

The *Gathered View*

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

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

May is PWS Awareness Month

Your Opportunity to Educate Others About PWS

By Jodi O'Sullivan, Director of Development & Communications

Do you wish PWS were more widely known? Then use PWS Awareness Month of May to make it happen! PWSA (USA) launched PWS Awareness Month, a public education initiative, so our members and friends can work together nationally, on a state level and as individuals in our communities to expand understanding of our rare syndrome with extra fervor.

Every year, PWSA (USA) and its volunteer Awareness Committee work to provide new items to build on what already exists to help in this effort. Read on to learn about new initiatives and then carry on with PWS awareness in May... and all year long!

*** Give a presentation:** The Awareness Committee created a new PowerPoint® presentation that gives an overview of PWS. That's right, the presentation has been prepared for you! Schedule a presentation to service clubs, a group of friends, colleagues at work, or to whomever else you want.

*** Set up a display booth:** Find out about existing events in your community and then ask to set up a table for PWS awareness. PWSA (USA) now has a hand-out about how to set up an awareness table.

*** Send a press kit:** Want to contact the media and don't know what to give them? Send a PWS press kit that PWSA (USA) developed just for Awareness Month! Offer to be interviewed and run with it.



Maureen Fiske, mom to Jacob (2, with PWS), and JB Fiske, Jacob's cousin, generated PWS awareness at the NASCAR Craftsman Truck Series last fall in Florida. JB, who works on Mike Skinner's team, got PWSA (USA) logo decals placed on most trucks in the event, which was broadcast on the Speed Channel. What a winning idea!

*** Increase visibility:** In May, PWSA (USA) will have available new promotional items to help with visibility. Order car magnets, window clings, shirts, pens, or sticky notepads and display them! Think of how many eyes will be on them.

*** Plan a fundraiser or send letters:** It's not too late to send letters or plan a simple fundraising event. Sample letters are ready for you and ideas

are a phone call away. Don't forget, you can also create a web page at www.firstgiving.com/pwsausa.

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Our Mission: PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those impacted by Prader-Willi syndrome.

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User Name: [pwsamember](#)

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Note: If you have difficulty logging in, please contact info@pwsausa.org.

E-mail Support Groups:

We sponsor nine groups to share information.
Go to: www.pwsausa.org/support

The Gathered View (ISSN 1077-9965)

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Published bimonthly by PWSA (USA) as a membership benefit. Annual U.S. membership: \$30 Individual; \$35 Family; \$40 Agencies/Professionals. Membership dues outside the U.S.: \$40 Individual; \$45 Family; \$50 Agencies/Professionals (U.S. dollars). We never deny parents membership for any reason.

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Craig Polhemus

Strengthening Our Partnership

Prader-Willi syndrome is different from most other conditions because it is so complex and variable, and affects each child differently.

So perhaps I should not have been surprised to learn that each of our chapters and affiliates across the country is also unique. (From here on, I use the term "chapter" to include affiliates as well.)

PWSA (USA) Secretary Julie Doherty has been calling each chapter to talk with the officers, obtain current contact information, and get a sense of ongoing and planned activities.

We currently have 30 chapters for which Julie obtained current information, though these cover many more than 30 states because of regional chapters like New England and Maryland-Virginia-DC. Unfortunately we do not have chapters in every state, and of course some chapters are more active than others. We also have a number of PWS support groups, though not throughout the U.S.

For some purposes — identifying parent mentors or facilitating parent interaction through our e-groups (see www.pwsausa.org/egroups) — PWSA (USA) can try to link parents with each other in states without an active chapter. But for community awareness, regular in-person gatherings, and state-level advocacy, parents in states without chapters face challenges alone that can be tackled collectively in states with strong, active chapters.

Five state chapters even have staff (California, New York, New Jersey, Georgia, and Wisconsin), so they tend to lead the way in many areas. Utah has recently developed and testified about a proposal for a full-time PWS care manager in their state health department. Colorado has one of the most active and attractive web sites. Some chapters hold frequent gatherings, others annually or not at all.

Chapters have a lot to share with each other and with parents. Based largely on chapter suggestions, we are doing the following:

- * Strengthening efforts to get new parents' consent to share their contact information with their local chapter.

- * Increasing use of the Chapter Leaders E-mail list (CLE) both for topical alerts and for more in-depth discussion of relevant topics.

- * Enabling chapters to receive, without regulatory or paperwork requirements, the proceeds from donated cars, trucks, and boats.

- * Changing the deadline to submit chapter documents to a month other than May, which is PWS Awareness Month.

- * Highlighting and updating the list of active chapters on www.pwsausa.org [inquiries are referred to PWSA (USA) where no chapter is active].

- * Including in chapter agreements authority to use the new PWSA brand (logo and "Still hungry for a cure" tagline) if they choose, ensuring compliance with the brand usage standards.

- * Asking each chapter to donate something for the Silent Auction held at the Annual Conference.

- * Scheduling conference calls among chapter leaders where I can share news, receive suggestions and complaints, and improve our working partnership.

- * Clarifying chapters' eligibility to receive some free publications and resources.

- * Providing access to new promotion items (car magnets, window clings, sticky note pads, etc.) that chapters can purchase for their use.

- * Sharing "best practices" of chapters successful in a particular area (advocacy, fundraising, awareness, parent support) to inform chapters in other states.

Chapters and support groups provide companionship, support, and expertise on their state's educational, service, and governmental systems. Our strategic plan "envision[s] a U.S. in which... each person... who is impacted by PWS has access to a strong and viable state chapter of PWSA (USA) that is supported by and supportive of PWSA (USA)."

Though we at PWSA (USA) will increase our efforts to bring this about, ultimately parents and others in each state or region make this goal a reality.

To get involved with your chapter, or help start a chapter or support group if none exists for your state or area, please email me at chapters@pwsausa.org. ~

Research View

Selective Deletion of *BDNF* in the Ventromedial and Dorsomedial Hypothalamus of Adult Mice Results in Hyperphagic Behavior and Obesity

By **Mayim Chaya Bialik, Ph.D.**

Obesity and problems with overeating can be influenced by a number of factors in the brain. One such factor is brain-derived neurotrophic factor (BDNF), which is involved in eating and energy regulation. BDNF is found in the brain in the cortex, the hippocampus, and the basal forebrain and it helps brain cells survive and grow. Low levels of BDNF have been linked to depression, dementia, schizophrenia, obsessive-compulsive disorder, Alzheimer's Disease and Huntington's Disease.

Unger and colleagues have recently explored the role of BDNF in energy regulation and eating behaviors by giving normal mice injections of glucose (sugar) and measuring the amount of BDNF in a brain region that is known to be important for these processes, the Ventromedial Hypothalamus (VMH). They found that glucose leads to an increase in BDNF, indicating that when the body gets enough sugar and is full, it signals the brain to make BDNF.

Next, they wanted to see if taking BDNF out of an *adult* animal's brain could affect eating behaviors and obesity as it has been shown to do in fetal and very young mice. Removing BDNF from the VMH and

another important brain region, the Dorsomedial Hypothalamus (DMH), caused them to eat more and become obese. Thus, BDNF normally signals when to stop eating.

This study showed for the first time that BDNF in the adult brain is important for energy balance. If further studies can continue to confirm the role of BDNF in obesity and overeating problems, this factor may be added to the factors important for understanding and managing weight and hyperphagia problems in people with PWS. The mechanisms of overeating involve (to name a few) leptin, insulin, melancortins, noradrenaline, dopamine, serotonin, and the gut hormone ghrelin. There is likely not one singular factor or protein in the brain that causes the complex eating behaviors and subsequent complications seen in those with PWS, but the study of BDNF may be the next step in better understanding the complexity of energy regulation in PWS.

Abstracted from an article in The Journal of Neuroscience, 26 December 2007, 27(52):14265-14274

Dr. Bialik serves on the PWSA (USA) Research Advisory Board. ~

Precautions Advised When Starting Growth Hormone With PWS

We advocate a sleep study before the start of growth hormone (GH) on infants, children and adults with PWS and a follow-up study 6-8 weeks later.

If obstructive sleep apnea (OSA) worsens on GH, temporarily stopping GH is recommended until the cause is understood. Frequently OSA can be corrected by removing the adenoids and tonsils or lowering the GH dose (in the face of an abnormally high IGF-1). We also recommend taking precautions during bouts of upper respiratory infections.

Dr. Merlin Butler also recommends obtaining a thyroid function test and cortisol levels (in a.m.) before starting growth hormone treatment. He has done a recent study on cortisol levels in 63 subjects with PWS and found one of four infants with PWS had a low cortisol level. There has been some discussion about adrenal hypofunction in a subset of PWS.

Studies have shown that in most individuals with sleep-disordered breathing due to PWS, GH

can actually improve (or at least doesn't worsen) the apnea (Haqq et al, 2004; Miller et al, 2006; Festen et al, 2006).

Withholding GH from those with sleep apnea may be detrimental on several levels, thus the recommended approach is monitoring children with PWS closely when starting GH to make sure that they do not worsen.

— **Jennifer Miller, M.D., M.S., Endocrinologist, PWSA (USA) Clinical Advisory Board;**

Merlin G. Butler, M.D., Ph.D., Chair, PWSA (USA) Scientific Advisory Board;

Daniel J. Driscoll, M.D., Ph.D., Chair, PWSA (USA) Clinical Advisory Board ~

Donations for Research in 2007

\$249,224

Donations since 1/31/08:

\$11,005

Skin Picking and Prader-Willi Syndrome

By Linda Gourash, M.D.

The “skin picking” behavior of PWS has a wide range of severity across the syndrome and sometimes in the same person over time. As Wigren reported in 1999, stability over time is more typical. Some have occasional minor skin picking while others maintain large open wounds.

In the “PWS Personality” presented in 2006, we separated *skin picking as a habit behavior* (common) from *self mutilation* associated with extreme emotional distress (less common). Here we will only address the former and leave the latter and rectal picking for another day.

Why do they pick? Some speculation.

Much of PWS behavior makes more sense when viewed as a failure to inhibit. The eating behavior is largely due to defective “brakes” called satiety. The drive to skin pick in PWS may be a normal drive (who has not picked a scab?), but the limiting signals are weakened. We speculate that these signals are pain and disgust; both are neurologically based but apparently reduced in PWS.

Skin picking as a habit behavior

Here, skin picking is defined as an activity that has no apparent function. It goes on when the person is calm and it does not appear to be causing any emotional distress. It has been related to boredom and anxiety, but objective evidence has been difficult to establish. It is characterized by opportunistic topography, i.e., convenient location. Features include:

- * Arms, face, scalp
- * Nose, nasal septum
- * Nail cuticles
- * Pulling out toenails, teeth
- * Peeling skin from soles of feet

No specific intervention has been uniformly effective. The behavior often extinguishes if wound healing is achieved. Success has been limited using protective dressings (Band-Aids) and an intense program of alternative activity until wound healing occurs. Behavioral interventions have been effective in some cases (see box on page 6).

Points on management

Because skin-picking behavior occurs intermittently and secretively, behavioral interventions target-

ing the activity itself are difficult to implement. A basic principle is that no attention (positive or negative) should be paid to the behavior itself other than to require the person to observe social conventions and good hygiene.

Obsessional, but not OCD

The behavior appears to be “compulsive,” however, it is not an obsessive-compulsive behavior, and medications targeting OCD (obsessive-compulsive disorder) or anxiety have not been helpful. If the behavior is clearly related to other signs of anxiety, then the anxiety should be addressed with environmental changes, including a re-evaluation of the person’s food security. Note: Anti-anxiety medications, while helpful for anxiety, carry the risk of increasing irritability or triggering mood activation (hypomania, irritability, increased impulsivity, restlessness, and increased goal-directed behavior including food seeking). Mood activation can begin weeks or months after medication has been started even when effective for reducing anxiety.

Use of Topiramate

Topiramate (Topamax) in low doses has been effective for some people and should be considered in those with severe picking. In 2002 Shapira¹ and others gradually increased to 150-200 mg daily and reported that some patients responded and some did not. Side effects include irritability, cognitive blunting, and RTA (renal tubular acidosis), all dose dependent and reversible. RTA is diagnosed when serum electrolytes show an elevated chloride and decreased bicarbonate in the blood. These issues should not deter a trial of the medication, but provide a guide for what the physician should monitor. If lesions heal, a trial off the medication makes sense, since healed lesions are often left alone. Allow 2-3 months on the medication to evaluate efficacy.

Anecdotally, sensory stimulation has been quite effective for some severe picking behaviors. Sensory modalities have included vibration or massage administered on a schedule multiple times per day. The sensory stimulation should not be linked verbally or temporally with the picking behavior, as this could result in rewarding the behavior. More information

Skin Picking continued on page 6

on using sensory integration techniques has been assembled by Janice Agarwal, P.T. and is available on www.pwsausa.org.

1 Shapira, N.A., Lessig, M.A., Lewis, M.H., Goodman, W.K. and Driscoll, D.J.: Effects of Topiramate in Adults with Prader-Willi Syndrome. *Am. J. Mental Retardation*, 109:301-9, 2004. ~

**A Program To Address Typical Skin Picking
Pittsburgh Partnership
Linda M. Gourash, M.D. Janice L. Forster, M.D.**

1. Tell the child that you want to help her sore to heal. Do not talk about the "picking."
2. Tell him that when the sore heals you will celebrate with a special reward.
 - * This reward should be motivating but not too motivating; rewards that are too motivating can create anxiety. Also there is the risk that an older, more clever individual will deliberately create wounds to heal to earn the reward.
 - * Be prepared to offer the same reward on multiple occasions.
 - * Try to anticipate situations when picking tends to occur. Before he starts to pick, remind him he is working to gain this reward.
 - * Once the reward is earned, offer it weekly (for very young or low functioning children or for severe pickers) or monthly for "no new sores."
 - * If a reward must be withheld because of a continued open sore, express your disappointment that the reward was not earned and your optimism that he can achieve it very soon. Most superficial sores if truly left alone will show marked improvement in a matter of 2-3 days.
3. Tell her that you have medicine to help the sore to heal.
 - * Plastic surgeons use Polysporin ointment on healing wounds to minimize scarring. It also keeps the area soft and slippery, apparently less tempting and less easy to pick.
 - * Use Polysporin ointment on the sore as frequently as possible (every ½ - 1 hour while awake) and apply thoroughly at bedtime. Use a dressing or some other barrier where anatomically possible. Your purpose is to make the picking less convenient.
 - * The ideal dressing is NOT airtight but is difficult to remove. On arms and legs this can be gauze wrap covered with cling wrap.
 - * If there is no evidence of picking during sleep, leave the area open to the air. Socks or mittens taped at the wrist have been used for nighttime picking. ~

Wound Healing With PWS — How Many Calories?

I am often asked about situations where a person with PWS gains a lot of weight in the hospital because the dietician states that patient needs to be on a high protein diet to heal the wounds.

A recent example is a 47-yr-old woman (height 4 ft., 9 in.) with two leg ulcers put on 1,500 calories in the hospital despite the fact that her mom had her on 1,200 calories prior to admission. She was 195 lbs. when she entered the hospital and gained 40 lbs. during that hospital admission. I asked two members of our PWSA (USA) Clinical Advisory Board to comment. Their responses follow.

—Janalee Heinemann, Director of Research & Medical Affairs

Response 1

People with PWS have healed deep bedsores while on a weight loss diet as low as 800 kcal per day and an exercise program. At no time should a person with PWS be permitted to gain weight while in the hospital for wound healing or any other reason.

Linda M. Gourash, M.D., Developmental and Behavioral Pediatrics, Pittsburgh Partnership, Pa.

Response 2

For weight loss, I would limit calories to 800-900 per day. This includes any calories provided from a protein supplement. Novartis (800-333-3785) makes Resource Beneprotein Instant Protein Powder. A scoop provides 6 grams protein, 25 calories. The dietitian can recommend how much, based on baseline albumin and prealbumin level.

Prealbumin should be followed at least once a week while inpatient to help adjust the Beneprotein additive. Note that other medical circumstances, such as kidney issues, may negate addition of Beneprotein to the diet. Your medical team will decide if a protein additive is appropriate.

Supplementation with vitamins A, C, and zinc may be helpful with wound healing of ulcers. The following regimen may be considered: vitamin C: 250 mg BID; vitamin A: 2500 units/day; zinc: 220 mg/ day; complete multivitamin daily. This would be given by mouth for 10 days. The dietitian should be sure a calcium supplement is added to the regimen (especially if the calories are restricted) to ensure bone mineral deposition. DRI/age for adults is 1300 mg calcium/day.

*Norma Terrazas R.D., L.D.,
Pediatric Dietitian, Texas Children's Hospital ~*

Adults with PWS Advisory Board Meets

The Adults with PWS Advisory Board met in Sarasota on January 26 and 27. They reviewed a PWSA brochure, took an eco-boat tour, created awareness cards, and developed a mission statement.

Mission priorities include:

- * Provide Peer Support through helping and educating people with PWS;
- * Educate professionals and providers of services/support;
- * Advocate for the development and support of appropriate residential programs for people with PWS;
- * Increase awareness through appropriate media representation;
- * Provide support and guidance to families including through state chapters.

The entire mission statement is posted on www.pwsausa.org ~



During their meeting, the Adults with PWS Advisory Board visited a local Sarasota resident, Leslie Espola, who also has PWS. Front L-R: Brooke Fuller, Conor Heybach, Leslie, Andy Maurer Back L-R: Lauren Lange, Shawn Cooper, Abbott Philson, Kate Kane

Get a Moove On!

Register Now for the 2008 PWSA (USA) Conference



We're expecting a great turnout for our 30th Annual PWSA (USA) National Conference! It will be held in Milwaukee, Wisconsin at the Wyndham Milwaukee Airport & Convention Center.

Scientific, Provider and Chapter President/Affiliate Day is July 2, followed by the General Conference July 3-4. The annual Gala Banquet will be held Thursday, July 3.

General Conference is a parent/caregiver-oriented program that brings together parents, caregivers, scientists, clinicians and professionals in PWS. It includes sessions of interest to all, plus breakout sessions specifically geared to issues of Adult, Youth (school age), and Children age 0-5. The conference includes a structured care Youth and Infant Program (YIP) for children with PWS and their siblings (limited to ages 0-5).

All programming is age appropriate, directed and supervised by trained volunteers and staff. PLEASE NOTE: The Pre-YIP Program for children ages 0-5 of Chapter Presidents and Affiliates on July 2 is \$50. YIP fees for the two days of General Conference programming are \$100 for ages 0-2 and \$125 for ages 3-5.

Registration will be available April 1, 2008 on the PWSA (USA) website. We have a block of rooms at The Wyndham Milwaukee Airport & Convention Center at the discounted rate of \$98 a night for up to four in a room. To make hotel reservations via Globetrotter Travel, call 800-322-7032 (Ext. 2), e-mail pwsa-usa@globetrottermgmt.com, or online at www.globetrottermgmt.com/pwsa-usa.

Don't miss the opportunity to meet new friends, renew old friendships and learn about the latest in nutrition, clinical care, research, and therapies. This is an event for the whole family.

To learn more about the conference and see the latest on presenters and invited speakers, go to the conference website, www.pwsausa.com/conf. ~

Will the Sun Ever Shine Again?

By Pam Eisen, President, International Prader-Willi Syndrome Organization

From my Journal: February 3 – February 6, 1980

Will the sun ever shine again? It doesn't seem possible. All around me babies are cooing and mothers are smiling, while my daughter lies limp and cold. A little girl just came into the hospital to peek in the nursery and meet her new baby brother. A precious child full of vitality, she's dressed in pink with ribbons in her hair and laughter bubbles over. I take one look at her and I can't stop crying, realizing that my daughter would probably never skip or laugh, or even live.

Didn't the doctor just say, "Your baby will die and if she lives, she will be severely retarded?" No, I never will see the sun shine again. There will always be dark clouds.

Didn't I say something was wrong all through my pregnancy? When I told the doctor my baby's not moving like my other children, he said, "All babies are different, some move more than others." When I asked why I wasn't gaining much weight, he said, "None of your babies were big; you have a small frame."

What went wrong? I took care of my health and did everything to insure my child a good start. I am swimming deep under the water and I can't come up for air.

Every time I look at my daughter, I cry. It was just a few weeks ago that I convinced my obstetrician that my baby would not go to the nursery and we would go home after only one night in the hospital. What am I doing here, holding my limp baby to my breast when she takes no interest in feeding? I haven't seen her eyes open once, she can't keep her temperature up, and I lean down close to feel if she's breathing.

I went into the shower and stood there with water streaming over my face. I could feel the scream beginning from my inner soul. It began low in my gut and rose through my body in a thunderous roar which no one heard. The torturous sound remained silent as I tried to force my sorrow out from the very depths of my body. All the tears in the world cannot console me and I am empty of emotion. Is this what Edvard Munch's [painting] "The Scream" personifies?

It's been many years since I've looked at these thoughts which I wrote in great sadness.



Pam Eisen with her daughter Gabriella, who has PWS

[My husband] Barry brought Jeremy and Benji to the hospital today and they demanded to see their little sister. Looking at her through the window of the nursery, Jeremy asked, "Why isn't my sister with the other babies? Why doesn't she move or cry?"

This was the hardest moment, putting on a pretend smile, fighting away the tears, and protecting my sons. "Do you remember when we planted our flower garden? Some flowers needed more care and water than others..." I began.

What will this mean for my sons? How will they cope? For their sake, I must get myself together. Stop crying, Pam, you must call every doctor you know and find out what you can do to keep Gabriella alive. There. I did it. I wrote her name down. It's so hard when I know she might not live. But look at her little helpless body, dislocated hips, turning blue, struggling to breathe... I must will her to live.

April 2, 2006:

The words above were some excerpts from a journal I kept; it's been many years since I've looked at these thoughts which I wrote in great sadness.

Gabriella continued on page 9

Yes, the sun does shine again; in fact, in many ways Gabriella is the sunshine! She has taught my family many of life's important lessons, but it took me a while to learn this.

Taken the second day of her life, the chromosomal analysis showed no abnormalities, and we did not have a diagnosis for a long time. Even at 1 year, doctors from three major medical centers told us Gabriella would die.

At [age] 3, when she began to finally gain weight, I realized something was strange. For the number of calories consumed, Gabriella was gaining too much weight.

Spending hours in a medical library, I came across an abstract written by doctors Prader, Labhart and Willi, and I knew instantly that there really was a reason for the strange pattern of her development; she had Prader-Willi syndrome. Nevertheless, although we traveled to many medical centers, even a special PWS clinic, Gabriella's doctors refuted this diagnosis.

It was not until she turned 7 that we received a definitive medical diagnosis. By this time we had learned to take each day and make the very best of each moment.

Life was different than we expected, there were many challenges (and still are), but we learned as a family not to take things for granted. Every small progress in Gabi's development has been a huge accomplishment and just because she is different does not make her any less beautiful to us.

When our children were small, my nephew declared that when he grew up he would be a paleontologist. My son Benjy said, "I'll be a famous writer."

Gabriella, despite articulation problems, asked clearly, "What be me?"

Without hesitation, my husband answered, "You'll be Gabriella!"

Gabriella smiled and exclaimed proudly, "I be Gabriella!"

The sun was shining brightly. It still does. ~

Her Light Shines Bright

By Janalee Heinemann, PWSA (USA) Director of Research & Medical Affairs

Pam Eisen wrote the article above for us months ago. Her husband Barry died 11 years ago of cancer. Gabriella is now 28 years old and settled in a wonderful, supportive living home. Pam has been the president of IPWSO for 4 years and prior to that was our PWSA (USA) delegate to IPWSO and an IPWSO board member. During Pam's term as president, she has helped grow the organization from 48 countries represented to 80!

I am very sorry to tell you that recently Pam was diagnosed with Stage 4 pancreatic cancer which has spread to the liver. Having worked so closely with Pam and traveled to many countries with her, I struggled to describe how special Pam is and what a significant role she has played in spreading information and hope to the world of Prader Willi syndrome. I decided the best way is to excerpt quotes from the many e-mails sent to Pam that I am collecting to put in a scrapbook for her children.

As long as she can, Pam plans to work to set the future direction of IPWSO, and do all she can to get the funding needed so her work lives on. The sun may set on Pam, but her light will always remain bright.

** I hope you are aware of your significance to all of us. . . . it is you who is always able to generate both a personal relationship and interest in everything we all are involved in with PWS. — Larry Genstil, Israel*

** I know that in times like this, words are useless, but since we are far, we cannot show otherwise our gratitude for everything you have done for us. I remember writing to you in a desperate gesture when I found out that my son was diagnosed with PWS. . . and then, like a rainbow over long rainy days, I have received your e-mail, it was for me "the hope" . . . we have found ourselves a family, IPWSO family. . . I will never forget you and thank you so much. — Vali & Eric, Romania*

** This association is formed only due to your support and inspiration and it was a dream which I saw from your eyes. . . . You mean the most to me and meeting you had completely changed my life. . . and you showed me the path . . . the motive in my life. — Shikha, India*

** From the very first time I met you, you greeted me with love and warmth and you immediately made me feel comfortable and welcome. You live and speak with your heart and your passion for individuals and families with PWS simply radiates from you — Karen Balko, Canada*

** What I do know, is your huge love and passion for everything around you and the enthusiasm and the feeling that people can breathe around you. This is something staying inside your soul and nothing and nobody can change or take away. . . . This is something special, something remaining in the wind, something surviving to any battle, something we will own for ever. — Beppe, Italy ~*

Fundraising From the Home Front



Beauties at the Capraro family fundraiser include, L-R: Courtney and Amanda Ciciora, Lea and Tori Capraro, and Benita Gingerella.

Capraros Host Thrilling Fundraiser

Thanks to the Capraro Family of Oak Brook Terrace, Illinois and friends of Lea Capraro, the fall 2007 *Thriller Night Spooktacular* at Butterfield Country Club netted \$105,000 to benefit PWSA (USA).

The adult costume party was attended by 200 people and included dinner, dancing, live and silent auction, prizes and entertainment. Bill and Tina Capraro's daughter Lea, who has PWS, and her siblings Will and Tori ran a card drawing that earned \$11,000.

Bill's company, CIMCO Communications, raised an additional \$30,000 from his generous vendors to cover event costs. "Several companies, such as Pat Fitzgerald of Source Four, who underwrote printing the invitations, saved us thousands of dollars. They were angels in disguise," said Bill, who serves on the PWSA (USA) Board of Directors.

Live auction items included an adult martini pool party, Chicago Bears tailgate party and a diamond necklace donated by jeweler Alan Rocca. Alan and his team also designed event-exclusive, Halloween-themed diamond necklaces that sold with a percentage of the proceeds benefiting PWSA (USA).

Tina and her committee spent over 7 months planning the event, the fourth fundraiser the Capraro Family has organized in the past 8 years. "We continue to be amazed by the generosity of our friends who support the PWS organization," said Tina, adding, "It was very rewarding to send a check to the folks at PWSA (USA)." ~

PWSA (USA) appreciates all the volunteers who conducted grassroots fundraisers and who raised approximately \$300,000 net in 2007! A BIG THANK YOU goes to those listed below (list continued from Jan.-Feb. 2008 issue of *The Gathered View*).

Co-ed Slow Pitch Softball Tournament in honor of Anneke Kramer, Stephanie Daale, Shannon Daale & Stacy Kramer, IA

Dress Down Day in honor of Madison Smith, Anita Streubel, NY

Dress Down Day & Pretzel Day at EDS, Heidi Metcalf, NJ

Elizabethtown College Student Night of Music, Autumn Metcalf, PA

Fun Day at the Moose for PWSA (USA), Barbara Emmons, IN

Fundraiser in honor of Chelsea Lyn Reddinger, Lori Reddinger & Bruce Loser, PA

Fundraiser in honor of Maddie Hurdle, Alan Beser Instructional League, CO

Gavin's Day, Jennifer Jones, FL

"Give Your Heart for Phillip" Fundraiser, Emily Sprague, NY

Golf Fore PWSA Charity Annual Golf Tournament in honor of Madison

Hurdle, Clint and Karla Hurdle, CO

In honor of Hudson Self's 1st Birthday, Megan and Josh Self, NC

In honor of Dillon Willis, N.E.S.C., KY

Jenna's Hope for a Cure, Pam & Emanuel Santos, MA

Julianna's Wish, Dawn & Tom Romine, OH

Macy's Shop for a Cause Day, Heather Valeo, NJ

McDougall Marathon in honor of Noelle, Amy McDougall & Family, CT

Nathan's Run, Natalie McGrady & Cheri & Denny Swartz, OH

Poker Night in honor of Ethan McElheney, C. Preston & Chea McElheney, NC

Premier Designs PWS Fundraiser, Denise Castiello, NJ

Putt for PWS in honor of Charlie & Riden, Dominique DeLeague, Jessica Howard, Fiona Olson, VA

Fundraiser in honor of Kaitlyn Disney, Laura Disney & Denise Castiello, NJ

PWS Pool - March Madness, Jim Kane, MD

PWS Yard Sale in honor of Trevor Wolfer, Roxanne Wolfer, CO

Ragnar Relay for Jett Lewis & PWSA, Dee Dee & Brett Lewis, WI

Richmond, VA Marathon in honor of Luke, Tim Mukoda, VA

Run to Heal, Jim Palmer, CA

Seattle to Portland Bicycle Classic Fundraiser, Mike Kuna & Scott Kuna, OR

Shawna's Walkathon for PWS, Shawna Bush & Joyce Bush, CT

Sophie's Walk for PWS Awareness, Jennifer Bolander & PWSA Ohio, OH

Tupperware Fundraiser for PWSA (USA), Yolanda Ornelas &

April Kercheville, NY

Vendor Fair in honor of Brooke Detiege, Nicki Detiege, MI

(We try to be accurate. Please let us know if you notice an error.) ~

Raise Funds on firstgiving.com

Creating a fundraising page to support PWSA (USA) in honor of a birthday, wedding, anniversary or any celebration is easy. With your personal web page on firstgiving.com, you can see all those who have donated, post your own pictures and personalize your message. Then all you have to do is send the page to everyone you know via e-mail and watch funds start streaming in. You can begin fundraising by going to:

www.firstgiving.com/pwsausa ~

Fundraising From the Home Front

Thanks, You Did It Again!

By Rachel Elder, Community Development and Jodi O'Sullivan, Director of Development and Communications

The Hurdle Family Knows Baseball

The 3rd **Annual Madison Hurdle Softball Tournament** raised more than \$7,700 for PWSA (USA). To honor their niece, Madison, 5 years old with PWS, Bobbi Jo and Dino Martello and 13 volunteers put together the awesome event. Nearly 200 people attended, along with Clint and Madison Hurdle. Bobbi Jo writes, "Clint was there from start to finish and he was wonderful! He signed hundreds of autographs and took many pictures. When Maddie got there she stole the show!"

The event included a silent auction, raffles, giveaways, autographs, and pictures that helped bring in funds. Bobbi Jo writes, "some families with children who have PWS [came] out. That was so special to me."

Celebrate Like Hudson

A very special **happy birthday to Hudson Self**, age 2 this year. In honor of his big day, his family asked that funds be donated to PWSA (USA). One avenue they used to collect funds was PWSA (USA)'s firstgiving.com fundraising site. Hudson's page reads, "This is a birthday present that will have more of an impact on my future than any toy I could receive! Your donation *will* help PWSA (USA) continue to provide priceless assistance to children and adults just like me that have Prader-Willi syndrome." The Self family raised more than \$3,000!

The Name of the Game is BINGO

In December, Anita and Kyle Perrault and their family hosted the 3rd **Annual Jacob Bingo Fundraiser** in honor of their son **Jacob Perrault**, 4 years old with PWS. The event continues to grow each year. "It was a huge success for us," writes Anita. This year they raised more than \$6,100 with help from a match by Johnson and Johnson. The family also auctioned baskets of donated items. Anita writes, "This was our biggest turnout of close friends and family (85) and the largest donation we have been able to give to PWSA [for] research. It feels so good to not only support an organization and to give back, but also to look around the room and see the love that is there for Jacob!"

Bowling for the Holidays

For the second year, Sharon Mayo and the Tuskegee Airmen Motorcycle Club of Virginia held the **Prader-Willi Bowling Fundraiser** in December, this year raising \$700. The holidays are busy, but nearly 100 people came to support Sharon and her family. Sharon's daughter **Johnae Mayo**, 10 years old with PWS, was the highlight of the event. Sharon said "A lot of people in our area just don't know about PWS. We wanted to let them know that this is something there is no cure for, but we're working on it."

The event has grown tremendously from the previous year — from six bowling teams in 2006 to 18 in 2007. "We definitely plan to do this again next year and hope to raise \$1,000," said Sharon.

Not Fore, but Four

November 2007 marked the 4th **Annual Prader-Willi Classic in honor of Josilyn Levine** (age 5, with PWS) and **Zak Bassel** (age 3, with PWS). At the PGA National Resort and Spa in Palm Beach Gardens, Florida, golfers teed off for this Pro-Am event. Every group played with a caddie and either a teaching or touring professional. Leta Lindley, LPGA pro on the tour, made a special trip from California to participate. Says Ronnie Levine, Josilyn's grandmother, "Josi's favorite LPGA golfer is Leta Lindley. Josi follows her career and tells people that she plays with 'my friend Leta.'"

Jamie Bassel, father to Zak and PWSA (USA) Board member, said Zak and Josi hit the first balls. "The special part about the event is having the opportunity to share this event and recognize that it's not something we do alone for the purpose of research and PWS." Janalee Heinemann, PWSA (USA)'s director of research and medical affairs, spoke about PWS.

Ronnie noted the community support and support from other local PWS families. She and Jamie agreed the highlight was Josi and Zak, who, for the first year, got up by themselves and thanked people for coming. The event raised \$20,000 for research. Now that feels like a hole in one! ~

Never Say Never

By Linda Ryan

I don't know if I can illustrate the wonderful feelings we're experiencing. Let me begin by saying to all parents of children with Prader-Willi syndrome: Never say never.

Two years ago, when our son Trevor was in 10th grade, my husband Mark and I sat in our annual IEP meeting. California had a new law requiring that all high school seniors pass the CA High School Exit Exam, known as the CAHSEE. It has two parts, English and math. Students need a passing score of 350 to graduate with a high school diploma instead of a certificate of completion.

Trevor was enrolled in special day classes at the time, with a few mainstreamed courses in his areas of interest. The exam is given in November and March, and students can take it as many times as necessary to pass.

At his first attempt in 10th grade, Trevor failed both parts of the exam. Not to worry, said the counselors and teachers, we have many more attempts before we get discouraged. In November of his junior year, Trevor's second attempt, he passed the English portion, but failed by one point in Math, scoring 349 out of 350.

Our next IEP held a remarkably different tone: Are you sure you aren't putting too much pressure on Trevor, his teacher asked. A high school diploma is not such a big deal, the principal said. It's not like he'll need it for future employment. Let's take him off the diploma track, said his counselor. Trevor's skin picking is increasing; he's nervous about letting you down, said the school psychologist.

We told Trevor that no matter what, he was a success to us. We asked if a high school diploma was important to him. He said it was.

Our next job was to convince the school district that we were not going to be swayed from our goal; we'd do everything in our ability to help Trevor be successful and we expected the same from them.

A little insider information here: we invited the school district's superintendent of special education to lunch and explained our position. We asked for as many accommodations as were legal — extra time, use of a calculator, a proctor to keep Trevor



Linda and Mark Ryan celebrate with their son Trevor, who passed the California High School Exit Exam.

awake, etc. We began tutoring twice a week with a math teacher who not only knew what to teach but how to teach it to Trevor, which I will admit is a tough task. Trevor gained confidence in trying new methods and we encouraged him along the way.

On testing day we were all a little nervous, but each of us knew deep down that we had given it our all. Weeks later I got a call from Trevor that I will never forget. "Mom!" he yelled into the phone. "I passed the CAHSEE!"

I truly believe this is one of the most cherished phone calls I've ever received. Never have I been prouder of the accomplishments of my son or, frankly, of my husband and me as parents of this wonderful young man. We all earned this moment. I encourage each of you to not listen to the doomsayers of the world. Instead, listen to your children and your heart, for they are the guides that will bring success.

Linda and Mark Ryan live with Trevor in Newhall, California. Mark serves on the PWSA (USA) Board of Directors. ~

Nothing to 'Lose' by Trying

If you'd like to shed a few pounds this spring, try reaching your goal with Lose-A-Thon. It runs until the end of May, which is PWS Awareness Month, so there is still time to sign up! Currently we have 37 Lose-A-Thon members. Participants have lost weight and gained nearly \$3,000 for PWSA (USA) so far. Sign up today at www.pwsausa.org/fundraising/lose-a-thon. ~

Mayor of the 11th Floor

By Lisa Peters

He sat bravely on his hospital bed, his tiny head covered in neat rows of shiny, metal electrodes, giant tears streaming from his eyes.

"Mummy, I don't want to put the buttons on," Nicholas screamed, kicking his feet and flailing his arms. I held him tightly and watched as the hospital staff prepared my 6-year-old son for an EEG.

"I know, Nicholas," I said, feeling a large, dry lump of helplessness and fear climb slowly up my throat. I tried to swallow that lump, but my throat was too tight. I watched as my son's head become lost beneath hundreds of tiny wires. I put my head down and swallowed again, trying so hard to get down that painful stone of emotion.

The glue holding the electrodes on Nick's head smelled like alcohol. It stung my tired eyes. "I will not cry, I will not cry," I repeated to myself. "I need to be brave for my son."

I thought about the many procedures my small son had endured in his few years of life. Why was he born with PWS? Why did this innocent child have to endure so much pain? Why was our life so hard? I asked many questions inside my head, knowing no one would answer them.

"We're done!" the nurse said.

I loudly blew out the breath I had been holding for hours. I thanked God that this torturous procedure was over.

"Oh, thank you!" Nicholas said enthusiastically, turning his wire-covered head to look at her.

"You're welcome," she said, stunned that this once screaming child was now quite composed and thanking her profusely for putting him through such a terrible ordeal. She finished by taping a gauze-like stocking hat gently over his head.

I prayed this ghastly vision of my son's tightly wrapped head would not make me cry.

The nurse attached his wired head to a battery pack that was tucked neatly inside a small black backpack.

Nicholas looked at the pack and smiled brightly.

He clapped his hands with glee and exclaimed, "Look, Mummy, a rescue pack, just like Diego!" He quickly put his arms through the straps of the backpack and smiled kindly at the speechless woman, melting her heart with his enthusiasm.



Nicholas is wired for an EEG

By quickly changing his mood, my unique son silently explained he understood the meaning of the word *resilience*.

I did not.

I wiped the tears from my face.

Throughout our hospital stay, I watched in awe as my son warmly touched the lives of so many fellow human beings. The entire neurology wing seemed pleased to meet this happy little soldier wearing his headdress. They nicknamed him "The Mayor" as he comfortably chit-chatted with people on the 11th floor. Nicholas warmly greeted all patients, janitors, doctors, and nurses. He treated everyone with compassion and appreciation.

Even the stern woman who monitored Nicholas's sleep came into his room smiling one day. She guided me into the lab where TV monitors recorded patient movements. There on one of the screens was the smiling face of my precious son, his head resting gently on the colorful picture of SpongeBob SquarePants that adorned his beloved pillow. It was difficult to discern who was happier, the silly, yellow sponge or the beautiful child wearing a turban made of gauze.

I am amazed at this young boy's desire to reach out to others despite the overwhelming difficulties in his life. I realize it is my life that is difficult, not his.

I am like all parents of children with PWS. My life is a mixture of incredible pain and thoughtful introspection. I must watch my beautiful son suffer more than most. But also I must watch as he easily makes people in the world around him smile.

When we packed our bags to leave Children's Hospital, many of the staff came in to shake Nicholas's hand good-bye.

"Good-bye," he said to them all, "drive carefully!"

Lisa and Jeff Peters live in Georgetown, Massachusetts with sons Weston, 8, and Nicholas, 6. ~

Maribel Finds Success At Wisconsin Group Home

I thought you'd like an update about my daughter, Maribel Rivera, who is 27 years old with PWS. Currently she's in a group home in Wisconsin, not too far from Milwaukee where Annual Conference 2008 is going to be held in July.

Maribel has been with the group home for two years now. Her initial weight was 235 lb. and she is now 130 lb. She has Diabetes Type II, but medication has been reduced, her behavior has been better and manageable. She no longer needs to use a C-Pap machine for her respiratory problems. She was honored in Special Olympics in bowling. Her first round she got third place, then second place in Regional and at State she received sixth place.

Maribel has come a long way. Maybe you recall my older daughter made a movie about PWS and Maribel. It became good awareness and had good publicity. I know there are so many good stories shared and this is another successful story.

Mercedes Rivera, San Diego, California ~

Awareness - continued from page 1

*** Blog it!:** Create a personal blog and write about PWS so others can begin to understand the impact PWS has on the family. Include a link to the PWSA (USA) web site so visitors can immediately learn more about PWS. Don't know how to get started? PWSA (USA) now has a write-up to help you and a link to a sample blog so you can see how it could work.

Visit www.pwsausa.org and click on "Awareness" to find tools you can use. Of course you can call PWSA (USA) to discuss ideas, too. We hope you'll help to generate more PWS awareness. May is a prime time for an integrated effort from all of us working together, but any time is a good time if it means more people will know about PWS.

Special thanks to Awareness Committee volunteers: Carroll Beeson, Cindy Galyean, Sarah Garrett, Lori Guthrie, Karyn Ogata Jones, Viki Knopf, Dawn Romine and Lisa Varndell. ~

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Chuckle Corner

One day my son Reagan (almost 5, with PWS) and I were discussing what kinds of foods are good for you and what kind of foods are bad for you. We were talking specifically about fish. I was explaining to him that there are many types of fish, salmon (which he does eat), mackerel, tuna, cod, etc. Then I asked, "Reagan, what kind of fish is your favorite?"

He responded, "Goldfish!"

He had me!

Diane Seely, Plain City, Ohio ~

National Parks Pass Available For Those With A Disability

Here's a great benefit from the National Forestry & Wildlife Division. It is a free lifetime access pass for any person with a disability or for the caregivers of a person with a disability. The pass allows access to all national parks free of charge.

All that is required is a letter from the physician stating the disability. Present the letter at your local National Forestry & Wildlife Division to get the pass. Each pass will admit up to four adults, and children under 16 are always free.

This link gives more information:
<http://store.usgs.gov/pass/access.html> ~

PWSA (USA) eSupport Groups

Go to www.pwsausa.org/support, and click on the group that interests you.

- Autism – Parents/providers of dual-Dx PWS/autism
- 0-5 – Parents/providers of infant/preschool children
- 6-12 – Parents/providers of school-age children
- Teens – Parents/providers of teens/young adults
- Grandparents – Grandparents of those with PWS
- Military – Parents and providers in the military
- PWS – For people with PWS
- Siblings – For siblings of those with the syndrome
- Spanish – For Spanish-speaking parents/providers

PWSA (USA) gratefully acknowledges the production, printing and mailing of our newsletter is made possible by a generous grant from CIBC World Markets Corp./Miracle Day

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Continued on page 14

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

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

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