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

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

Light Bulbs and Changing the World

By David Crump, Development Coordinator

"How Many Light Bulbs Does it Take to Change the World?" I read an article recently by this title, about compact, energy efficient fluorescent bulbs – the ones that look like a soft custard ice cream cone. The theme was how increasing use of these bulbs will dramatically decrease the use of electric energy and the associated production of greenhouse gases around our planet.

This got me thinking about light bulbs in another way – in connection with *Prader-Willi syndrome awareness.* You've seen the cartoon images – a brightly lit light bulb suddenly popping into view above a character's head. It signals a new idea, or the sudden understanding or recognition of something that was previously vague or unknown. *"Suddenly the light came on."* Or, *"Finally, it dawned on me."* Or, *"Aha!"*


Alex Agarwal, age 11

Of course, these images and phrases also describe what we want the outcome of awareness to be. For example, when you set out to "increase awareness" about PWS, isn't it your hope that folks will experience that proverbial light bulb appearing above their heads? Once they've seen, heard or experienced something about our family's story or about the challenges faced and victories achieved by our family member with PWS, isn't it our hope that the words from their lips will be: *"Now I understand. It's like a light has come on!"*

So I wonder: **How many awareness light bulbs does it take to change *our* world, the world of our PWS community?**

When we talk about awareness, we should be thinking of at least two different audiences. First, there is awareness work to be done ***within* our community**. There are parents and family of a child newly diagnosed with PWS. There are also those who have been part of this community for a long time but don't have the latest warning, treatment, or research information. Our task here is to increase the light, to add to understanding that will continue growing over a lifetime. At the national PWSA (USA) offices our staff works with folks in both these categories every single day, providing a listening ear, and helping families connect with a wide array of resources and other supports.

The second audience to reach out to are those ***outside* our community**. This can include members of our extended family, our neighborhood and town, government officials, and our nation and world. Many have never heard of PWS. They don't have an inkling about what it is. The bulbs we hope to light for them are more general. For example, if we can make the words "Prader-Willi syndrome" no longer strange, but words that they now connect with a person, or a picture, or a conversation; if when they hear that name, they remember that persons with this syndrome experience an insatiable hunger, then we have begun to turn on the light.

With the vision of helping us, together, increase our effectiveness and impact, this year PWSA (USA) is launching Prader-Willi Syndrome *On The Move,* a first annual national awareness campaign.

So how many awareness light bulbs does it take to change *our* world? The answer isn't as easy as comparing energy consumption between traditional bulbs and "ice-cream-cone bulbs." However, I think we all would agree

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that the more *awareness bulbs* we can light up for PWS, the better! Our vision is for ever-increasing knowledge and understanding within our own community, within the larger community, and in the entire world.

While certainly part of what we are doing all year long, the month of May is a special time when we in the PWS community focus on spreading awareness. With the vision of helping us, together, increase our effectiveness and impact, this year PWSA (USA) is launching **Prader-Willi Syndrome *On The Move,*** a first annual national awareness campaign. Chapters and other groups around the country are signing up. The goal is to grow awareness and to raise funds for local initiatives as well as for the national Association. To help with this effort, PWSA (USA) has created a campaign graphic and theme, including the Prader-Willi *move character.* We are also offering event guides, fundraising websites, and campaign-branded t-shirts and water bottles. To learn more, go to www.pwsausa.org and follow the links for the National Awareness and Fundraising Campaign.

Here's the challenge: Commit! Set a goal! Whether on your own, as a family, or with a larger group, plan how you are going to help increase awareness concerning Prader-Willi syndrome this May. Together, let's see how many *awareness bulbs* we can light up. As a result, our world *will* be changed!

P.S. Let us know what you will do to help light *awareness bulbs* this year. Send a note about your plans to: development@pwsausa.org. ■

> *Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.*
>
> Margaret Mead

Medical and Research View

Knee Problems with PWS – bilateral patellar subluxation

Q: My daughter, 18, has knee problems (bilateral patellar subluxation). We have tried Physical Therapy (PT) in the past. It has seemed to have worsened. She is not on growth hormone anymore. Would growth hormone (GH) help with this? What treatments have other children with PWS had success with?

A:

Harold J. P. van Bosse, M.D., Shriners Hospital for Children, Philadelphia; PWSA (USA) Clinical Advisory Board member

The patellar subluxation is usually due to quadriceps (knee extension muscles, on the front of the thigh) imbalance. The initial treatment is Physical Therapy (PT) -- quads setting and vastus medialis obliquus (VMO) strengthening. Next line of treatment is PT. Third line of treatment is…PT. Only if all else fails do you go to surgical realignment, anywhere from a simple lateral retinacular release (loosening the tight tissues on the outer side of the kneecap) and medial retinacular reefing (tightening up the tissues on the inner side of the kneecap), to big muscle redirections and transfers. I don't think GH would have any impact on this particular problem. I now pass this question to Janice, a physical therapist and parent of a child who has PWS.

Janice Agarwal, Physical Therapist, Indiana; PWSA (USA) Board member

I agree with Dr. van Bosse. It's interesting that while I was a therapist in New York the very first child I treated with PWS had this very same issue. Start with Physical Therapy to strengthen the VMO and also to strengthen the hip abductors and flexors for balance and pelvic stabilization. Remember that good footwear helps overcome ankle pronation (the foot turning in) which can cause problems with the knee. Bracing, taping, and orthotics can provide symptomatic relief and could therefore be very beneficial. Please talk with your PT about options.

From a PT's point of view, many children with PWS have abnormal femoral neck angles (the femur is the thigh bone) due to poor development of the pelvis and legs at early ages when bones are forming. Thigh muscles need to overcome this abnormal angle, placing stress or pressure on their attachments on the inside or outside of the knees. On the inside (or medial aspect) of the knee, this pressure causes "knock knees." When I see pictures of our older kids, this is one trait that often stands out. One joint down, the ankles try to compensate by turning in, causing excessive pronation of the foot. Increased weight will exacerbate this problem and adds to pain. Because of all this, most of our older children are at risk for patellar subluxation.

What can we do? We stress strengthening, weight control, and orthotics for our younger kids. We focus on PT, PT, PT (VMO and hip abductors/flexor strengthening), weight loss, and knee bracing for our older kids.

Harold: In regard to the patient in question: I would start with another round of PT, plus NSAIDs (non steroidal anti-inflammatory drugs) on a scheduled basis. I tell patients that if they take Motrin/Advil/Aleve only on an as-needed basis, it acts only as a pain killer. If they take it on a scheduled basis, then it can reach a therapeutic level in the blood and decrease the inflammation, which can help decrease

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Knee Problems, *continued from page 2*

the pain. My favorite: Motrin (Advil, Ibuprofen) 200mg three times per day after meals for kids under 100 pounds; 400mg (2 pills) three times per day for kids over 100 pounds and adults. If they can't take it at lunch because they are in school, then with an after-school snack or night-time snack. Naturally, this has to be worked out with the child's PWS eating schedule. I do this for two weeks, then have the parents titer down the medications as needed for ongoing symptoms.

It can take several days, up to a week or so, before the blood levels stay high enough to drive down the inflammation. If the medication does nothing by two weeks, it is probably not helpful, so discontinue it. If there's a moderate response, then continue it a bit longer, 3/day, or try 2/day. If the problem is all better, then go to an as-needed basis.

The biggest concerns are gastrointestinal (GI) upset and decreased blood coagulability, fairly unusual in kids. Parents should be on the lookout for unexplained bruising or bleeding of gums after tooth brushing. GI discomfort is unlikely in our PWS patients, so they should look for blood in the stool, or tar-like stools (melena), suggestive of GI bleeding.

Once the pain is back in control, the most important thing is for the patient to continue doing their exercises. So often I find that patients have excellent results with PT, but get pain back in 6 months to a year. When I ask them if they have continued to do their knee exercises, nearly all have abandoned them!

Janice: The other issue is that children with PWS are really good at compensating by using other muscles and joints to get around a problem. Once pain is gone, however, it's hard for our kids to stop using these other muscles and to go back to using their muscles the "right" way. Unless they receive pretty intense retraining focused on their walking or gait pattern, they will keep on compensating and will not relearn how to move correctly. Strengthening may show rapid improvement in the knee, but if strengthening has not focused on the pelvis and trunk muscles, the pain just moves to other joints.

It's really important that we work on the muscles and joints above and below the joint targeted for therapy. This reduces overuse of the joint being treated and retrains the joints and muscles to stop compensating for the painful joint and begin to work correctly. Finally, if there is pain in the right knee, I would also look at the left hip, knee, and ankle to see if the increased stress placed on that side of the body has affected those joints and muscles, too. ■

New York group publishes

Sleep in Infants with Prader-Willi syndrome

By Mary Cataletto M.D.[1], Gila Hertz, Ph.D. [2], Moris Angulo, M.D.[1]

Prader-Willi Center, Winthrop University Hospital, Mineola, N.Y.

Huntington Medical Group, Sleep Disorder Center, Huntington, N.Y.

Sleep has been an important focus of study as we learn more about Prader–Willi syndrome. Cataletto, Hertz and Angulo examined the sleep characteristics of 20 infants with PWS between ages 2 and 36 months in their study, recently published in The Romanian Journal of Rare Diseases. They examined overnight sleep studies in infants with PWS before the onset of obesity and without concomitant medications.

Sleep disordered breathing, defined as AHI > 1, was identified in 80% of the infants studied. Within that group, 55% had obstructive sleep apnea syndrome as defined by obstructive index (OI) >1. Fifty seven percent of all sleep disordered breathing events were central apneas, and 43% were obstructive apneas and hypopneas.

Additionally, sleep in a subgroup of infants with PWS was compared to that of infants without PWS but with similar degrees of sleep disordered breathing. Rapid eye movement (REM) latency, on the average, was significantly shorter than normal in infants with PWS.

These authors speculate that shortened REM latency may be a precursor of the REM abnormalities seen in older children and adults with PWS. ■

PWS Growth Hormone Precautions

Update – 2/11

Jennifer Miller, M.D., M.S.
Endocrinologist --PWSA (USA) Clinical Advisory Board

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

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

We advocate a sleep study before the start of growth hormone (GH) on infants, children and adults with Prader-Willi syndrome, and then a follow up study 6-8 weeks later. If there is worsening of obstructive sleep apnea (OSA) on GH, temporarily stopping the GH is recommended until the cause is understood. Frequently the OSA can be corrected by removing the adenoids and tonsils or lowering the dose of GH (in the face of an abnormally high IGF-1). We also recommend taking precautions during bouts of upper respiratory infections.

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There are reports and discussion in the medical literature about adrenal hypofunction in PWS. Single measures of cortisol levels will not be helpful, and adrenal challenge tests may be warranted. Please consult an endocrinologist for their input and advice before starting growth hormone treatment.

Infants with PWS, may have gastroesophageal reflux disease (GERD) which causes obstructive hypopneas/apneas, so if an evaluation is positive for GERD, an anti-reflux medication may be prudent before starting GH.

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 monitoring the child with PWS closely when starting GH to make sure that they do not worsen is the recommended approach.

The FDA has a statement warning that there could be an increased risk of death associated with GH due to a recent study in France indicating that there may be a slightly increased risk of death in certain individuals treated with GH. PWS is not one of the groups mentioned as being at increased risk - they specifically mention idiopathic short stature and isolated GH deficiency.

Medical Home Portal

Have you visited this site?

Chuck Norlin, MD, Director, Medical Home Portal (www.medicalhomeportal.org) wrote that "the Prader-Willi Diagnosis Module on the Medical Home Portal...is one of our most 'popular' modules, receiving more visits than most others, and the PWSA (USA) site is the most frequent referring site to the Portal." This management overview of PWS can be found on the PWSA (USA) web site under the "medical" section. Dr. Merlin Butler, chairperson of our PWSA (USA) Scientific Advisory Board, reviewed and edited this website written for families and primary care physicians.

Your Help is Needed in Advancing PWS Research

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

What is a Rare Disease?

- A condition affecting fewer than 200,000 Americans, or a disease with greater prevalence but no reasonable expectation that the costs of developing the drug can be recovered by the sale of the drug in the U.S.
- There are over 6,000 rare diseases – Prader-Willi syndrome being one of them
- 25 million people in the U.S. are affected by a rare disease

Why is the Rare Diseases Clinical Research Network (RDCRN) important?

- It encourages collaborations for scientific and clinical studies
- Facilitates uniform collection of data and biological samples for sharing
- Makes meaningful large-scale studies possible
- Brings patients with similar concerns together
- Provides needed research for 95 rare diseases
- Includes 161 institutions world wide
- Includes 19 different research consortia (groups) and a coalition of 88 patient advocacy groups (CPAG)

The Prader-Willi, Rett and Angelman syndromes consortium, is only one of five renewed from the ten consortia that were part of the first five/six year grant.

How can I get involved to further PWS research?

The purpose of this study is to evaluate the clinical features, treatments and genetic causes of PWS **and to determine how these conditions affect a person throughout a lifetime. Extensive workups and consultations are provided by PWS experts.**

For more information, and to sign up to be part of this PWS natural history study **go to www.pwsausa.org/research/clinicaltrials.htm or to the PWSA (USA) web home page which will link you to the site.**

At the present time there are four RDCRN sites that are actively studying the natural history of PWS and others with Early-onset Morbid Obesity. They are the University of Florida, Kansas University Medical Center, University of California at Irvine and Vanderbilt University. Two RDCRN sites that currently need more participants are:

Kansas University Medical Center (ARPWS), Kansas City, Kansas
Principal Investigator: Merlin Butler, M.D.
Contact Person: Merlin Butler, M.D.
Office: 913-588-1873
E-mail: mbutler4@kumc.edu

University of California at Irvine (ARPWS), Orange, California
Principal Investigator: Virginia Kimonis, M.D.
Contact Person: Virginia Kimonis, M.D.
Office: 714-456-2942
E-mail: vkimonis@uci.edu

Keep in mind that Angel Flights may be available for participants. For more information go to www.pwsausa.org/research .

Be the change you wish to see in the world! Gandhi

Executive Director View

Evan Farrar

The Collaborative Imperative

The challenges facing people and families living with PWS are greater than ever. What does this mean for PWSA (USA)? It means that collaboration is a critical mission imperative because it enables us to maximize our work on behalf of those we serve.

So, as you read this issue of the Gathered View I invite you to pay special attention to two wonderful signs of PWSA (USA) responding to this collaborative imperative:

On page 11 you will read about the first joint research fundraising project supported by PWSA (USA) and the Foundation for Prader-Willi Research (FPWR) called the **One Small Step** walk. The article is written by my colleague, Keegan Johnson, who is the new Executive Director of FPWR. One hundred percent of the proceeds from this walk will go towards funding agreed upon PWS research projects developed at the PWS Research Strategy Workshop two years ago.

On the front page, you will read an article inviting you to participate in the first PWSA National Awareness Campaign called, "Prader-Willi Syndrome *On The Move*." This campaign is designed to raise PWS awareness and provide support for local initiatives and PWSA (USA)'s programs and services. But it is also designed to foster a new spirit of collaboration between PWSA (USA) and chapters, local communities, and families as we create together new ways to tell the stories of the PWS community around the United States.

For those of you who've been around PWSA (USA) for a while, you know that collaboration is not new to PWSA (USA). For years, we've worked collaboratively with families and professionals across the country and even the world. But we can't rest on what is already established. We need to seek out new partners to share this journey of providing support and services to people with PWS and their families. For some of us, for sure, it will mean rethinking some old ways and trying some new things which isn't always easy or comfortable. But I firmly believe that by working together we can accomplish more for the people we serve. And that, after all, is our greatest mission imperative of all! ■

> *Participate in... a new spirit of collaboration... as we create together new ways to tell the stories of the PWS community*

Evan Farrar

Fundraising

By Jodi O'Sullivan

"The progress of the world will call for the best that all of us have to give."

~ Mary McLeon Bethune

David Crump talks about awareness light bulbs then challenges everyone to set a goal to increase awareness about PWS. He recognizes that it's not so easy to know how may light bulbs it will take to get our message out there and defines the light bulb as the moment someone has a sudden understanding of something previously unknown or vague to them.

Now ask yourself: At what level do *you* recognize that it is you who can turn on the light switch for the awareness light bulb? How brilliantly lit do you want the world to be about PWS?

Not taking on the challenge dims our light so we encourage everyone to find a way to keep it fully bright. PWSA (USA)'s first annual national awareness and fundraising campaign, **Prader-Willi Syndrome *On The Move***, is an excellent choice. Planning an event that raises funds also raises awareness. It's effective and keeps PWS progress "on the move." No matter what kind of event, how big or small, or when it occurs, ultimately there's a chance for light bulb moments, each one bringing us closer to our goals. *You* supply the power that could illuminate many light bulbs. Will you turn on the light switch or ignore your power? Many thanks go to those below and a great many others who create awareness light bulbs for PWS.

Grandfather **Bill Fleming** planned his **5th Annual Superbowl Party** last February in New York and raised $4,390 for hyperphagia research.

In honor of the third birthday in June of **Lexie Reeves**, who has PWS, her big brother and big sister raised $250. Their mother, **Sherry Reeves**, from Virginia, wrote, "They are very proud of her."

Michele Shingleton, mom to **Carter Shingleton**, age 9 with PWS, increased her power this year along with Carter's babysitter, **Shawna Bush**, to plan their **4th Annual PWS Walk-A-Thon** in Connecticut in June in Carter's honor. They raised $4,500 (gross).

Also in June in Connecticut, **Larry Grundy** and the **Town of Groton** held their **2nd Tour De'Noank** to raise $5,600.

In June four sisters hosted the **4th Annual "Strike Out PWS" Softball Tournament in honor Anneka Kramer**, 4 with PWS. Her mom **Stacy Kramer**, and aunts **Shannon Daale, Stephanie Daale, and Jenna Huitnik** raised $12,726 (gross) for PWSA (USA) and the Iowa chapter.

Birthday candles were the kind of light lit for **Rebekkah Allred** who has PWS and turned 31 in July. The occasion raised $90.

Father **Scott Beauchamp**, relative **Dan Beauchamp**, and other TORC Sportsman Super Stock Truck competitor race car drivers in Bark River, Michigan in August hit the track in their off-road championship series with a PWS awareness message on their vehicle hoods. **The Bark River Lions Club** joined in support and, together with fans, they raised $550 and PWS awareness in honor of **Luke Beauchamp**, age 4 with PWS.

Brittany Callahan wrote of her niece **Lexie Reeves**, "Lexie is doing wonderful and a very bubbly and bright little girl," when she sent in a donation of $385 for research from her employer **Generous George's** in Herndon, Virginia. The restaurant donated 10% of sales from one day in September and the servers donated a portion of their tips.

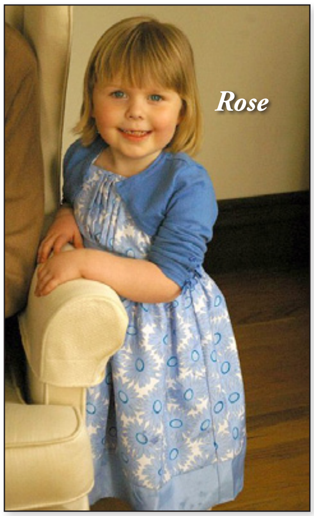
Grandmother **Dorothy Morse**'s friend **Margaret Hoese** was moved enough to host a **Mahjongg Tournament** in October in Texas which raised $1,020. Wrote Dorothy, "(Margaret) has never met my daughter, **Charlotte Peterson**, mother of **Roxy**, 8 with PWS. What a great and generous friend."

One-year-old **Emerson Lynn Parker**, who has PWS, will one day be aware of how much her family is already doing in her honor. In October, aunt and uncle **Cynthia Wilson Loeb and Justin Loeb** donated 10% of daily proceeds from their Oliva Italian Eatery restaurant in Texas to celebrate Emerson's first birthday and "to spread awareness." In December, the **North Texas National Kitchen and Bath Association** (NKBA) held a benefit and raised $4,000. Wrote Emerson's mom, Kelli Parker, who is president of the Texas North Plains Chapter, "Our chapter made PWSA (USA) the beneficiary for our 2010 holiday party and auction. We received wonderful donations and support to raise money and awareness for PWS from many local and national suppliers along with the Texas Rangers and Clint Hurdle." ■

Below: A check presented to PWSA (USA) from National Kitchen and Bath Association in Texas. Left to right: Kelli Parker, Denise Dick, Gene Cherrnay, Sean Boutwell.

Rose in Bloom

By Alysa Miller



Currently 4 years 11 months, Rose was diagnosed with PWS at 72 days. She had a pretty rough start with feeding tubes, then physical therapy, occupational therapy, dietician, and many more doctors' appointments. In fact, Rose had so many appointments that I quit my job to be a stay-at-home mom so that she could make all her appointments.

When she was 2, we were told that she no longer needed all of those appointments because she was doing so well. One of her doctors even called her the "prodigy child". I don't understand it. I hear all these stories of PWS families, and I don't understand how Rose can be doing so well when others seem to be struggling with EVERY step. She is having a few transitional problems at pre-school, but otherwise she has been doing GREAT.

However, Rose has started to put on a little more weight and is on the high side of the weight vs. height scale. She is in the 95% and she should be at or below 50%. I keep checking her weight vs. her height, and she isn't gaining a lot--she's just gaining faster than she is growing. She's in the 10% for height. The last couple of times we went to the doctor she gained two pounds (in about 3 to 6 months) but she only grew one inch. We have scheduled more appointments to see if Growth Hormone is something that we should look into or what our options are.

Rose is such a loving and caring person. She says "Hi" to everyone. She gives out hugs like most people do handshakes. If someone is crying within 20 feet of Rose, she is right there seeing what is wrong and giving hugs to make them feel better. Rose is also so smart she's already learning how to write her name. However, she doesn't always want to be smart and independent. She wants people to help whenever she sees fit (i.e., getting dressed, getting her shoes on, and sometimes writing her name), but other times she is very independent.

She can also drive me crazy with her questions: Are we there yet? Will we be there soon? What's Grandma doing? What's my Uncle doing? Where are my friends? I love my friends! Every time we get in the car she wants to play 50 questions and expects me to know all the answers. It can be overwhelming at times, especially when I'm in a hurry. I've also noticed something else about Rose; if there is a song on that she recognizes, she wants to hear it over, and over, and over, and over again.

We now have another addition to our family, James, age 9 months, and Rose has been such a helper with him. Her doctors suggested having Rose help by getting diapers/wipes to keep her active in the house, and she has been such a terrific little girl. We do have a few behavioral problems, typical of most four-year-olds, but she is such a happy little girl. Rose is still currently in speech therapy because she was slow to start talking and now needs help with her pronunciation of words. I can't wait to see what other little surprises Rose has to offer. ■

~Alysa Miller
Eyota, Minnesota

If you are a Federal Employee, you can help!

Combined Federal Campaign

PWSA (USA) CFC ID Number is 10088

PWSA (USA) qualified for membership and is part of the Combined Federal Campaign (CFC). If you work for the federal government and its agencies, you can make a donation via the CFC to PWSA (USA)! Funds derived from the CFC offer essential support for programs and research supported by PWSA (USA) and, with the help of those who can participate, will continue to do so. The CFC holds activities during their campaign in different local areas around the nation. You can participate by selecting PWSA (USA) to receive donations, and spreading awareness of PWSA (USA) so others can learn about PWS and make donations, too! The PWSA (USA) CFC identification number is 10088. Thank you to all those who support PWSA (USA) this way! Your contributions are greatly appreciated and help ensure our loved ones with PWS have the best futures possible! Questions? Please call PWSA (USA) at (800) 926-4797 and ask for Debi Applebee. ■

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

The November 2009 Webinar entitled

"The Truth about Consequences"

discussed the ineffectiveness of punishment for persons with Prader-Willi syndrome and suggested other management techniques for difficult behaviors.

The following are responses to some of the follow-up questions.
All the questions and answers can be found in Members Only on the PWSA (USA) web site.

Prepared by Mary K. Ziccardi and Evan Farrar

1. How do you best balance understanding of consequences for behavior that is unacceptable?

The brain of a person with PWS functions in a way that impairs the ability others might have to understand and respond to negative consequences. A positive behavioral approach that targets and encourages and rewards desired behaviors is far more effective – and healthier – in the long run. If a consequence is to be applied, if it is to have any impact, then it should be applied as close to the incident as possible and in very clear and concrete terms. However, even done this way it is unlikely to change future behavior so a positive behavioral support plan should always be the foundation of managing behavior of a person with PWS.

2. Any suggestions to minimize the perseverations?

Perseveration is an example of when a person with PWS gets stuck or begins using repetition in response to anxiety. The best technique involves putting limits on the perseveration, especially after you are confident the person knows the information. For example, tell the person with PWS you will answer their question three times--but after that you will move on to something else. Another method is to distract the perseverating person so that you can move them off the topic. Finally, ignoring is another method that can be employed, although not always successfully. The worst response is to try to reason or talk the person out of the perseveration. This tends to only reinforce the behavior.

3. If you sense a tantrum/negative behavior brewing, is it best to get the PWS person away from their current situation and let them take a walk?

Yes! This is a great example of prevention. Knowing when a person with PWS is becoming stressed is really important so that preventive techniques (such as changing activity or location) can be employed. Predicting situations that cause anxiety is the best strategy for managing tantrums and meltdowns.

4. Do individuals with PWS say they are sorry for their behavior? Do they really know what that means and what they are sorry for?

Yes, people with PWS say they are sorry. And some mean it. Others do it because they are told. Actually, a lot like humanity as a whole! We discourage people from trying to figure out whether a person with PWS knows what it means when they say they are sorry. Saying sorry is a part of how people relate in a socially acceptable way so we want to encourage people with PWS to follow this custom. However, it is clear that people with PWS can feel very sorry and upset when they hurt someone else so don't assume saying sorry doesn't mean anything. If a person with PWS says they are sorry, accept it and move on. Don't cause another power struggle to begin by refusing to accept an apology.

5. Are your behavior strategies and management skills appropriate for all with PWS?

There is a great deal of diversity among people with PWS. But over the many years PWSA has been working with and for people with PWS, positive behavioral strategies have shown the best results. We freely admit there are exceptions to every rule, but it is rarely damaging to go with a positive behavioral approach whereas a negative consequence approach can be very damaging.

6. How do you handle taking the child with PWS out of their comfort zone? Such as on vacation or a time they do not have their usual schedule?

As much as possible, try to recreate in the new setting as much of the old structure and predictability as possible. Work with the child to help them understand that their routine is going to be different while on vacation, but provide reassurance - through good advance planning, verbal, and visual reassurance - that issues of food security and basic comfort will be addressed. The reality is that the needs of a child with PWS can be met anywhere as long as they are planned for and the child is confident in that plan.

7. How do you handle a meltdown in a store?

The best way is to avoid it in the first place! So use meltdowns as an opportunity to process afterwards what happened to learn about possible triggers that can be avoided or managed differently. When a meltdown does happen, try some techniques such as giving the child space to work through the issue if possible, remove the audience, use a calm and steady voice, don't over talk or try to reason the child out of the tantrum, and in worst case scenarios remove or restrain the child if a threat to self or others exists.

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The Truth, *continued from page 8*

8. What is the best way to stop physically aggressive anger at school?

Physical aggression is one of the scariest behavioral outbursts. Yet it should not be handled any differently than other behavioral problems. The basic questions such as what is triggering the anger must be asked so that stressors can be eliminated or managed. Offering alternative ways to express frustration is important as well (a notebook, drawing board, etc.). PWS is a disability that hinders a person's ability to self-regulate emotion including anger. So helping a child with PWS to express emotions appropriately is an important part of heading off anger. If the physical outbursts are injuring others, then it would be appropriate to have the child evaluated for any underlying psychiatric issues that might be increasing the intensity of physical aggression.

9. Assuming that lying by individuals with PWS is also behavior that shouldn't be punished, what is the appropriate response to obvious and not so obvious lies?

While lying is troubling, it is also just another behavior which is best managed by a positive incentive strategy. Reminding your child of how important it is to tell the truth is a helpful strategy because it is important to help a child with PWS understand what acceptable social customs are and how you expect your child to behave. The motivations for lying (as with all people) are many, including shame over getting into trouble, wanting to hide food consumption, and trying to fit in with peers. It doesn't necessarily have any relationship to the deficit in ability to process events and actions. Instead, it is one of those common features all people struggle with. The best response is to help your child understand why it is not appropriate and help them to be truthful. ■

Educational Opportunities in 2011 Including the PWSA (USA) National Conference

By Julie Doherty, Secretary, PWSA (USA)

As most of you know, our Webinar series was initiated in 2009 as a way to serve our members by providing education in a cost-effective manner. We presented several topics of interest which were well attended by parents, grandparents, care providers, and educators. However, because we are gearing up for our **national conference in Orlando, Florida, November 11-13, 2011,** we are not scheduling any webinars for 2011 because the conference represents our primary educational opportunity for parents, families, and professionals this year.

Currently, the conference committee is selecting topics and speakers that will provide our members with much-needed information on Prader-Willi syndrome – everything from a basic introduction to PWS to ways to handle stress in our lives, behavioral and nutritional topics and much more. There will be a YIP/YAP program entitled "Survivor: Orlando" based on the Survivor TV series. Many exciting activities are being planned for participants. A new addition this year will be a separate Sibling Program for those seven and older, where they will have fun activities of their own, share their thoughts and feelings about being the sibling of a special-needs child, and learn from and interact with other siblings just like them. Registration will open in late summer/early fall. Details will be sent via the weekly E-Bulletins, posts on our homepage, and in the *Gathered View* - so stay tuned.

Can't wait till November for cutting edge PWS information? Then we invite you to take advantage of another unique educational opportunity for our members. The International Prader-Willi Syndrome Organization's 2010 conference was held in Taiwan in May. The conference was professionally recorded and is in a set of five DVDs available for only $40 for members, $50 for nonmembers. A sampling of the speakers and topics included on the DVDs:

Dr. Dan Driscoll, USA: *A Clinical Overview of PWS, including the role of genetic testing*

Dr. Anthony Holland, United Kingdom: *The Role of Research – Is There a Cure?*

Dr. Maite Tauber, France: *Endocrine Dysfunction in PWS*

Dr. Anthony Holland, United Kingdom and Dr. Janice Forster, USA: *Psychotropic Medications*

What a wonderful resource – all the information from a conference, and an international one at that, for such a low price. No flight and no passport required! To order, please call 800-926-4797 or e-mail cbeles@pwsausa.org with your request. ■

New PWSA (USA) e-Bulletin

Beginning early in 2011, PWSA launched its new, weekly e-Bulletin, with announcements and other time-sensitive information of interest to all of us in the PWS Community. To sign up, go to www.pwsausa.org/

A Thank You for the Medical Alert

Betty Perry, from Pennsylvania, called to say "thank you" for having the Medical Alert and other medical articles. She took copies of them to the ER when Victoria, age 35, was having severe stomach problems. She had a twisted bowel and they had to do surgery. She says that the doctors were grateful to get the information, and one said, "Thank you for teaching me and my staff about PWS." Victoria was the first patient they ever had with PWS. ■

Another Thanks for Medical Information

I meant to reply to your timely and invaluable e-mail response to our request for the latest medical alert much earlier, but during and after our son Paul's surgery for rectal cancer on July 15, 2010, we had a busy time and our hands and hearts full with arrangements, adjustments, visits and apprehensions for Paul's future, etc.

Paul [age 46] returned from the hospital to his supervised home on August 3, 2010. His attitude and coping skills so far are superb and beyond our expectations. The head nurse complimented Paul for his cooperation and attitude. She said she would miss his early morning singing before breakfast. By the way, he thought the last two weeks of his hospital stay were like a first class hotel. The hospital was very mindful of his uncontrollable appetite and made sure he got only what he needed.

We are truly blessed with a wonderful son teaching us many lessons in patience and confidence in our Lord.

We still are extremely grateful for the e-mail information [which was] well used by hospital care professionals. ■

~Hanna and Henk Dennewold
and Paul
Calgary, Alberta, Canada

The Way It Used to Be

My daughter is 40, and it seems so distant from her childhood and the constant pressure of going to her IEP sessions and having to argue for every little bit of additional help. There was no such thing as a teacher's assistant; as a matter of fact, the teacher's aide changed constantly, and I can remember one that couldn't speak English. Her job was to keep Christine from running out of the classroom and from finding and eating any food she could lay her hands on. There was no food control. Doughnuts and muffins were routinely passed out. It was almost viewed as an activity. My cute little blonde daughter who was 4' tall weighed more than 150 lbs.

Thank God things have changed. ■

~Harry Persanis
New York

Parent 2 Parent

Life does go on after PWS enters our lives, although things may be different. We encourage you to send your story for The Gathered View, as Alma has, to encourage others who may be feeling overwhelmed and despairing.

Life Goes On

Alma Schneider posted this to her 0-5 e-mail group—and to all of us.

Hi everyone. After some soul searching, I have decided to share something with all of you, something of which I am very proud. There was an article in the December 2010 issue of *Family Circle* magazine about me and the non-profit organization I started, *Parents Who Rock*, six months after my now six-year-old was born with PWS.

What was not stated in the article was that I was so devastated and depressed after my son's diagnosis that a friend suggested I get back to my creative "core" to help heal. Taking her advice, I decided to get back into singing and performing. What started as an exercise in recovery ended up being the beginning of a very successful and fulfilling non-profit made up of parent musicians who perform concerts for local charities.

*[A quote from the article] I will never forget how I felt when I returned home after our first fundraising performance. I was alone in my bed with a huge grin on my face (my husband was driving the babysitter home). I was pumping milk with my breast pump (which I did for a year), for a child who could not suck and would receive it through a feeding tube in his stomach. A child, with what seemed to be to me, one of the most horrible syndromes I could imagine, but I **still** had a grin on my face.*

I was able to experience true happiness because I chose to live my life and focus on things that I loved--music and helping others.

In addition, I have not let PWS keep me from pursuing a career in... food! I am, and always have been, a huge foodie, and I decided to create a blog and business (takebackthekitchen.com), helping people overcome their practical and psychological obstacles to cooking. I began this journey two years ago, not because of Lincoln, but despite his diagnosis. I was a foodie and a clinical therapist before he was born and wanted to keep that part of my life full and interesting.

One of my greatest fears when I received Lincoln's diagnosis was that my life and my family's life were over. It would have been extremely helpful for me in the early days, weeks, months, and years, to have read something about how life goes on with the families of kids with PWS.

Thank you for reading my story and please share yours, or create a story for yourself, so that you can write about it. ■

~Alma Schneider
Montclair, New Jersey

"I'm ALL In"

By Keegan Johnson, Executive Director Foundation for Prader-Willi Research

"Happy Birthday, your son has Prader-Willi syndrome". I heard those words on my 30th birthday, 3 weeks after our first son Dante was born. I remember my wife, Tanya, starting to cry. I asked "What does that mean?" to which the doctor replied, "His speech will be delayed, his growth will be delayed, he will have low muscle tone, he will never have children and he will always be hungry!" I could barely think as I blinked back the tears and asked, "What about his cognitive abilities?" The geneticist replied, "Those will be delayed as well." My life would never be the same.

Tanya and I wanted to help Dante, but I had no idea what to do. We had no fundraising, non-profit, scientific or medical experience. Tanya is a teacher and I had just co-founded a company to eliminate online fraud. I still remember the day, when I came home and Tanya said, "I booked a park, we're running a walkathon". Life was about to get interesting.

We looked at Dante's tiny feet and thought, if nothing else, we can take "One SMALL Step" and that's how we named the walk. We still had no idea how to make life better for Dante, until we met Theresa Strong. Theresa is a mom of 4 children, including a young man with PWS and a girl with Down Syndrome. In addition, Dr. Strong is a geneticist and cancer researcher at the University of Birmingham in Alabama. In her spare time, Theresa leads the research program at the Foundation for Prader-Willi Research.

From Theresa, I learned research is a way of finding solutions to challenges. When we think of research we typically think of laboratories, test tubes and complicated genetic codes. These are a part of research, but are just the tip of the iceberg. I learned research can be finding simple solutions to common behavioural challenges. I learned research can be identifying different learning styles or finding the early indicators of mental illness. The path became clear to me. We could list all of the PWS challenges and then use research to find solutions. We needed a plan.

Funded by the Foundation for Prader-Willi Research and the PWSA (USA), Theresa organized a workshop with 65 of the top researchers. The researchers created the PWS Research Plan. The plan describes the initial research projects we need to complete to eliminate the challenges of PWS. Now, we can focus on funding the research.

Proud father Keegan with Tanya, Dante and Denzel

Throughout the year, we will be hosting One SMALL Step walkathons across the USA and the world. All proceeds will fund the PWS Research Plan, jointly developed by PWSA (USA) and FPWR. You can host your own event, attend a location near you or walk around your favourite park. I would like to ask you to take One SMALL Step by registering at http://onesmallstep.fpwr.ca. Last year, 10 parents led 10 locations and raised over $200,000. Imagine what we could do if every parent reading this newsletter registered.

Dante is now 6 years old, running, swimming and learning to read, add and subtract. He loves to dance, swim and play with his brother, Denzel. Denzel is one of the most charming, compassionate and intelligent 5 year olds I have ever met. Dante and Denzel share Tanya's love for life and we couldn't be prouder.

I have seen the PWS community take huge strides in coming together and working towards eliminating the challenges of PWS. Unfortunately, everything is moving too slowly. We WILL be able to cross off the challenges of PWS, but when?

After meeting hundreds of families, raising almost $1,000,000 and reading the PWS Research Plan, I decided, I'm ALL IN! Therefore, I started working as the Executive Director of the Foundation for Prader-Willi Research.

The one desire all parents share is "To eliminate the challenges of Prader-Willi syndrome" … but we cannot do it alone. We cannot eliminate the challenges in Tennessee or in New York. FPWR cannot do it alone and neither can PWSA(USA). The only way, is for the "People" of the PWS community to eliminate the challenges of PWS.

I look forward to meeting you and stand committed to eliminating the challenges of Prader-Willi syndrome. ■

Just four months after attending the International Prader-Willi Syndrome Organisation conference in Taiwan in May, Dr. Loisel Bello sent pictures of the very first PWS meeting in **Cuba** and a letter to Giorgio Fornasier, Executive Director of IPWSO (who translated).


Loisel's daughter Gabriella showing how she is now after Loisel and his wife Marlen learned a lot about PWS after IPWSO in Taiwan.

"At last I kept my engagement and promise to help our patients in Cuba: to give just a small piece of what Marlen [his wife] and I learned to each of these families, together with much love and understanding. Thanks to this small first meeting we could evaluate and know what they all need and this is just the beginning. We are very happy and satisfied we could start this difficult road which has not 10,000 plans in it, but just the path our children with PWS in Cuba have to follow and walk along.

"Many thanks to everybody as all of you were present at our historical meeting. In a way or another you changed our life completely." ■

Marlen and Loisel

PWSA recently received the following e-mail from Dr. Loisel with pictures of his daughter Gabriela: *"In 2009 we recived your DVD, Food,behavior and beyond, it was the most important present to us and Gabriela,because the life of my daughter begon to change , in this moment Gabriela do not use GH yet.The big change just was with diet and exsercise, thanks to Your DVD, IPWSO informations and Taiwan conference, maybe when Gabriela begin to use GH will be better."*

"The Scanner", a **United Kingdom** film on PWS showing how the latest medical technology influences the lives of people with PWS, won a national documentary award at the Sheffield Doc/Fest. The film features Kate McAllister and Dr. Al Garfield of the University of Cambridge, who discuss current research and explain the irregular satiety response in PWS.

Al, who works on brain control of obesity, said, *"The sensations of hunger and fullness are the two sides of our appetites, but whilst we often consider them to be feelings of the body, it is actually the brain that coordinates and controls our relationship with food. Working on PWS has highlighted how obesity as a condition is often stigmatised. Kate and I hope this film and our next larger project will go some way to changing public perception and understanding of such conditions."*

Kate, who works in Tony Holland's group at Cambridge, commented, *"Through working with PWS, I am really aware of the stigmas surrounding obesity and wanted to do something to alleviate this. I have been really surprised at what a great reception we have had--parts of our film have even been shown on television in the Philippines! PWS families from as far as Australia have been in touch to say they were really heartened to know that there are researchers out there who are focused on understanding more about conditions of appetite."* ■

Anil Kumar, Moderator for **India PWS Association**, posts from New Delhi to the India YAHOO! group, showing how far India has come in just two years.

I am glad to put on record that the support and encouragement from our respected doctors are overwhelming. We are grateful that within a short period of time 51 doctors are supporting our noble cause. This has given us strength to reach out to more diagnosed and suspected PWS families. Last week 8 PWS families have been identified. We wish them very best and extend our full support to them. [A] Few families with the help from their Doctor also availed free diagnosis facility from Bird Lab in Italy…On behalf of all PWS families, we are really thankful to all supporting doctors. We are in the process of making a package containing literature and CD…We will be sending the package to all doctors and family members by post/courier. It has got a lot of information for PWS awareness…Our slogan is "Awareness is Enlightenment". ■

☺ CHUCKLE CORNER

My 15-year-old son with PWS was asked what he would like to do this year for April school vacation. He responded that he "would like to go to Rome, Italy." I said, "Rome? Why do you want to go to Rome?" He responded, "To meet God." I said, "I don't understand. God is in Rome?" His answer, "Yes, Mom, today in school we learned about all the Roman gods!"

~Andrea Glass
Foxboro, Massachusetts

TAE KWON DO for Ramon

By Kelly Gibbs, Spring, Texas

My grandson, Ramon Madrid, age 6, has been an inspiration to our family. Ramon was born prematurely; for weeks we did not understand why he had an issue with nursing. His twin sister was fine except for being premature. Luckily we live just north of Houston, Texas, and its wonderful Medical Center.

After much testing, we were saddened to hear that he had Prader-Willi. My daughter worked through the gastric tube feedings like a champ, and we all learned how to take care of him. Eventually, Ramon was able to graduate from the g-tube to regular bottles.

Yes, he has always been physically a little behind, but he is catching up by leaps and bounds. We were fortunate to learn about Human Growth Hormone and its benefits with kids with PWS, and his mother began it early. He is actually passing up his twin sister!

Ramon is now in first grade in the school where his mother teaches. He is in regular classes and pulled out for the classes where he needs some extra attention. He is a smart little cookie and just has problems with a speech impediment and sometimes attention issues.

At his doctor's suggestion, his mom tried him out in soccer and gymnastics; that wasn't his cup of tea. Ramon's inability to concentrate made it too hard to get his cooperation. Brandy, his mother, then tried him in a trial class of martial arts and was told that it wasn't working out.

About a year and a half ago, my daughter enrolled Ramon in a Tae Kwon Do class. After looking around, she found Olympia Tae Kwon Do and Master Bruce. It was most fortunate that Master Bruce had worked with other kids with challenges, and so he was more than willing to give Ramon a go. Now I am not here to say that it has all been sunshine and peaches, but he has progressed very well with the principles imparted by the instructors at the studio. Ramon is so crazy about his degree belts that Master Bruce found that a very good way to entice good behavior. There have only been a couple of times that he has had his belt taken away for bad behavior and then he had to work to get it back.

> ***It has been amazing how much better Ramon's respectfulness and attitude has become.***

Ramon

It has been amazing how much better Ramon's respectfulness and attitude has become. He has learned at class that you must respect your parents at home as well as your instructors. When he enters the studio, he bows and declares, "Hello, Master Bruce". This is expected of all the kids. Also when he enters the actual workout room, he must remove his shoes and socks, open the door, and ask "May I enter, Coach Lance."

In just a year, Ramon has gone from white to yellow to orange belts. He has had such great support, not just from the instructors but the kids also. Where it takes some of them just two kicks to break the board with their feet during a test, it could take him a dozen. When it looks like he is tiring, the whole class starts cheering him on. He really looks forward to his two evenings a week at the studio and being with his instructors. Ramon is also very careful with his uniform and belts. He goes home, takes them off and hangs it all up, and folds his belt like it was made of gold. His self-confidence has greatly increased.

I think Ramon and all of us in the family would highly recommend Tae Kwon Do to any kid with PWS who is looking for a sport. ■

Counselors Corner

Good news! A new member has been added to the crisis intervention counseling team. After a competitive search to find a full-time Crisis Counselor, Jeremy Johnson has accepted the position. We thought this would be a great opportunity to introduce Jeremy to the PWSA (USA) community.

Prior to joining PWSA, Jeremy worked as a special education teacher for twelve years. During that time, he taught students with a variety of significant disabilities, including students with PWS. He enjoyed teaching, especially community inclusion activities for his students. However, in the last few years, he began to see his future more as an advocate or a counselor for the families of the students he taught than as a teacher.

Jeremy explained, "The greatest joy I had as a teacher was connecting with the families of my students and letting them know I was there for them and understood the challenges they face." Jeremy was born with severe scoliosis that required surgery as an infant; that reduced the progression, but the scoliosis has remained a challenge to overcome all his life. Therefore, he understands what many families face with disabilities. He adds, "The greatest moments I had as a teacher was being invited over to share a dinner at my student's house."

He decided he wanted to find a job where he could help and advocate for families with disabilities. For a few months before joining PWSA, he lived in an L'Arche community, a faith-based community where adults with and without disabilities share life together in a family or home environment. He wanted to learn and experience how different services are provided to adults with disabilities.

When a PWSA Crisis Counselor position opened, Jeremy applied because he thought this was a great opportunity to use his school and residential care experience as well as his ability to connect with families of people with disabilities. He also understands the challenges the parents face with a child with PWS in the school system because, as a teacher, he had to advocate for his students with PWS to make sure his students had the best quality of education available.

Jeremy hopes that his school background as well as his compassion for people with disabilities will be a great asset to help the families he serves as a new Crisis Counselor. Very excited to be a part of the support services available at PWSA, he brings to our team a compassionate voice who wants to give the best quality of crisis intervention counseling that our families need and deserve.

See you next time in the Counselors Corner!


Jeremy Johnson

Chapter View

PWSA of Ohio is planning the annual Family and Friends Festival for Saturday, April 9, 2011, in Columbus, Ohio. This is a day of swimming, crafts, carnival games, bingo, a pine car derby, networking and information sharing. Included is lunch and loads of prizes for those with PWS and their siblings. Contact pwsaohio@aol.com or check the web site: www.pwsaohio.org for more information and registration.

New York's annual conference will be held April 28-29, 2011 in Albany, NewYork. Please see registration information at www.prader-willi.org

The following names are those who donated to the **2011 Angel Fund** up until January 31, 2011 either In Honor of (IHO) someone very special to them or In Memory of (IMO) a person whose memory is deeply treasured.

Angel IHO

Alex Agarwal
Milka Mandich
Aaron Alsnauer
Judy and Dan Alsnauer
Ian Alton
Chester and Theresa Labus
Derek Anderson
Lori Anderson
Kandra Anderson
Bruce or Susan Dehn
Stephanie Appel
Heinrich and Anna-Maria Froehlich
Stephanie and Nicole Appel
Charles and Ellen Alpaugh
June Varcoe
Ethan Arbuckle
Lorraine and Robert Arbuckle
Frank Arnold
Gateway Coding Inc
Asher Atkins
Cathleen and Paul Griffith
Isabella Bacanegra
Jose Venegas DDS, PA
Rebecca Baird
Brian Baird
Jean and Ronald Jakubowicz
Lois and Jeffrey Pallotta
Stephanie Lynn Baker
Richard and Darlene Smith
Braden Bale and Family
Patricia Webb
Linda Lee Barnett
Robert and Deanna Barnett
Jacob Ford Barron
Margaret Warren
Nicholas Baskin
David and Maureen Pagnucco
Gavin Baugher
Earl and Connie Baugher
Hannah Behnken
Bob and Jane Easton
Gary and Sharon Seedorf
Peter Behringer
Michael and Christine Bachmann
Linda and Ralph Behringer
Karen Bennett
William Bennett
Nathan Bennett
Judith Bennett
Deborah Carpenter
Noel Bensaid
Douglas and Wanda Terrell
Matthew Berl
Phil DuBois
Brendan Bernstein
Neil Kurtz and Geralyn Lyman
Sheila and Gerald Levin
Jack Bevacqua
Nicole Albert
Robbin Gilbert
Lynn-Ellen and John Lacey
Kate Bianco
John and Carolyn Rodman
Page Bintz
John and Marilyn Bintz
Kelly Bitzer
Robert and Fern Bitzer
Samuel Bladel
Joanne Bladel
Sophie Bolander
Richard and Jackie Bolander
Nolan Carl Bonk
Keith and Donna Johnson
Meghan Boucher
Allan and Kathleen Boucher
Kean Bracht
Mary and Holger Bracht
Brenda Brenneman
Quinta Bontrager
Erika Breneisen
Jere and Isa Breneisen
Savannah Brice
Marsha Gamelin
Genevive Bruns
Beth and Ron Bruns
Fisher Bryden
Dianne and Jeff Bryden
Logan Buchanan
Kate Loper
Julianna Burgin's 4th Birthday
Lori and Brian Burgin
Joshua Burke
Marsha Samuel
Isabella Burnham
Joanne DeYoung
Katie Burst-Lazarus
James Lazarus
Nicholas Busfield
Lenore Trimmel
Emily Bush
Charles and Margaret Bush
Ariel Campbell
David and Michelle Campbell
Lea Capraro
David and Cathy Braner
Deborah and Michael Capraro
Joseph and Bernadett Coletta
John and Ann Elward
Maryellen and Leo Magrini
William Capraro
Vivian Chavez
Florence Larsen
Rachel Casey
Patrick and Filippa Casey
Ryan Casey
Julie and Dan Casey
Jason Castle
Bill and Judy Castle
Hope Chang
John and Teri Knowles
Jennifer Collom
Sally and Chet Collom
Jace Coltrane
James Van Becelaere
James and Wava VanBecelaere
John Ross Comes
John and Susan Comes
Kathleen Conry
Mary and Ken Conry
Madison Copeland
Franca and Larry Copeland
Christine Cornnell
Allan and Dorothy Cornnell
Emily Costa
Erika Good
Elizabeth Prochazka
Elana Couch
Anita Whitaker
Brayden Crosson
A-1 Pumping
Bryan Culbertson
Eileen Posch
Emily Curran
Jacque Reid
Brandon Dahan
Marcia Dahan
Ray and Sherry Davis
Neal and Angela Spradlin
Ben Dawley
Anne Packard
Tanner Dean
Virginia Moore and Melanie Brown
Harper Dean
Sandra Jarrett
Joseph DeLillo
Annette Baudo
Natalie Saathoff
Brooke Detiege
Tom and Darlene Benoit
Jeanette Schoen
Brooke and her Friends
Anina and David Pfeiffer
Jessika Dickinson
John and Mary Ann Bellanti
Michael McManus
Matt and Becky Reardon
Danielle DiCola
Paul and Patricia DiCola
Kurtis Dinardin-Schinasi
Thierry Dinardin and Karin Schinasi
Kaitlyn Disney
Marie Hartung
Michelle Phillips
Riley Donovan
Downtown Chiropractic
Tim Holman and Meridith Sewell
Lois Zeman
Tony Dorn
Leslie and Laurence Hall
Jacob Douglas
James and Judith Austin
Gloria Fisher
Joslyn Ecker's Birthday
Darrow and Renate Nelson
Ada Edmonds
Calla Jean and Joe Wright
Anwen Elder
Robert and Nancy Elder
Ani Elder
Sara Hooley
Nichole Englund
Lee and Rose Englund
Luke Eurillo
Barbara Hannevig
Dan Sokoloski and Joane Stoneberg
Stephen Fabio
David and Judith Fabio
Mike and Debbie Fabio
Erin Favret
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Pauline McIlrath
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Tristan Ferdig
Mark and Penni Coatney
Patrick Donnell
Frank and Karen Washburn
Jacob Fiske
Gustin and Winnie Buonaiuto
Ross and Jane Dudley
Carolyn Garcia
Beth and John Garrison
Dominique Wade
Doug Wells
Janice and Jim Wollam
Ryan Fochs
Harlan and Melba Hamlin
Peter Funai
Philip and Kathleen Beichert
My Sister Gail
Jill Notte
Kyle Gallagher
Robert and Claire Brown
Sydney Gardner
Christy and Josh Gardner
Larry Garnder
Steve and Barbara Asbury
Corbin Garrett
Tom and Joan Garrett
John Garrick
Bob and Katie Saumweber
Heather Gibson
Frederick Browne
Gavin Gill
Rosemary and Joseph Carr
Donna and Edward Doyle
Elaine and Robert Loewen
Anne O'Connor
Edward and Brenda O'Connor
Harry Uhlman
Sara Gilmore
Dan Gilmore
Sienna Grace Godfrey
Lois Bascom
Ramona and Chuck Shawver
Hope Graesser
Guyla Husman
Rodney and Garnet Petersen
My Granddaughter
Kathleen Swepston
Cameron Graziano
Lisa and TJ Graziano
Chuck and Melinda Morrow
Brandon Greco
Susan Sup
Zachary Greenberg
Wendy Kochevar
Louise Greenswag
Donna Siegel
Alexandra Grussing
Ann and Paul Grussing
Chester and Roberta Lonnquist
John and Karen Meslow
Greg and Louisa Ritter
Kirsten Guinn
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Myrna Toungette
Mia Maria Joffroy
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Carol and Jerry Williams
Lillian Marie Jordan
Susan Bumpous
Jim Kane
Daniel Ryan

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Irl and Patricia Duling
Sister Mary Helen Kane
Harold Marshall
Haley Kavrell
Catherine Masi
Brenner Keating
Sandra Keating
Drew Kelly
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Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to **www.pwsausa.org/donate**

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Sarasota, Florida 34238
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Fax 941-312-0142
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Our Mission: PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those affected by Prader-Willi syndrome.

Staff & Other Key Contacts

Evan Farrar, Executive Director
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Sign up today at www.pwsausa.org!

> *"It has been amazing how much better Ramon's respectfulness and attitude has become. He has learned at class that you must respect your parents at home as well as your instructors."*

Read "Tae Kwon Do for Ramon", page 13.

Did You Know?

Most rare diseases still have no treatment. Of the 6,800 listed on the NIH website, only about 200 have FDA-approved treatments one being growth hormone for PWS .

The word "rare" is misleading. Nearly 25 million Americans have rare diseases.

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Mark your calendar and plan ahead!

PWS Best Practices Guidelines

Now available. See page 7 for more details!

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