWS.  
2. To prepare the way for the permanent Executive Director.

I am pleased to report that we have accomplished these goals and am delighted that we are welcoming Kim Weinberg as our new Executive Director. She brings to our agency a track record of success leading non-profits and energy and ideas that we need to move effectively into the future. We are very happy to have her join the PWSA (USA) team!

I think for all of us this is a time to be grateful for the many blessings we have as an organization. Not many other organizations could navigate a sudden executive director leadership change with such skill. But this was not by any means a one-person effort. So I want to close my final Executive Director’s View appropriately with words of thanks to:  
- All of my talented staff colleagues who helped me in so many ways during this transition. This was truly a team effort!  
- The Board of Directors for their support  
- The Executive Committee for taking the time in weekly calls to talk through the issues we faced. Words are not enough to express how much I appreciated the collegial way we worked together for the benefit of PWSA (USA).  
- The many members and friends of PWSA (USA) who expressed their faithful support for us through this time of transition. And now with Kim’s arrival the promise of change is all around us. May we all greet this new beginning with renewed energy and enthusiasm for faithfully carrying out our mission to serve and support people and families living with PWS.

Evan Farrar

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The Gathered View ~ Prader-Willi Syndrome Association (USA)  
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Ask The Parents II

This feature continues with the many wonderful responses to our question.

Q. None of us expected to have a child with a disability or a birth defect, let alone Prader-Willi syndrome. How do you mentally approach that this has actually happened to you, that you have a child with PWS?

There are times I look at Sonny and just cry. There are times I feel so overwhelmed that I truly don’t know what to do with myself. I feel trapped in my own body not being able to imagine how he could be feeling having PWS. The way I’ve learned to cope is to just tell myself…”One day at a time”. Thinking too far into the future is extremely overwhelming. My heart breaks for Sonny.

I sometimes think, what if he didn’t have PWS? How would his quality of life change? How would he be? Would he be more active? How much stronger would he be? Would he be able to speak better? Would he do better in school? What type of friends would he have? Who would his wife have been? How would his children have looked? He loves babies and knowing that he will never have one of his own hurts me so.

Can I describe how I mentally approach this? How does anyone truly know how to mentally approach something of this magnitude? My son has been afflicted, not just with PWS but with seizures, severe asthma, GERD, gastroparesis, numerous hospitalizations and more that 10 medications per day. So to answer the question, you mentally approach that this has happened, carefully, with much thought, with patience in yourself as well as others, love, understanding, compassion and tenderness and you try to never ask “Why?” (a box of tissues won’t hurt).

As much as I’ve cried over Sonny and all of his afflictions, he has made me laugh ten fold, and I just love him with all my heart and soul.

Have to wash my face now, my makeup is running down my cheeks!!!

~ Nina Roberto (mom to Sonny, 7)

I was so thrilled to have a baby that I just jumped into caring for her. She was in NICU for 28 days. I spent most of every day and part of every night there. I thought I was lucky since she only had a feeding tube and could not hold her heat. After we were home and I started her OT, PT and speech schedule, I was excited about every tiny achievement.

When Cathryn was 2, I learned she had Prader-Willi. I read all the information the geneticist gave me, checked the PWSA (USA) web site and cried.

At 8, her geneticist did not think that my daughter had the behavior or diet issues of kids with PWS. Wow, was she surprised when I told her what our days were really like.

After a really rough year with behavior and school issues, we attended our first PWS conference. I got a very needed boost of energy from it. Cathryn was able to meet other children just like her and attend a camp.

When I am getting overwhelmed, prayer seems to be the only thing that can really help me. I pray a lot for patience and the ability to calm back down quickly before I make the outburst worst. Deep breathing is great for when Cathryn is yelling. I just take each day as they come. I do plan for the near future but I try not to worry about it.

~ Rosemary Tack (mother to Cathryn, 11)

Dean is only 10 weeks old and was just diagnosed 7 weeks ago, so we’re still in the midst of figuring this all out. One thing we do is to try to focus on what is going *well* and what is working with Dean, as opposed to talking about his shortcomings. We’ve thought a lot about the word “normal” and what it really means. As a therapist, I have met with many people who by external definitions are “normal,” and yet their dysfunction makes them anything but. So being externally “normal” is not a safeguard against anything, and we have to remember this.

We have also embraced the diagnosis in the sense that we know it explains what’s going on with Dean and so we have been tireless in asking questions and compiling information about PWS. Also, instead of thinking about our baby as having special needs or a disability, we call him our “limited edition” baby. After all, you only get a baby like him every 15,000!

Most of all, we remember that he is our son, and that regardless of whether there is anything noticeably “wrong” with him, we would do the best of our ability to help him achieve all he can.

~ Ali Shenk (mom to Cole, 22 months, and Dean, 10 weeks, PWS-del)

I have to admit in the beginning I was downright sad. I didn’t really know it, but everyone else did. Nothing was pleasurable. I was completely focused on my job of keeping track of ccs consumed by mouth and NG tube, placing new NG tubes when it was time, and doctor and therapy appointments. I’ll never forget the call from the neonatologist, saying that the test results came back and she has Prader-Willi syndrome. He gave me grim descriptions of what my
baby Genevieve was going to be—and so far he has been wrong.

I didn’t go out of the house much. Kind friends for about five months brought meals, did shopping, and drove my other four children to school and activities. As I write this, I’m realizing that it must have been when I allowed myself to carry on with life that my deep emotional distress slowly dissipated. It was a slow process, not rushed by family or friends. I was mourning the loss of a “normal, healthy baby”.

There isn’t one thing that I remember helping me come out of my sadness. Genevieve has been a participant in our family life from the beginning and allowing her to be has probably helped us all. We have always taken her to church, First Communion, block parties, dance recitals, etc., despite her little tube being taped to her face in the early months.

PWS isn’t what I wanted for my Genevieve, but it could be worse. We don’t know what the future holds for any of our children. I pray every night for them all.

~Beth Bruns (mom to Genevieve, 4)

When Ellie was 2 and we were told that she has PWS, my husband and I were terrified. Terrified of what this was going to mean for her future and ours as a family. Afraid that our little angel was going to become a different person suddenly or how the world outside of her loving family would accept her. After about a week of grieving our “loss,” we realized that we were blessed with an amazing child and that we would not trade her in for anything in the world. We also learned to take life one day at a time. That looking too far into the future is dangerous and unrealistic. We have always cherished every moment with Ellie, and PWS was not going to change that.

A couple days after we learned of Ellie’s diagnosis, I turned to a friend and asked, “So what do you think, it was just God’s will?” Her reply resonated with me, “I think God must really trust you.” This snapped me out of mourning and into action. I realized that I could remain paralyzed in fear about the future or begin moving to make a better future for my daughter.

~Rachel Johnson (mom to Ellie, 2 with deletion)

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Sibling View

August Larmer DiFilippo, Mill Valley, California wrote the following speech, which he gave at his 8th grade graduation from Marin Horizon School about his sister Grace, 11, who has PWS. Each graduate in his class made a speech on a theme of their choosing, and August’s was “joy and perseverance.” His mom reports that there was not a dry eye in the house!

My Sister Grace

During my time at Marin Horizon I have been taught many qualities like confidence, independence, and tolerance for my fellow human beings. But even before I came to MHS, I was already learning tolerance and perseverance from a family member, my 11-year-old sister, Grace. Grace is probably the bravest and strongest person I know because of the colossal challenge she faces every day of her life. She has a disability called Prader-Willi syndrome, but even with this syndrome she finds happiness and enjoyment in life. For this, I admire and learn from her.

What Grace deals with is an anxiety-based disorder that causes issues like slow growth and limited coordination. Another branch of the syndrome involves a strong connection with food. She always has to know what’s going to be served for snack, how much food she can have, and when she can have it. If something doesn’t go her way, it triggers her syndrome and she might lose the ability to control her emotions. She goes to speech therapies, physical therapies, gets a shot every night, and has had multiple foot surgeries. Doesn’t that sound like a lot to deal with?

Despite this, my little sister keeps smiling with her teachers, her friends, her pet rats, and our family. I can still hear her laughter when her smallest rat, Phoebe, somehow managed to find her way down my shirt. I remember the first time I went to one of her horseshows. Watching her trot around on Harry the horse and seeing her face filled with pride and joy simply impressed me.

All Grace accomplishes every day influences me to struggle through my problems. When she messes up, or Prader-Willi pushes her down, she gets right back up with an outing with Peggy Shayron and the dogs. She teaches me to get right back up whenever I’ve fallen, and I use this every day of my life. Marin Horizon, at tennis, and everywhere I go. With the school Jamband, I drop an average of one drumstick per performance. Sometimes people notice, but usually they don’t as I “pick myself up” by grabbing another one. Last time this happened, I smiled and my eyes just wandered to my sister in the audience.

I’ve realized that my sister is a remarkable person. I admit, having a sister with Prader-Willi syndrome can get pretty annoying at times, but we, my family, get through it. She’s happy with her life, and I respect that so much. I respect and admire her so much. Grace was born without a drumstick, but she keeps the beat going, with her hand.
Fundraising
“The difference between try and triumph is a little umph.”
unknown

A Hurdle to Thank
When approached by PWSA (USA) to ask for his blessing in creating an event to thank him for his tireless support of the association, Clint Hurdle said he didn’t want the event to be about him. He would do it only if it was about all of us, the whole PWS community. And so began the planning for the PWSA (USA) Tribute Dinner Honoring Clint Hurdle that took place on September 21 at Coors Field in Denver, Colorado. It was a fitting location for the former manager of the Colorado Rockies baseball team and father to 7-year-old Madison, who has PWS. Almost 150 friends took over the site for the cocktail hour, dinner and silent auction. After dinner, several speakers shared stories of Clint’s exploits – on and off the field. The highlights of the evening were a presentation to Clint of a bat signed by three dozen children and adults with PWS and Clint’s acceptance punctuated by his commitment to our cause and his urging for everyone in attendance to join him in this effort. PWSA (USA) is grateful to Clint and the entire committee for the event which raised $33,000.

‘Sock It’ for PWS Awareness
Play golf? Like animals? Know someone who does? This adorable Monkey Made of Sockies golf club cover will support PWSA (USA) and raise awareness for PWS. 10% of the gross proceeds of any Daphne’s Headcover purchased through the link, www.headcovershop.com/praderwillisyndrome, will be donated to PWSA (USA) — that’s any headcover, not just the Monkey Made of Sockies headcover although that’s the official PWS cover. You can also order by calling 800-327-4632 and mentioning the PWSA (USA) donation or by visiting the PWSA (USA) web site, www.pwsausa.org, under “Get Involved” “Spread Awareness.” This holiday season you can even find them in Golf Galaxy stores with a PWSA hangtag! Talk about awareness!
It’s a great gift for the holidays.

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School in Greenville, SC.
Capraro Surprised Us All

In September, Bill Capraro had quite the surprise for his 50th birthday…he was ‘arrested’: Lea Capraro (PWS) who turned 14 on her daddy’s 50th birthday, along with her mom, Tina, brother Will (16), and sister Tori (12), helped host a surprise party for him at the family’s ranch in Michigan, where police dropped him off. Many family and friends helped both

Lea and Bill celebrate their special day. Instead of birthday gifts, the family asked for donations to PWSA (USA). In total the event raised over $20,000, another nice surprise! Lea said it was the best night of her life as she danced the night away—she even had her dog Casey out on the dance floor. “The evening was overwhelming. I thank everyone for their friendship, love and support of PWS, especially my wife, Tina,” said Bill. What is not a surprise is how much the Capraro family cares for all those who have PWS. It was a very happy birthday, indeed.

Counselors Corner

At the Professional Providers Conference held in Baltimore in June, 2009, participants spent extensive time discussing and working through scenarios involving a variety of topics including:

- How do I prepare for ER visits and doctor appointments?
- Motivation for exercise
- Food security
- Vocational opportunities
- Behavior and crisis management

While many of these issues were discussed in relation to residential programs, much of the information might also be useful to families with adult children living at home. So if you are a provider or an interested family member, please e-mail (efarrar@pwsausa.org) or call me if you would like to receive materials summarizing the conference discussions.

Evan Farrar
Crisis Intervention Counselor

Valentine’s Day is coming! That means so is the PWSA (USA) Annual Valentine’s Day Research Fund Campaign! It begins January 1st and is an ultimate expression of love. Just send letters to everyone you know asking for donations and/or set up a page on www.firstgiving.com/pwsausa under this event and pass on the link (donations go directly to PWSA (USA)) in honor/memory of your special valentine. All proceeds are used for research. We’ll have a sample firstgiving page and letter template. We’ll even help you set it up or prepare your letters for you. To participate, contact Dorothy Sass at dsass@pwsausa.org or 800.926.4797 and then put your heart into it.
Caregivers From Many Countries Gather in Germany

During her term as President of our international organization, IPWSO, Pam Eisen was committed to the idea that the caregivers of persons with PWS should have a “home,” i.e., a conference of their own where they could share ideas and receive support for the challenges that they face. The First Caregiver’s Conference in Herne, Germany, in 2008 was so successful that it was decided that the next caregiver’s meeting should not wait until 2010 in Taiwan. Pam’s death in November of 2008 only strengthened this resolve. With much work and good fortune it became possible to have the second conference at Akademie Mont Cenis in Herne on July 6-8, 2009, thanks to Norbert Hödebeck-Stuntebeck and Dr. Hubert Soyer.

The purpose of this conference was to continue the task of developing guidelines and standards (best practices). There were two work groups devoted to gaining broader consensus for “Environmental Structure of Living” and “Behavior Management,” and two new work groups focused on “Interpersonal Relationships” and “Self Determination.” Near the end of the conference there were presentations for everyone summarizing the best practice statements from each of the four work groups. The response to these guidelines was offered from the perspective of the caregiver, the provider and the parent.

There were also two new lectures that in the future will become part of every caregiver’s conference: The Pam Eisen Memorial Lecture and the International Lecture. Janalee Heinemann and Giorgio Fornasier, past president of IPWSO and current CEO, gave an emotional tribute to their longtime friend Pam Eisen. The first Pam Eisen Memorial Lecture was given by Tony Holland, M.D., Professor at Cambridge University in the UK. This outstanding lecture, dedicated to Pam and her daughter Gabriella, contrasted the amount of knowledge that was available at the time that Pam’s daughter Gabriella was born in 1980 with the information that is known for parents today. He identified the most important research findings and how they have affected clinical care. (This lecture has been transcribed and will be available in several months.)

The first International PWS Lecture was presented by Professor Jeyachandran from India. His lecture reviewed the history of India over the past 5000 years, integrating the development of medical care and the current health system of India today. There are over one billion people living in India. Due to the initial efforts of IPWSO regarding awareness on PWS in India, we hope to see considerable progress over the next ten years in the diagnosis and management of PWS throughout India.

The 2009 Herne conference was smaller (80 attendees) but more intense; each work group was held twice to increase the number of participants and to build consensus. There were more countries represented this year (17). Attendees were caregivers, providers, psychologists, psychiatrists, physicians, teachers, and physiotherapists.

The 2009 Herne experience was most memorable, characterized by hard work and good times. It provided another opportunity to develop guidelines that will have an impact on the world of PWS for many years to come. The Caregiver’s Conference is Pam Eisen’s wonderful legacy. We look forward to the Caregiver’s Day at the Seventh IPWSO conference next year in Taiwan where many of the best practice guidelines will be presented.

Respectfully submitted,
Conference organizers: Mr. Norbert Hödebeck-Stuntebeck, Dr. Hubert Soyer, Dr. Leopold Curfs, and Dr. Janice Forster with special thanks to Mrs. Linda Thornton, IPWSO liaison.
Chapter View

The Spotlight is on the 2009 activities of the PRADER-WILLI CALIFORNIA FOUNDATION.

~ Lisa Graziano, M.A., PWCF Executive Director

The Warriors professional basketball team hosted Warriors Against PWS and spread the word through TV and radio about PWS, thanks to the efforts of Ashley Hurdle, Michael Moore, and national PWS spokesman Clint Hurdle.

PWS Family Day held at the extraordinary The Painted Turtle camp provided families of youngsters with PWS and their siblings the opportunity to participate in a full day of amazing activities.

PCWF maintains several support groups throughout this vast State which meet regularly to provide much-needed support and networking opportunities. Multiple personalized trainings are provided to California’s group homes and vocational work sites by Theresa McGrath, PWCF’s new Residential Training Consultant. Fran Moss continues her committee’s work to create a new residential staff training DVD.

Personalized advocacy packets, telephone calls and in-person school site advocacy and trainings are provided to support the school age child. Educational in-services were provided to Albertson’s grocery stores and the California Association of Superior Court Investigators. A film project was held at the California Art Institute. April and May saw PWCF’s 9th annual Walking for PWS awareness and fundraising events that were enjoyed by over 500 families and friends across the State.

PWCF provided grants to support PWS Clinics throughout the state and grants to support local research. New brochures and articles are always being produced and translated to Spanish by Carina Chiaj.

PWCF’s annual conference on November 7 will present vital, state-of-the-art information from Drs. Ann Scheimann (GI issues), Michael Gottschalk (endocrine issues), and Dawn Huebner (anxiety issues). Despite being surrounded by a collapsing economy, Prader-Willi California Foundation is proud to be making progress, and we continue to work hard to provide education, advocacy and support to California’s families and the professionals who serve them.

Our chapters are serving their members in so many ways. Texas, Tennessee and the Carolinas have recently revived or created a chapter in their state. Please contact Barbara McManus at the national office if you wish to join one of these new chapters or to help create one in states where there are none.

PWSA-Carolina, which includes both North Carolina and South Carolina, is going through the paperwork to become incorporated. The current acting officers are (President) Becky Smith from Raleigh, NC, (Vice President) Cindy Gaylean from Sandford, NC, (Secretary) Christy Matkovich from Fort Mill, SC, (Board member) Lillie Tucker from High Point, NC, and (Board member) Linda Johnson from Greenville, SC. They are still in search of a treasurer and anyone else interested in being a board member. We encourage all Carolinians to join! A new eSupport group has been created to keep everyone informed. Please visit http://health.groups.yahoo.com/group/pwsa-carolina to become a member. The newly formed group attended a PWS Conference Day provided by the PWS Clinic at UNC-Chapel Hill in July. The chapter hopes to have 3-4 meetings a year. They are excited to kick off the coming year with growth and success!

Tennessee Prader-Willi Association, Inc., has established the necessary paperwork to become a chapter of PWSA (USA). (President) David Campbell from Old Hickory, Tennessee, (Vice President) Angel Sims from Ringgold, Georgia, and (Secretary) Steve Asbury from Nashville, Tennessee, have agreed to be the initial officers of the organization. A chapter meeting is planned at Mt. Juliet Community Center (suburb of Nashville) on November 11, 2009 from 1 p.m.– 4 p.m. Dr. Elizabeth Roof from Vanderbilt University is also assisting with the formation of this new chapter. To keep everyone informed of events a new eSupport group has been created. You can join this group by visiting: http://health.groups.yahoo.com/group/PWS-TN

Texas Prader-Willi Syndrome Association is off to a great start! They are in the process of becoming incorporated and getting their 501(c)3 charitable giving organization set up. (President) Lindi Kessinger from Whitehouse, (Vice-President) Erica Black from Waco, (Secretary) Rachel Elder from Austin, (Treasurer) Jesse Riha from Houston, and (Membership) Olivia Riha from Houston, lead this new chapter. Board members and officers come from all across this huge state, making sure that everyone in the state is represented. Their eSupport group http://health.groups.yahoo.com/group/PWSfriendsofTexas has over 70 families on it! You only need to visit this link to join. The list discusses resources in Texas and offers tremendous support for the families there.

PWSA of Ohio held its Fall Weekend Camp for children and adults 8 and up at Recreation Unlimited October 16 to 18. A camp is held each spring and each fall. ■
From The Home Front

Christmas Reflections

Each major holiday, birthday or milestone, I can’t help but reflect on where we were and where we are now. Christmas gets me thinking and feeling. Mostly I am so thankful. But as Luke’s mom, each Christmas is filled with so much emotion, from fear and sadness to joy and pride. Over the years, Christmas revolved around extensive planning to accommodate Prader Willi syndrome, but this year, Luke’s 6th, is our first year we have come to the point in healing where we will watch him for his safety, of course, but can focus on the joy of family and the splendor of the holiday.

When Luke was 3, I was astonished at all the free time I got at the holiday by not over cooking and being stuck with leftovers. It was also a year where he reached plenty of milestones. As the hypotonia was leaving, I began to know more about my child. I felt like the hypotonia masks so much of the child’s thoughts, abilities, and means of expression. But still we were terrified of this stranger Prader-Willi. We watched him meticulously for behaviors and never let him out of our sight, not even for a minute so others at Christmas wouldn’t ever have to see what we feared. It was all unknown. And all that energy was a waste. He was just a little boy - a toddler.

At 5 years of age, I reflected again. I shared my feelings with the parents on the 0-5 board with whom I spent every day online. “…I wrote a note on this board when he was 3. I just re-read it. It’s amazing, but over these 2 years I’ve forgotten a lot of the challenges we’ve had. I’ve forgotten all the things that became missing when I imagined our life with PWS. All that seemed to have been taken was replaced in abundance.

“Instead, it’s been a life of many challenges, but challenges we could accomplish. And mostly, it’s still nothing like we were initially told. I for a long time could not understand what the other mothers meant about the joy of having a special child. I now am beginning to understand.

“I’ve spent a lot of time watching him and his peers, and I’ve realized no one is ready all the time and none of the ‘other’ children are perfect. Their parents are always on pins and needles about something, too. I realized all these moms are just as vulnerable as I am when it comes to their children.”

At this Christmas holiday, my son is 6. We celebrate many joys and are proud of many ‘ordinary’ accomplishments. I absolutely relished the day he did homework, a dinosaur poster project. Even better was getting to put the rubber bands on it and send him to school just like any other child. I know chapters are written about behavior, hyperphagia and the like, and our family certainly can relate to those, but little is written about the ‘ordinary’ accomplishments and simple joys that make us special parents.

~Robert and Lisa Ranieri,
Hoover, Alabama
Mom to Luke 6, William 4,
Mallory Lynn 2 and Baby Vincent

One Man Awareness Campaign

We are always looking for ways to spread awareness. People hold fabulous fundraisers, seek out media coverage, and network in their communities to get the word out about PWS. My son Zachary, 11 with PWS, and I watched the piece on Good Morning America featuring the Kane family (great job, Kanes!!). Later that afternoon I took Zach with me to my dentist appointment. The hygienist walked in and said hello to Zach, and that was all he needed for an open door. He began with “I’m her son and I have Prader-Willi syndrome.” Of course, when he said it it was more like prarweesynome....but I was there to remind him to slow down and speak carefully. He told her what it was, how it made him feel, and that it was on the news that morning. Then he told her all about Kate Kane. I was so impressed and

There Are Those Special Times...

Yesterday AJ had his first cross country meet. He placed 10th out of 17. He was the only child with special needs running; the rest were typical 5th graders. Most people there know nothing of AJ so I am sure that they did not understand why the tears were streaming down my face! The monitor at the 3/4 mile said he was the only one still smiling when he ran past! At the finish line they were passing out punch and cookies. AJ looked at them and said, “I can’t have that” I interrupted him and said, “You bet you can have a cookie and punch! You just ran a mile without stopping!!!!

~ Shanna Houghton
Post Falls, Idaho

Zach, continued on page 13
Zach, continued from page 12

so proud of him. Here I am, contemplating fundraisers, helping with focus groups, educating everyone Zach comes into contact with...and Zach is his own one-man-awareness-campaign. Go Zach!!!

~ Tammy Reals
Liverpool, New York

A Success Story

I would like to tell you about my stepson, Tyler Goolsby. Tyler is 19, and he is one great kid. To know him is to love him. When I met Tyler’s mom Vickie, she was a single mother with no help, and Tyler ended up in a residential school for about a year. At 16 his weight was 168 pounds, and he stands 4’9”. His pants size was men’s 36-28. He would not play with other kids if he had to move to do so. His mother and I were growing concerned about health. So Tyler moved home with us. Things could not be better. Tyler LOVES his 3:00 snack. So we got him a Tony Little Gazelle. He started out with five minutes a day. In no time he was up to an hour a day. With the help of the Gazelle and Michelina’s Lean Gourmet, we are so happy to say that Tyler weighs 110 pounds and his pants size is a boy’s 10. He runs around with all the other kids. He even plays soccer. He is a much happier kid.

~ Mark Templeton
Galatin, Tennessee

Mark has been great with him and has been a Godsend to our family. We have been a family for a little over 4 years now. I credit Mark with the wonderful job that he has done with Tyler—the calorie count, preparing healthy meals, and ensuring that the daily exercise was, and still is, getting done. As you know, they can be “difficult” when it comes to saying no to food or trying to get an exercise routine to stick. Mark has read everything he can get his hands on about PWS and the proper care. Tyler responds well to his patient manner.

Tyler graduated from the public school system in May this year (not a moment too soon!), and he now works two mornings a week in an office, filing. He loves his paycheck! Food and “temper tantrums” remain a constant struggle, but we have controls in place that make everyone’s life easier. He has done a great job losing his weight and knows that if he wants “a little something extra”, he bargains to do additional exercise in order to get it. He will be 20 years old Nov. 11, and we enjoy every day that we have with him!

~ Vickie Templeton

In the previous issue, credit is due for the photo of Julie Mitchell. Many thanks to Oaktree Photo & Video Inc. of Scranton, PA.
Contributions

We Remember

PWSA (USA) has lost a very special member of its family, Norma Rupe, a dedicated, longtime volunteer who was our Bereavement Coordinator for years and sent out comfort to so many others. On September 23 Norma lost her battle with the illnesses that had beset her.

From Giorgio Fornasier, executive director of IPSWO, came these words: “…my family had the opportunity to spend a lovely evening with Norma while we were in Sarasota. Her house with the colours of Christmas decorations and the sunset light coming through the windows was as bright as her heart and face. We will never forget her.”

John Kraft, father of Jennifer Kraft, born in 1972 with PWS, died in August. His wife Bonnie sent memorial donations she had received to PWSA (USA), which totaled $6,450. Heartfelt thanks and deepest sympathy go to his family.

Norma Rupe, 1925-2009
with husband Bill

We Remember

Thank you for Contributions in August and September 2009
We try to be accurate in recognizing contributions, and apologize for any errors or omissions. If you notice an error, please tell us.

In Memory of

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Mitchell and Francine Cohen
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Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to www.pwsausa.org/donate
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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