

# The *Gathered View*

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

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

## 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.



Kim Weinberg

**Please welcome Kim  
to the Prader-Willi syndrome family!**



Maya

### In this Issue

Ask the Experts.....	2
Skin Picking Survey.....	3
Ask the Parents II .....	6
Valentine Research Campaign.....	9

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

## PWSA (USA) Advisory Board

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



Kate Kane, Brook Fuller, Andy Maurer, Lauren Lange, Conor Heybach, Shawn Cooper, and Abbott Philson on the computer screen.

Our PWSA (USA) Advisory Board (adults who have Prader-Willi syndrome) met October 17-18<sup>th</sup> 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
- Losing more weight. Moving out

(of my family's home). Getting a job. Taking college courses. Changing rigid routines

#### **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*



## **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](http://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, Korzilius, & 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

*NIH, continued on page 5*

---

NIH, continued from page 4

---

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). ■

---

## 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. ■



## 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



## 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 than 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

*Ask the Parents, continued on page 7*



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.

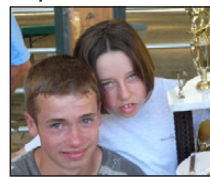
A couple days after we learned of Ellie's diagnosis, I turned to a friend and asked, "So what do you think, it was just God's will?" Her reply resonated with me, "I think God must really trust you." This snapped me out of mourning and into action. I realized that I could remain paralyzed in fear about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

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



## **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



*Clint and Karla Hurdle*



*Left: Stephen Leightman, event chair and PWSA (USA) board member, presents Clint Hurdle with a special bat.*

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/praderwillisynndrome](http://www.headcovershop.com/praderwillisynndrome), 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](http://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!

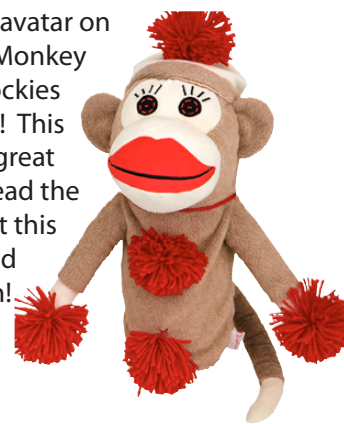
It's a great gift for the holidays.

Plan ahead for PWS Awareness Month of May and order yours now. Coordinating a golf fundraiser? Promote these at your event. Use them as puppets for your kids or decorate the top of the Christmas tree with one.

LPGA player Leta Lindley, along with other LPGA members, will be carrying it at the Leta Lindley Prader-Willi Classic on December 7 in Palm Beach Gardens, Florida, which supports Josilyn's Foundation and PWS research. Learn more about this event at [www.pwclassic.com](http://www.pwclassic.com).

Monkey Made of Sockies is a character from Shannon Grissom's children's book of the same name. The author and illustrator said, "It seems fitting that a portion of proceeds benefit children. My mother was a special education teacher who had a tremendous impact on her students." Grissom inherited the original MMOS after her mother's passing. She added, "Through our support of Prader-Willi, my mom will continue to help children in perpetuity."

Shannon Grissom also has created an avatar on Twitter so Monkey Made of Sockies is tweeting! This is another great way to spread the news about this monkey and her mission! ■



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 50<sup>th</sup> 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



The Capraro family, left to right: Mom (and wife) Tina, Lea, brother Will, Dad (and husband) Bill, and sister Tori

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



Photos courtesy of Jennifer Mayo Studios

Dad with daughter Lea sharing a special birthday moment raising money and awareness for PWSA (USA)



Bill Capraro under "arrest"

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

I ♥ U

Valentine's Day is coming!

That means so is the PWSA (USA) Annual Valentine's Day Research Fund Campaign! It begins January 1<sup>st</sup> 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](http://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](mailto:dsass@pwsausa.org) or 800.926.4797 and then put your heart into it. ■

## International View

# 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.



**East Meets West**  
A New World for Prader-Willi Syndrome



**VII International  
Prader-Willi Conference**  
**May 21-23, 2010 - Taiwan**

For more information - <http://www.pwsa.org.tw/meeting>

## Congratulations, Elisabeth!

Elisabeth Dykens, Ph.D., has been named permanent director of the Vanderbilt Kennedy Center. Professor of Psychology in Peabody College, she serves on the Scientific Advisory Board of PWSA (USA). She is a national and international leader in research focusing on the mental health challenges and unique strengths of persons with genetic syndromes, such as Prader-Willi syndrome, Williams syndrome, and Down syndrome.

## 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 9<sup>th</sup> 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 6<sup>th</sup>, 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

### **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*

---

### **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

*Zach, continued on page 13*

---

## **Zach**, continued from page 12

---

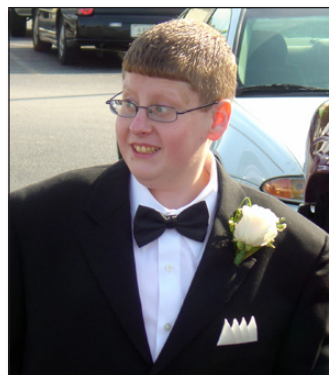
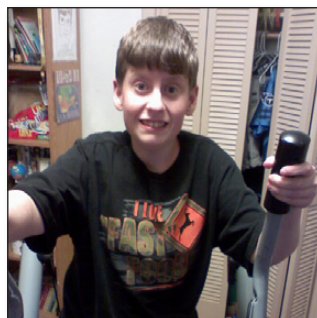
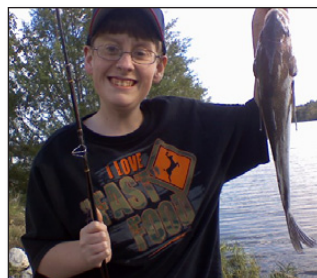
so proud of him. Here I am, contemplating fundraisers, helping with focus groups, educating everyone Zach comes into contact with....and Zach is his own one-man-awareness-campaign. Go Zach!!!!

~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 Michelin's Lean Gourmet, we are so happy to say that Tyler



Above: Tyler before.  
Left: top and bottom Tyler the angler and working out on his Tony Little Gazelle.

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.*

---

## **CHUCKLE CORNER**

I was talking to my son Davis, age 12 with PWS, about Santa Claus, explaining that although he is not real, his spirit is. It looked like he finally "got it." He then thought about this for a while and later said, "If Santa Claus isn't real, Mrs. Claus must be real lonely."



~ Mary Raymond  
North Reading,  
Massachusetts



Pennsylvania Chapter family Bonnie Azzara, Brian Hinshaw and Tommy, Nicole Hinshaw, Mike Azzara and Mikey (who has PWS) celebrate Christmas!





## 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



*Norma Rupe, 1925-2009  
with husband Bill*

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.

## Contributions

**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

#### **Deborah A. Barkeley**

Norman and Cynthia Barkeley

#### **Patricia Breslin**

Walt and Marge Foran

#### **Irving Cohen**

Mitchell and Francine Cohen

#### **Jonathan Ross Davis**

Dennie and George Lindsey

#### **Helen Watkins Garlick**

Jim and Sue Fuller

#### **Donna Garnsey**

Heidi Thorstenson

#### **Jack Gatlin**

Chris and Sally Toler

Bill and Jean Voss

Virginia Gumula

Edwin and Theodora Sojka

#### **John Kraft**

Shelly Ammon

ArcelorMittal Tubular Products

Shelby, Inc.

Baker Tilly Virchow Kraus, LLP

Doug and Margene Bergstrom

John and Patricia Bliss

Betty Braly-Molinaro

Richard and Diane Buechel

Tami and Jack Carpenter

John Clark

Jourdan Dern

Wendy Drew

Dave Ebben

Douglas and Heidi Edwards

David and Margaret Ewaskowitz

Kirk and Molly Fischer

John and Claire Flannery

Kathy and Ernest Foley

Jil and John Ford

David and Patricia Frankhart

Willis and Bonita Fry

Andrew and Karen Groshek

Daniel and Ruth Haggerty

Justin Happel

John and Sally Hattenhauer

Susanne Heinritz

Peter and Nancy Hessert

Harlan and Barbara Hunger

Jarp Industries Inc.

Laura Jennings

Michael and Terri Jennings

Colleen Jowett

Robert and Marjorie Julian

James Kemerling

Steve and Anne Kluge

Donna Knapp

Kathleen Krueger

Sherman and Mary Laviolette

Mary Mahoney

Sara Marquardt

Peter and Judith Mattiacci

Daniel and Linda Mescheffs

Jill Metcalf

Ann and Larry Meyer

Claire Molnar

Thomas and MaryKay Obert

O'Malley Automotive, Inc.

San Orr

William Reif

Thomas and Phyllis Riiser

James Romanski

Katherine Rossman

Kenneth and JoEllen Schaefer

Gilman and Kathleen

Schimmoler

Trygve and Tula Solberg

Timothy Sondelski

Deborah Sutton

Jean Tehan

Ann Werth

Larry Wetter

#### **Shirley Levan**

Betty Schutz

#### **Summer McVey**

1st Independent Leasing Inc

Claudia Andrews

Donna Baker

Leilani Bennett

Richard Brown and Brenda

Booth

Barbara and Curtis Close

Lauren Gearhart MD

Tami Laflen

Justin Sykes and Mike and

Amy McLean

Mt. Hood Solutions

Lisa Nelson

Andrea Parks

James and Kim Safranski

Rhea and Jim Sleeman

John Tipton and Staci Tone

#### **Eugene Metzger**

Alice Metzger

#### **Josephine Miller**

Betty Cox

#### **Dr. John M. Mook**

David and Jo Berry

Lorenzo and Jean Burzimati

Dolores Chapman

Jean and Andrew Clem

Dean and Roberta Couch

Mary Delaney

William and Doris Edwards

Linda Jordan

Hope and Nelson Leonard

Molly Stark School

Bob and Cathy Mook

Alan and Romayne Noble

Richard and Ann Reynolds

David Schmidt

George and Essie Welch

#### **Mary Grace Pflieger**

Jill Peach

#### **Stephen Pikul**

Edwin and Theodora Sojka

#### **Andrew Richardson**

Anthea Richardson

#### **Tina Riggs**

Judy Werner

#### **Norma Rupe**

Cindy Beles

Julie and Jeff Doherty

Jodi and Ryan O'Sullivan

Ann and Jerry Seigel

Karen Singer

Trudie and Stanley Smith

#### **Erin Schavey**

Sue and Harlan Schavey

#### **Charlotte Yvonne Smith**

Linda Hancock

#### **Nicolas Tersigni**

Helene and David Dahan



## Contributions, *continued*

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

Agape Enterprises NFP  
A. J. and Roswitha Agarwal  
David and Janice Agarwal  
Dawn Allard  
Robert Bastiaans  
Baylor College of Medicine  
Alan D Bossart LLC  
Merrick and Gail Bromberg  
Catrina and Scott Bubier  
Central Parking System  
Prader-Willi Syndrome of New England  
John Clark  
John and Donna Coffey  
Mitchell and Francine Cohen  
Colorado Rockies Baseball Club Foundation, Inc.  
Vince and Florence Connelly  
Joseph Conrad  
Derek Cordes  
Alan Czarnowsky  
Robert Daale and Ronald Daale  
Double Blessings Mothers of Twins Club  
Robert Engel

Ferrara Pan Foundation  
Alan and Phyllis Fishman  
Peter and Gayle Girard  
Daniel and Nancy Gulling  
Philip and Laura Gutman  
Roger Harbert  
Chris and Tonya Hardman  
Tim and Carol Hearn  
Clint and Louise Hurdle  
Mark and Mary Ann Kaufman  
James Kemerling  
Lori and Darrin Kerbs  
Bill and Barbara Kerrigan  
Steve and Anne Kluge  
Steve and Michele Leightman  
Bernadette Lerner  
Liberty Sports Holdings LLC  
Living the Dream Foundation  
Wallace and Virginia Livingston  
Magner International Corporation  
Mallon Family Foundation  
Damian and Beth Ann Marano

Merle's of Littleton Inc.  
Sean Mullen  
Donovan Nichols  
Northwest Linings & Geotextile Products, Inc.  
Office Liquidators  
O'Malley Automotive, Inc.  
Michael Peebles  
Joseph and Kathleen Perrino  
Polis Schutz Family Foundation of the  
Jewish Community Foundation  
Jeff and Kari Porter  
Progressive Packaging  
Jeff Ruden  
St John's Military School  
Adam Stillo  
Tyler Terch  
Torbert Produce Inc  
John and Jeanne Vazzana  
The Wetter Foundation  
Marcia White  
Paul and Amy Wissmann

### In Honor of (Honoree in bold)

**Ally Arant**  
Mary Beth Ritthaler  
**Linda Lee Barnett**  
Nancy Kenner  
**Oliver Alden Barrett**  
Penelope Barrett  
Prudence and Tom  
Nelson  
**Matthew Berl**  
Robin Derwin  
Amy Youmatz  
**Antonio Cital**  
James and Margie  
Sappington  
**Rachel, Andy,**  
**Anwen & Madoc**  
**Elder**  
Sonia Castaneda  
Ralph and Ruth  
Reitmeyer  
**Luke Charles Eurillo**  
Joane Stoneberg  
Jeane English  
**Ashley Fender**  
Michael Culos  
**Charlie Graham's**  
**2nd Birthday**

Shelly and Eric  
Graham  
**Ashley and Cloe**  
**Hanamoto**  
Gene Hanamoto  
**Sam Handweger**  
Marcy and Brian  
Lasky  
**Sean Patrick Healy's**  
**6th Birthday**  
Sharon and John  
Healy  
**Madison Hurdle's**  
**7th Birthday**  
Joe and Sue Iversen  
**Madison Reilly**  
**Hurdle**  
Polis Schutz Family  
Foundation of the  
Jewish Community  
Foundation  
**Peter Ingalls**  
Barbara Wentworth  
**Kate Kane**  
Henry and Charlotte  
Blum

**Tom Keating's**  
**Birthday**  
John and Maureen  
Yates  
**Julia Kenney**  
Lynn Bergman  
**Lauren Lange**  
Debbie and John  
Lange  
**Anna Leightman's**  
**Birthday**  
Steve and Michele  
Leightman  
**Ben and Janis**  
**Leightman's**  
**65th Wedding**  
**Anniversary**  
Jacob Brodzki  
Edith Garson  
Ray and Ida  
Leightman  
Steve and Michele  
Leightman  
**Raymond and**  
**Ida Leightman's**  
**Anniversary**

Steve and Michele  
Leightman  
**Steve Leightman's**  
**Birthday**  
Ray and Ida  
Leightman  
**Lawrence London**  
Steve and Michele  
Leightman  
**Duncan McRae**  
Thomas and Patricia  
McRae  
**Steven C. Neiger**  
Susan Roubal  
**Nicholas Paige**  
Kathleen and Ralph  
Paige  
**Lauren Pfeiffer**  
Mel and Chris Pfeiffer  
**Kaylee Anne Quast**  
Jill Quast  
**Luke Ranieri**  
William and Barbara  
Ranieri  
**Trevin Redner**  
Crystal and Todd  
Redner

**Ashlyn Ricardo**  
Elizabeth and Wayne  
Morse  
**Amanda Riha**  
Susan and Tom Nebel  
**Brett Rogers**  
Linda Steppe  
**Lily Clare**  
**Schactman**  
Howell and Suruba  
Wechsler  
**Abbey Seelig**  
Don and Betty  
Vincent  
**Barri Seitz**  
Ben and Raina Nadler  
**Hudson Liam**  
**Slocum**  
Sharon and David  
Butler  
**Molly Speiser**  
Clinton and Mary  
Speiser  
**Leslie Torbert's**  
**Birthday**  
Tommy and Michelle  
Torbert

**Sophia Tweel**  
Jen Johnson  
**Cameron Wallace**  
Chris and Catherine  
Barras  
**Garrett Weaver**  
Bill and Claudette  
Slaughter  
**Richard Weiner's**  
**80th Birthday**  
Lillian Blumberg  
Warren and Irma  
Lackstrom  
Rita and Bill Needel  
Robert Resnick  
Estelle Sugarman  
Lester and Tobey  
Weiner  
Arlene, Arnold and  
Elizabeth Winston  
Larry and Mary Beth  
Zarinsky  
**Alden Charles**  
**Young**  
Alden and Kimberly  
Downs

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



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

# USA PRADER-WILLI SYNDROME ASSOCIATION

*Still hungry  
for a cure.*

8588 Potter Park Drive, Suite 500  
Sarasota, Florida 34238  
800-926-4797 ~ 941-312-0400  
Fax 941-312-0142  
[info@pwsausa.org](mailto:info@pwsausa.org)  
[www.pwsausa.org](http://www.pwsausa.org)

**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.

## Staff & Other Key Contacts

**Kim Weinberg**, Executive Director  
**Evan Farrar**, Acting Executive Director  
**Janalee Heinemann**, Research/Medical Affairs  
**Cindy Beles**, Triage Advocate  
**Kate Beaver**, Alterman Crisis Counselor  
**David Wyatt**, Crisis Counselor Emeritus  
**Prentice Lantzer**, After-Hours Medical Crises  
**Jodi O'Sullivan**, Development/Communications  
**Rachel Elder**, Community Development  
**Sharon Middleton**, Business Manager  
**Lin Sherman**, Accounting & Systems Assistant  
**Barbara McManus**, Family Support  
**Dorothy Sass**, Administrative Assistant  
**Gus Schrowang**, Communications Specialist  
**Vicki Knopf**, Parent Mentoring II  
**Kerry Headley**, Conference Coordinator  
**Jim Kane**, Research Advocacy  
**Julie Doherty**, Volunteer Support

**Members Only:** See our Web site, [www.pwsausa.org](http://www.pwsausa.org), for downloadable publications, current news, current research and more. Limited to members only.

User Name: pwsamember

Password: sarasota8588

Note: If you have difficulty logging in, please contact [info@pwsausa.org](mailto:info@pwsausa.org).

E-mail Support Groups:

We sponsor nine groups to share information.

Go to: [www.pwsausa.org/egroups](http://www.pwsausa.org/egroups)

**The Gathered View** (ISSN 1077-9965)

Editor, Lota Mitchell

GV Designer, Sara Dwyer

Published bimonthly by PWSA (USA) as a membership benefit. Annual U.S. membership: \$50 (individual, family, or agency/professional). Annual membership outside the U.S.: \$60 (individual, family, or agency/professional). We never deny parents membership for any reason.

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

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

## Officers & Directors

**Co-Chair** - John Heybach, Ph.D., Chicago, IL

**Co-Chair** - Ken Smith, Pittsburgh, PA

**Secretary** - Julie Doherty, Tallahassee, FL

**Treasurer** - Bert Martinez, Bradenton, FL

Janice Agarwal, Zionsville, IN

Michael Alterman, Atlanta, GA

Jamie Bassel, D.C., New York, NY

Gregory Cherpes, M.D., Pittsburgh, PA

Dan Driscoll, M.D., Ph.D., Gainesville, FL

Kerry Headley, Upper Arlington, OH

Carol Hearn, Plymouth, MN

James Koerber, Corydon, IN

Stephen Leightman, Cherry Hill, NJ

Carolyn Loker, Mattawan, MI

Jackie Mallow, Oconomowoc, WI

Lisa Thornton, Salt Lake City, UT

Michelle Torbert, Homestead, FL

## Scientific Advisory Board

**Chair** - Merlin G. Butler, M.D., Ph.D., Kansas University Medical Center, Kansas City, KS

**Chair Emeritus** - Vanja Holm, M.D., University of Washington, Seattle, WA

Suzanne B. Cassidy, M.D., U.C.I. Medical Center, Orange, CA

Anastasia Dimitropoulos, Ph.D., Case Western Reserve University, Cleveland, OH

Joe Donnelly, Ed.D., University of Kansas, Lawrence, KS

Elisabeth M. Dykens, Ph.D., Vanderbilt University, Nashville, TN

David Ledbetter, Ph.D., Emory University School of Medicine, Atlanta, GA

Sue Myers, M.D., St. Louis University, St. Louis, MO

Robert Nicholls, D. Phil., Children's Hospital of Pittsburgh, Pittsburgh, PA

Ann Scheimann, M.D., M.B.A., Johns Hopkins School of Medicine, Baltimore, MD

David Stevenson, M.D., University of Utah, Salt Lake City, UT

Rachel Wevrick, Ph.D., University of Alberta, Edmonton, Alberta, CN

Barbara Y. Whitman, Ph.D., St. Louis University, St. Louis, MO

## Clinical Advisory Board

**Chair** - Daniel J. Driscoll, M.D., Ph.D., University of Florida Health Science Center, Gainesville, FL

David M. Agarwal, M.D., Indiana University School of Medicine, Indianapolis, IN

Moris Angulo, M.D., Winthrop University Hospital, Mineola, NY

Ivy Boyle, M.D., Bellefaire JCB, Cleveland, OH

Gregory Cherpes, M.D., The Children's Institute, Pittsburgh, PA

Marilyn Dumont-Driscoll, M.D., Ph.D., University of Florida Health Science Center, Gainesville, FL

Janice Forster, M.D., Pittsburgh Partnership, Pittsburgh, PA

Linda Gourash, M.D., Pittsburgh Partnership, Pittsburgh, PA

Bryan Hainline, M.D., Ph.D., Riley Children's Hospital, Indiana University School of Medicine, IN

Jim Loker, M.D., Bronson Methodist Children's Hospital, Kalamazoo, MI

Jennifer Miller, M.D., M.S., University of Florida, Gainesville, FL

Todd Porter, M.D., M.S.P.H., Children's Medical Center, Denver, CO

Norma Terrazas, R.D., L.D., Texas Children's Hospital, Houston, TX

Harold J.P. van Bosse, M.D., New York University Hospital for Joint Diseases, New York, NY

Barbara Y. Whitman, Ph.D., St. Louis University, St. Louis, MO

## Liaison Members

Suzanne B. Cassidy, M.D., Scientific Advisory Board

Janalee Heinemann, M.S.W., Director of Research & Medical Affairs, PWSA (USA)

Ken Smith, Board of Directors, PWSA (USA)

## Professional Providers Advisory Board

**Chair** - Jackie Mallow, Prader-Willi Homes of Oconomowoc, WI

Patrice Carroll, Advocates, Inc., Framingham, MA

Jeff Covington, Catholic Charities Services, Albany, NY

Steve Drago, ARC of Alachua County, Gainesville, FL

Evan Farrar, PWSA (USA), Sarasota, FL

B. J. Goff, Goff Associates Disability Consultants, Springfield, MA

David Wyatt, PWSA (USA), Sarasota, FL

Mary K. Ziccardi, REM Ohio, Inc., Valley View, OH

## Adults with PWS Advisory Board

Shawn Cooper, Georgia

Brooke Fuller, Michigan

Conor Heybach, Illinois

Kate Kane, Maryland

Lauren Lange, Georgia

Andy Maurer, South Carolina

Margaret Miller, Pennsylvania

Abbott Philson, Maine