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

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

Extreme Makeover meets Prader-Willi syndrome!

By Lota Mitchell, Editor

Thousands of volunteers braved a horrific winter storm in Tulsa, Oklahoma, to do an *Extreme Makeover* on the home of Toen and Amy Starkweather, parents of nine-year-old Ethan, who has Prader-Willi syndrome.

During the week of Jan. 24, five families in Tulsa who had been nominated waited breathlessly to find out who would be selected for ABC's *Extreme Makeover: Home Edition.* On Thursday, Amy relates, they knew that they were the family chosen when they heard Ty Pennington on his bullhorn yell "Good morning, Starkweather family!" Their family of five was whisked off for a vacation in Disney World, and work commenced on Friday.

Back in 2008 they had applied for Ethan to Make-a-Wish Foundation of Oklahoma, which subsequently nominated them for *Extreme Makeover*. Ethan is very medically involved with respiratory and GI issues. He's usually in the hospital twice a year with pneumonia. He likes stories, especially about Peter Pan, to distract him from all the procedures. His wish was to fly with Peter Pan and to ride a whale. And indeed on their Make-a-Wish trip last year to Disney World he got to meet Peter Pan and feed the dolphins.

This trip inspired Ethan to want to help others, and now he is the one inspiring people to help. Ethan has become a Make-A-Wish Foundation of Oklahoma ambassador, helping to raise money for other children to have wishes fulfilled. He considers this his "job." Amy observed, "Most adults aren't motivated to volunteer and work half as hard as he does." He likes to do artwork for Make-a-Wish fundraisers. One painting he did was sold for $800. He said, "This is going to help the next kid get his wish." Also, he makes speeches at events, sometimes with a bit of help if his words aren't quite clear, and afterwards is anxious to know how much money was raised and how many kids will get their wish.

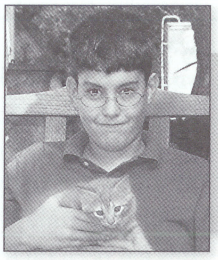


The Starkweather family at the front door of their new house (photo provided by Susan Bowen)

Amy and Toen bought their house near the University of Tulsa as a fixer-upper. But Ethan's diagnosis changed things, as did his engineer dad Toen's encounters with the layoffs of this past decade. Amy, a stay-at-home mom who has reached out to other parents of children newly diagnosed with PWS, says she "can't imagine life without Ethan's huge ray of sunshine!" More sunshine comes from Ethan's older brothers Jared, 15, and Ryan, 13. Their mom marvels at having such great teenagers. The University of Tulsa gave each of the three children a four-year undergraduate scholarship and is providing Ethan with audiology evaluations and speech therapy.

Late Wednesday afternoon, Feb. 3, hundreds of people, yelling "Move that bus!" waited for the Starkweathers to see the unveiling of their new home, built in spite of the snow and ice in such a few days where their old home had been. Several of the volunteers said the bad weather was actually the reason they were able to come and help. In the VIP section there were four people who have PWS, plus staff and parents, wearing PWS t-shirts pinned on the front and back of their coats.

The *Extreme Makeover* episode is expected to air May 2. For "the rest of the story," as Paul Harvey used to say, be sure to watch!



Micah

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Volume 35, Number 2 ~ March - April 2010 ~ Our 35th Year of Publication

PWSA (USA) Working for YOU

Prader-Willi Syndrome Association (USA) is about you, for you, and is you. Our wonderful staff keeps right on doing all they can to support our families. Here are some recent communications about a variety of services provided.

Hi Mary K. & Evan,

Can't even believe how well things are going! I keep trying to be optimistic and not presume that the floor is going to drop out from under us again!

The meeting was nothing but good, positive and supportive!!

First one in 5 LONG years!!! I complimented them all and thanked them and they were very happy about it! I asked about the conversation with Mary K. and they all were very excited and thankful for your support and help.

Mrs. Tedone stated that she used a couple of the tools you provided today to help him. I wanted them to go over the questions that they had for you with me, too. I wanted to know what was Hayden doing etc...It was very *productive*...can you believe I am using that word!

How am I ever gonna repay you both and the National organization for all that you have done for us???? I am forever grateful! ~ *Hope & Hayden*

Thank you for your helpful website. I am currently working with a beautiful young girl who has Prader-Willi syndrome. I will use this information in order to be a better music therapist to her. I especially appreciate the "Positive Behavior Tips for Educators". ~ *Lori, Board-Certified, State Licensed Music Therapist*

Good Morning, Janalee,

Thank you so very much for the attachments. I plan to give a copy to Jennifer's primary care physician next week. It is so comforting to know you are there when we have unforeseen behaviors in our PWS children. ~*Jeannie*

Evan,

We wanted to extend our special thanks to PWSA for the support that has been provided to help with Babcock [residential provider] in South Carolina. We are very much appreciative of Mary K.'s visit and her assistance. Surely good things will come from such genuine care and support. Thanks again and please call on us if PWSA needs help. We'll help if we can. ~ *Leo and Kathy*

Janalee,

Thank you for sending me the information on PWS…We really appreciate how much you personally and the PWSA have done to help out the future for all of our kids. ~ *Cinda*

Hi, Janalee,

I just wanted to update you to let you know that I got the test results back from the Methylation and my son actually has Angelman's Syndrome. I tried contacting the Angelman's organization but only got a machine. I left a message…I cannot thank you enough for all the support that the PWS organization has given me. I'm about to embark on a new journey that I don't know much about. After all, I spent the last nine months learning all I could about PWS thinking that is what my son had. Now that I have a real answer, I am trying to adjust and learn the most I can about Angelman's. ~ *Alexa*

Order of medical alert booklet:

We are members of your organization who live in South Africa. In our search for answers to many questions **your website has been invaluable**. We have only found three doctors in South Africa who could be considered to have some knowledge of Prader-Willi Syndrome. As you can imagine, this has been pretty daunting for us.

We would like to order 6 copies or alternatively pay for an electronic version of the booklet which we can print ourselves for family caretakers and the various medical professionals that we deal with. Please advise us if the latter is possible as we realize you will need to add substantial postage to the first option. ~ *Janet*

Hi to you both,

We got the information and have used it extensively in our petition and as exhibits. Thanks from the bottom of our hearts! You are the dream team. ~ *Lisa*

Good Morning Evan,

I'm so happy to report that the medical waiver has been approved!...I will be receiving some papers through mail, and I will be informed how soon my son will be allowed to stay in Gainesville. I cannot thank you enough for everything that you have done for me and my son. I could [have] never done this alone, and I have you to thank for making it this far. I would like to keep you updated on my son if you don't mind, and I hope I can always refer to you if I have any questions or concerns. Once again, thank you for your dedication and support. ~ *Nancy* ■

COMING SOON

A TRAINING DVD FOR RESIDENTIAL STAFF

PWSA (USA) is collaborating with the Prader-Willi California Foundation on an extensive training DVD for residential staff. The script is written and has been edited by multiple experts in the field, and filming has begun. Watch for announcement in *The Gathered View* and on the PWSA (USA) web site when it becomes available. ■

Adults Who Have PWS Enjoy Life – and Give Back

Our PWSA (USA) Advisory Board members (adults who have Prader-Willi syndrome) are a shining example of how many of our children and adults with PWS lead productive, active lives.

The following is a list of ways that our eight PWSA (USA) Advisory Board members are involved in their community:

- Going horseback riding, attending regular horse shows, Special Olympics horseback riding. Special Olympic bocce ball practices and tournaments.
- Going to the gym to work out and do yoga class. The staff drops me off with no money or pass. The rec center staff watches out for me.
- Special Olympics bowling and tournaments, horseback riding, group board meetings.
- Residential Consumer Advisory Board, PWSA Adult Advisory Board, Residential Facility committee meeting.
- Special Olympics swimming, Sunshine Activity Center.
- Going to church and participating in the worship—reading, ushering, volunteering.
- Working with low income kids in the Chicago area
- Writing to the state (Illinois) house and senate and to the Governor and the Lt. Governor.



(Left to Right) first row: Brooke Fuller, Conor Heybach, Shawn Cooper second row: Lauren Lang, Kate Kane, Abbott Philson, Andy Maurer

- Getting more people involved with the state chapter and volunteer work with the state.
- Go to the YMCA and working out with a personal trainer.
- Working at the Cherokee Training Center.
- Volunteer on Board of Recipient Rights through Network 180.
- Volunteer on Board of Directors of Kent ARC.
- Make financial contributions to United Way.
- Swim class, belly dancing, line dancing lessons (with seniors).
- Piano lessons, volunteering in a community garden.



The John Heybach family will be featured on The Discovery Health Channel show, *Mystery Diagnosis*, expected to air March 22, 2010 at 10 pm EST. John is Co-Chair of the PWSA (USA) Board of Directors, and son Conor, 29, has PWS.

Dear Donors of Angel Fund contributions made "In Honor Of" or "In Memory Of"–

Thanks to your generosity, PWSA (USA) will be able to continue providing the needed services for our families and professionals. Although we do not have room to acknowledge all individually in *The Gathered View* without taking pages away from our educational articles and stories, please know that we are extremely grateful for your support.

A full list may be viewed on the PWSA (USA) website, www.pwsausa.org.

Efficacy and Safety of Long-Term Continuous Growth Hormone Treatment in Children with Prader-Willi syndrome

By Dr. de Lind van Wijngaarden, Dutch Growth Research Foundation Rotterdam, The Netherlands

Patients with PWS have an abnormal body composition with increased fat mass and decreased lean body mass, and short stature. Some studies showed normalization of adult height when GH treatment was started before onset of puberty. Although improvement of body composition is considered the most important effect of GH in children with PWS, there are no reports regarding effects of long-term GH treatment on body composition in a large group of patients.

We investigated long-term efficacy and safety of GH treatment on body composition, growth, bone maturation, and safety parameters in 55 children with PWS included in a 4-year national multicenter prospective follow-up study. The mean ± SD age at start of study was 5.9 ± 3.2 years. All children received somatropin 1 mg/m^2·day. The following data were annually obtained in one center: fat% and lean body mass (LBM) by dual-energy x-ray absorptiometry, height, weight, head circumference, bone age, blood pressure, and fasting IGF-I, IGFBP-3, glucose, insulin, HbA1c, total cholesterol, HDL, and LDL. SD-scores were calculated according to Dutch and PWS reference values (SDS and SDS_{PWS}).

Fat%SDS was significantly lower after 4 years of GH treatment ($p<0.0001$). LBMSDS significantly increased during the first year ($p=0.02$), but returned to baseline values the second year and remained unchanged thereafter. Thus, LBM stabilized during long-term continuous GH treatment, which is in contrast to the persistent decrease of LBMSDS commonly observed in untreated children with PWS. Mean ± SD height normalized from –2.27 ± 1.2 SDS to –0.24 ± 1.2 SDS ($p<0.0001$). Head circumference SDS increased from –0.79 ± 1.0 at start to 0.07 ± 1.1 SDS after 4 years. $BMISDS_{PWS}$ significantly decreased. Mean ± SD IGF-I and the IGF-I/IGFBP-3 ratio significantly increased to 2.08 ± 1.1 and 2.32 ± 0.9 SDS, respectively. GH treatment had no adverse effects on bone maturation, blood pressure, glucose homeostasis, and serum lipids.

Our study shows that 4 years of continuous GH treatment with a standard dose (1 mg/m^2·day) had a significant favorable effect on body composition, heightSDS, $BMISDS_{PWS}$, and head circumference SDS, without adverse effects on blood pressure, glucose homeostasis, and serum lipids. Importantly, the favorable effect on body composition persisted during the 4 years of study. Based on our findings, it is recommended to keep IGF-I levels between 2 and 3 SDS for optimal effects in children with PWS, without adverse effects. **In conclusion, long-term continuous GH treatment is an effective and safe therapy for children with PWS.**

(We have Dr. Wijngaarden's permission to share this summary of their research. The full report may be found in The Journal of Clinical Endocrinology & Metabolism Vol. 94, No. 11 pg 4205-4215) ■

PWSA (USA) Awards Two Best Idea Grants on Hyperphagia

By Janalee Heinemann, Director of Research and Medical Affairs

As most of you will recall, the Prader-Willi Syndrome Association (USA) sponsored the 1st International Conference on Hyperphagia in June 2009. The puzzle of hyperphagia (the extreme unsatisfied drive to consume food) was the focus of this unprecedented scientific conference in Baltimore. It was the first time experts from around the world from various disciplines and various disorders that have hyperphagia as a hallmark characteristic gathered together to discuss developments and unanswered questions of appetite control and hunger.

One of the outcomes of this conference was that PWSA (USA) offered a Best Idea Grant (BIG) that was available to those who attended the conference. We are pleased to announce that after the review of many applications, grants were awarded to the following two groups with the possibility of more awards in the near future.

Leptin resistance in mouse models of hyperphagia

By Rachel Wevrick, Ph.D.
Department of Medical Genetics, University of Alberta

Hypothesis: They hypothesize that leptin receptor (LepR) signaling defects cause congenital leptin resistance in PWS hypothalamic neurons, preceding obesity and contributing to hyperphagia and obesity in PWS

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and similar genetic disorders such as Bardet-Biedl syndrome. The insensitivity to multiple hormones signaling energy needs (e.g. ghrelin) and broader phenotypes of PWS suggests that more complex processes are additionally affected in PWS, also because of defective intracellular signaling pathways that may overlap with the leptin response pathways in the brain.

Aim: To examine leptin sensitivity in murine models of PWS and related disorders, including mice carrying targeted inactivation of the Snord116/MBII-85, necdin, and Magel2 PWS candidate genes, the Smith Magenis gene Rai1, and BBS genes. The long-term goal is to determine whether defective LepR signaling is responsible for hyperphagia in PWS and related genetic disorders, and possibly contributes to hyperphagia in the general population.

Expected Significance: Congenital leptin resistance secondary to LepR mutations has been identified in rare individuals, in the db/db mouse and in the Zucker rat. Varying degrees of leptin resistance are found in most obese individuals, although there is no formal test for leptin resistance in humans. Decreasing leptin resistance is a major goal in pharmaceutical obesity research, and exenatide and pramlintide acetate have shown some promise in this area. Dietary restriction and weight loss are partially effective in the obese population, although rebound weight gain is attributed mainly to continued leptin resistance. Finding that one of the PWS genes (for example, loss of MBII-85) specifically confers congenital and pre-obese leptin resistance in genetically hyperphagic mice would allow therapies directed at minimizing leptin resistance in the mice (for example, targeting the snoRNA pathway). The knowledge that individuals with PWS are congenitally leptin resistant would draw attention to this disorder as a model for other forms of leptin resistance and would provide a sound and logical explanation for the severe post-weaning hyperphagia that is so characteristic of PWS.

Brain-Derived Neurotrophic Factor in Prader-Willi Syndrome and MC4R Function-Altering Mutations

By Joan C. Han, M.D.
Senior Clinical Fellow, Unit on Growth and Obesity
Jack A. Yanovski, M.D., Ph.D.
Head, Unit on Growth and Obesity, Program in Developmental Endocrinology and Genetics
Eunice Kennedy Shriver National Institute of Child Health and Human Development, NIH

Abstract: Brain-derived neurotrophic factor (BDNF) is a protein that is important in nervous system development and function. BDNF is well-expressed in the hypothalamus, a key region in the brain for energy homeostasis, and appears to function downstream of the leptin-melanocortin signaling pathway to control appetite. In both animals and humans, diminished BDNF function is associated with hyperphagia and obesity. They propose to study BDNF in two hyperphagic disorders: Prader-Willi syndrome and MC4R function-altering mutations. They hypothesize that patients with PWS may have increased BDNF during infancy, followed by a decline in BDNF that precedes the onset of hyperphagia and persists after the onset of obesity. They also hypothesize that patients with MC4R mutations will have decreased BDNF, the severity of which will be associated with the degree of MC4R functional loss caused by the specific mutation(s) in each individual. To test these hypotheses, they will conduct 2 cross-sectional studies comparing serum BDNF concentrations in: (1) 75 subjects with PWS (25 infants, 25 non-obese children, and 25 obese children) and 75 healthy control subjects matched for age, sex, race, and BMI; (2) 50 subjects with MC4R mutations and 50 healthy control subjects matched for age, sex, race, and BMI. If alterations in BDNF are found to be associated with PWS and/or MC4R mutations, these investigations could lead to future studies of BDNF receptor agonists as mechanism-specific pharmacologic therapy for hyperphagia and obesity in PWS and MC4R mutations, or BDNF receptor antagonists for failure-to-thrive in neonatal PWS.

Hypotheses:

1) Patients with PWS will have increased BDNF during infancy, followed by a decline in BDNF that will precede the onset of hyperphagia and persist after the onset of obesity.

2) Patients with MC4R mutations will have decreased BDNF, the severity of which will be associated with the degree of MC4R functional loss caused by the specific mutation(s) in each individual.

Significance: These studies will further our understanding of the role of BDNF in human energy homeostasis. If alterations in BDNF are found to be associated with PWS and/or MC4R mutations, these investigations could lead to future studies of BDNF receptor agonists as mechanism-specific pharmacologic therapy for hyperphagia and obesity in PWS and MC4R mutations, or BDNF receptor antagonists for failure-to-thrive in neonatal PWS. ■

Timmy Story #2

Smile as you read about another of Timmy O'Leary's many exploits in the e-mails from his mother, Judy O'Leary, to Janalee.

BIRTHDAY BASH, TIMMY STYLE

By Judy O'Leary
St. Louis, Missouri

Oct. 26, 2009

You won't believe this. You know how I have a birthday party for Tim every year, controlled - so I know what to expect. Well, so much for that.

Tim's residential provider has given him access to the phone for the past three months (he has not ever been allowed to do this), and he ordered 'stuff' from all sorts of companies to be delivered at his party on November 8. He told them a check would be waiting for them, and he has signed most of the contracts that were mailed to him. All of this unbeknown to everyone until he spilled it to my boyfriend, Judge Terry Burnet.

- *Catering for 100 people at a cost of $750*
- *Clown - $200*
- *Cake to be delivered - $100*
- *Balloons to be delivered $50*
- *Face painter $75*
- *Petting zoo with ponies $1200*
- *8 piece brass band - $1800 were expected to play from 2-4:00*
- *Ralph Butler Band $3000 - they were also expected to play from 2-4:00*
- *20 x 20 ft. tent for the bands in case it rains - $350*
- *Ice cream truck - FREE*

Needless to say, I had a sit-down meeting with the agency to discuss his access to the phone. They could not believe that Tim was this smart. Little did they know!

October 27, 2009

When I called the petting zoo to cancel, they were so grateful I called. They were indeed planning on attending at a cost of $1200. They informed me that Tim had been calling for three months, confirming every detail every week, and promising them a check. They said he was very persistent. The zoo company informed Tim that the ponies were small and only for little kids. Tim said he was a kid and he was small. When they asked how old he was and Tim said 39, they knew something was amiss but still did not question him. The company then told Tim he had to be under a certain weight. Know what Tim said? "Can you bring in some horses instead of ponies?"

October 28, 2009

When I called the catering company to cancel, the owner said he couldn't believe how smart and persistent Tim was about ordering the food for his 40th birthday party at a cost of $750. The catering company said he called every week for three months. The company did not expect payment until they arrived, and Tim promised them a check would be ready. Tim told them to arrive at 10:30 sharp, BBQ in the driveway, serve at 2:00 (hot dogs, hamburgers, brats, and steak).

After we hung up, the owner called me back because he got to thinking how impressed he was with Tim. *Ready for this?* He asked me if Tim could work unsupervised in the evening at his office, cleaning and washing the floor. I said, "Sure, if you want him to use the phone all evening and order whatever his heart desires and bill your company." He started laughing because he hadn't quite thought it through.

God only knows who is going to show up on Tim's birthday. It will not be pretty. I'm sure glad Judge [Terry] Burnet will represent Tim as he will need one.

Signed
Judy the Party UNplanner

November 3, 2009

Tim has now contacted his lawyer because he wants to divorce me as his guardian. *Will this ever end?* All I am trying to do is give him a stupid birthday party.

Signed
Judy the Divorced Guardian

Judy reports the follow-up: Tim's party went smoothly because I was able to cancel everything. Sixty



people showed up. When I say he has a birthday bash, Tim has a birthday bash. However, Tim has never ever been this angry with me and wouldn't speak to me for almost four weeks because I canceled what he ordered and because I cleaned his room. I clean his room once a year before his birthday because it becomes a fire hazard (compulsive hoarder). He told staff to screen any calls and if it was me he wouldn't take them. It was awful, really. I love him so much and the fact that he had nothing to do with me was so hurtful.

It was only after he hired a lawyer (Mark, who is my best friend, thank God) could we work things out. We all three met and went over all Tim's issues. *There is absolutely no reasoning*

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Don't just think, do. ~Horace

From Josi, to Leta, to the White House

LPGA (Ladies Professional Golf Association) player Leta Lindley and 18 other LPGA players attended the **6th Annual Prader-Willi Classic** with Leta Lindley in honor of **Josilyn Faith Levine** on December 7th in Palm Beach Gardens, Florida. Event organizers **Ronnie and Ira Levine**, Josi's grandparents, have grown this golf tournament from a friends-and-family event to the current larger affair, attracting individuals from the general public who flew in from as far away as Philadelphia to play.



Josi Levine and Leta Lindley

Lindley graciously lent her name to the event after she met Josi, now 7 who has PWS. Inspired by Josi's charm, she volunteers her time to attend and promote the tournament. This year the Levines donated $15,000 to PWSA (USA) for research through their foundation, Josilyn Faith's Foundation.

Lindley was chosen by the LPGA to be a representative for First Lady Michelle Obama's national campaign to combat childhood obesity, Let's Move, due to her work for PWS. Next year's Classic is scheduled for January 22, 2011. For more information, visit http://www.pwclassic.com/.

Events

In October, high school student **Kelsea Ranck** fulfilled required credits for a community project by raising funds for PWSA (USA) in honor of her cousin, Madison Hurdle. The basket bingo event was a public awareness campaign, raising $3,867, thus also a successful fundraiser. Kelsey's mom, **Sheryl Ranck**, said the event took place at their local fire station in Pennsylvania and that Madison's father, Clint Hurdle, flew in from Colorado to attend the event.

Thanks to **Jennifer Bolander and PWSA of OHIO**, PWSA (USA) received a donation in January of $2,203 resulting from their **4th Annual Sophie's Walk for Prader-Willi Syndrome Awareness** that took place in June in Fairview Park, OH. The event, started in honor of Sophie Bolander, now 6, actually raised twice the amount, with the other half of funds supporting the chapter.

A family event in June in Mississippi called **A Cure for Jack** was a fun day for all attending. **Jack,** 7, is the son of **Suzanne and Scott Lindsey**. The Lindseys' friend, **Beth Hemeter**, organized the fundraiser and sent a donation for research totaling $7,177. Beth wrote, "Jack is a very special child in our community."

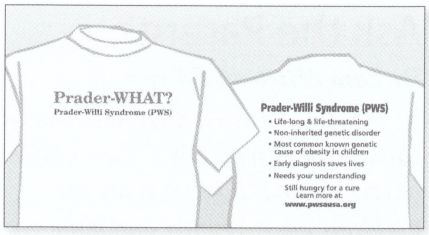
Awareness Month

May is PWS Awareness Month. Take the time to educate others and raise funds for PWSA (USA).

Here are some ideas to inspire:

Jennifer Cheshire of Florida is mom to one-year-old **Ethan** who has PWS. She has designed t-shirts and is making them available to anyone who would like to purchase them. She is donating proceeds from the sales of the shirts to PWSA (USA).

For awareness month, she created a shirt, "Prader-WHAT?" based on an article that had appeared in The Gathered View. The front asks this question with the syndrome name directly underneath it. The back of the shirt bullets five main points about the syndrome, developed with help of PWSA (USA)) and gives the PWSA (USA) web site address.



Jennifer also designed a shirt for Valentine's Day which can still be ordered and worn anytime. The front of the shirt simply states, "I (heart) Someone with Prader-Willi Syndrome."

To order the shirts, please contact Jennifer directly at Jennifer_Cheshire@comcast.net. They are available in youth and adult sizes, short- or long-sleeve, and range in price from $12-$18 each. Please contact Jennifer for more information on ordering and delivery.

Avid cyclist **Tammy Rinkenberger** of California is mom to two-year-old **Hope**, who has PWS. Her friend generously donated the graphic design work to use on biking apparel. Tammy has already ordered and worn her clothes in races and for training, and so have her friends.



The graphic on the shirt is red, white and black with a red swirl design. The front says, "ride for Hope" and the PWSA (USA) logo. The back has the organization name, web site, and "Still hungry for a cure." The sleeves have the number "15" denoting the 15th chromosome that's affected.

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Ask the Parents

By Lota Mitchell, Editor

Q. If you have a high-functioning child or adult with PWS (low normal or even normal IQ), what are the problems you encounter and have you found any solutions to deal with them?

"My daughter is 14, has PWS and is in a "gray" area, because she is quite capable intellectually…However, the weight has always been a problem...the more she tries to lead a so-called normal life…I just want to hear from other parents who have a similar situation with a child with PWS who has what it takes to be a functioning part of society in some aspects–but who is hurt by the food issues that are so much a part of every event." – *post on the New York chapter Yahoo e-mail group.*

We are all pleased when our children with PWS are bright and perform well in school, but does that mean fewer problems – or more – or some different ones? So the question was posted on all our e-mail groups except 0-5:

Food, weight gain and behavior issues

The dozen-plus responses all indicate that high-functioning persons with PWS have the typical problems of the syndrome, along with OCD and compulsive behaviors, with the same mild-to-severe range as others with PWS.

Terri, mother of a son, 8, noted that he "has tested at 109 and 100 for IQ (has also tested lower). He is in typical second grade with behavior mod and 1:1 aide. Our biggest challenge is behavior. We use positive reinforcement and he takes Seroquel 75 mg at night. Life is good."

Michelle's son is almost 7, has PWS by imprinting, is in a regular class and above average in IQ… speech is normal. "I do find that he struggles with social skills and has more OCD behaviors than other kids that I have seen with PWS."

Jill says of daughter, 20, "Besides sneaky, she's just so smart! We have some keys hanging in the kitchen (locked but also our laundry area). Recently my husband hung up his housekey, having added a small key to our padlocks. She spent much of Monday in the kitchen doing her own laundry. Most of the time one of us was watching her, but…she managed to slip those keys into her pocket. She used it to open the door to our bedroom, where I keep a small stash of candy to handle my insulin reactions. Consumed it all back in her own room before we discovered the lapse. Sigh.

Mary describes food drive of daughter, Tressa, 7: "We have placed walls inside our home, dead bolts and individual locks. If she sees a gap in security, she is on it before anyone can figure it out. She has eyes not only in the back of her head but 360! She has ears like no other--the neighbors can be opening a bag of something and she can hear it."

Dan's son, Jacob, 18 "…used to have major rage episodes, but has lately become more mellow and mature."

Daniel, 19, "knows what he can and can't have. He can be trusted for the most part; as long as someone is with him, he will follow the rules. Leave him alone with some money, and he will be at the deli down the block, getting himself something he shouldn't have."

High IQ-Specific issues

John Heybach, co-chair of the PWSA (USA) Board of Directors and father of a son, **Conor**, age 29, who with a great deal of support has graduated from college, sent the following thoughtful list:

- As a high IQ individual with PWS grows to adulthood, a discrepancy can develop between the person's intellectual ability and the person's emotional maturity, "executive functions"' and social capabilities; the high IQ can lull caregivers into thinking that the individual with PWS can function normally in these areas also, which is not the case.
- A higher IQ individual with PWS can be much more creative in food seeking and manipulating the environment and others for food or money; e.g., Conor has talked banks into allowing him to withdraw money from joint accounts without my signature.
- The biggest struggle for Conor has been the inability to live independently of supervision despite his normal/above normal IQ; this has required counseling help for him on an ongoing basis.
- High IQ can be a limiting factor in some cases in receiving services.
- More in-depth understanding of the condition and its manifestations can lead to anxiety.
- Appropriate companionship and social activities that are interesting become more of a challenge.

Respondents certainly reflected John's list. **Jill's daughter, now 20,** "didn't qualify at first for special ed services in Indiana because she was too intelligent; the only way we got her in was as "orthopedically impaired" because of her low muscle tone…She was able to graduate from high school with a regular diploma, but that means she doesn't qualify for further services through age 22 as those who just get a certificate of completion do…She would probably be capable of working at least half-time, but the only waiver she can get at this point in Indiana is a support services waiver that will only provide one-on-one supervision in a workplace 8 hours a week. She realizes that

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isn't 'normal.' I think it's harder in a way because she understands so much and sees the gap between what she wants and perhaps would be capable of and what's open to her."

Pat notes that the unique problems of the high functioning individuals with PWS are often overlooked and offers her own list:

1) Their arguments can last "forever" because they can keep coming up with new reasons and you have to deal with each and every one and have logic for each one. Each new reason becomes a new argument.

2) They can think of THE MOST INNOVATIVE ways of getting food!

3) They will leave no stone unturned in finding someone…anyone!…who will support their side of the issue – right up to the legislators at all levels of government. **Sara, 33,** calls all these offices herself. We're Canadian so our government is different than yours, but she has had her issues in the premier's office, heard in the legislature, dealt with by the Ombudsman's Office, written up by our provincial member of parliament, also in the federal member of parliament's office…and on and on. Not to mention all the social workers and so on who are aware of her situation.

4) Sara's younger brother is married and her sister is in a relationship, and Sara so seriously wants these things for herself. She's always just a step away from depression due to her lack of these.

5) Sara had freedom in the past and hence learned bus routes all over the city. Now she has to be reined in more than ever because she can find her way around and purposely could go literally anywhere on her own and it would be a nightmare finding her.

Next issue:

We'll print some more responses, look at a few solutions, and see what some parents say about the impact on them. A great big thank you to all who contributed! ■



BLUE ROSE

~ Author unknown

After shopping I headed for checkout only to be blocked in the narrow aisle by a young man who appeared to be about 16. I patiently waited for him to realize that I was there.

Then he waved his hands excitedly and declared loudly, 'Mommy, I'm over here.' It was obvious now; he was mentally challenged and also startled to see me waiting to squeeze by. His eyes widened with surprise as I said, 'Hey buddy, what's your name?' 'My name is Denny and I'm shopping with my mother,' he responded proudly. 'Wow,' I said, 'that's a cool name; I wish my name was Denny, but my name is Hal.' 'Hal like Halloween?' he asked. 'Yes,' I answered. 'How old are you Denny?

'How old am I now, Mommy?' he asked his mother as she came from the next aisle. 'You're 15, Denny; now be a good boy and let the man pass.' I talked to Denny for several more minutes about summer, bicycles and school, and I watched his brown eyes dance with excitement because he was the center of someone's attention. Denny's mom thanked me for taking the time to talk with her son.

I told her that there are plenty of red, yellow and pink roses in God's garden. However, 'Blue Roses' are very rare and should be appreciated for their beauty and distinctiveness. You see, Denny is a 'Blue Rose', and if someone doesn't stop and smell that rose with their heart and touch that rose with their kindness, then they've missed a blessing from God. ■

MANAGEMENT ANNOUNCEMENT

PWSA (USA) is now managed by an Executive Management Team. This team is composed of Evan Farrar, Janalee Heinemann and Sharon Middleton in the Sarasota office. This team will report to Ken Smith and John Heybach, co-chairs of the board of directors, and Mary Kay Ziccardi, former board member, who will provide active oversight and support. The staff and board are pleased with these changes in responsibilities that build on our strengths and continue to allow the organization to focus on serving individuals and sponsoring meaningful research affecting those with PWS and their families. All of our programs, support functions and research projects are moving ahead, and many new initiatives are planned for the near future.

Kim Weinberg is no longer with PWSA (USA). ■

When the Presence of Patient Representatives at Conferences Really Makes a Difference!

By Matina Manolias, applied statistician, Statistics and Insurance Dept. University of Pireaus, Greece, active member of the Orphan Drug Task Force of EURORDIS and mother to Konstantine (PWS 8 yrs) and Polyxeni (12 yrs)

I was asked to participate as patient representative/advocate at a conference organized by DIA (Drug Information Association) that took place in Paris, on a topic that I really heard for the first time in my life. HTA was the subject matter of the sessions, and it stands for Health Technology Assessment, Health Technology including drugs, devices, procedures, etc.

There were people from the pharmaceutical industries, EU and EMEA officials, doctors, economists, statisticians and almost ten patient representatives.

This amazing feat of professionals meeting a number of patient representatives was very much the result of EURORDIS (Rare Diseases Europe), which for the last ten years brings together associations from all over Europe and unites them in a magic way. I was very satisfied to see that the participants of the conference panels were very exceptional speakers with exceptional knowledge and a very humanistic attitude.

The one, however, that I do not think anyone will forget was Lesley, whose daughter passed away two years ago. This woman, an English Literature graduate who has spent almost thirty years in creating a new future for people with metabolic disorders in Great Britain, had the courage to continue her volunteer work with EURORDIS after the death of her daughter. She is a patient representative in the Committee for Orphan Medicinal Products (COMP) and gave everybody a lesson of life with the simple title "Jennie". Actually, she showed how transparency could perhaps have saved the life of her daughter, and she showed it in a very simple, direct and human way.

The doctor who spoke immediately after her said: ***"I want us to give an applause for this woman who personally reminded me why do I wake up and go to work every morning."*** I will always remember this speech for it gave the words that each one of us patient representatives have in our mind and are not always given the chance to pronounce them. Thank you, Lesley, for letting me take Jennie home with me Dec. 2, 2009. ■



Annual Valentine's Day Research Campaign

Thirty-four participants raised over $8,000 for the 8th Annual Valentine's Day Research Campaign. THANK YOU to each participant, donor and the sweetheart who inspired them!

Fundraising Events, *continued from page 7*



The design can be modified for runners by changing the shirt text to "run for Hope."

The shorts design is black and red with the red swirl design and has the PWSA (USA) web site down both legs written in white.

Tammy has volunteered to coordinate ordering of these items for anyone interested. There is a 10-item minimum order. Each item is approximately $60. Please contact Tammy at lilsprocket@mac.com for more information. Please expect *at least* eight weeks or longer to receive these items. ■

Timmy Story, *continued from page 6*

with Tim, and his lawyer had to work so hard to keep from laughing. Bottom line - Tim will plan his own party, and instead of me working with him, he will plan his party WITH HIS LAWYER!

And oh yes, he wants to obtain dual citizenship in the United States and his favorite foreign country, India. ■

CHUCKLE CORNER

One Sunday, we were watching football with some friends. Our son, Joe, who was 7 at the time, likes to hang around and listen to adult conversations. We had been talking about the Green Bay Packers. Later on, Joe asked us who won the football game, the Packers or the Hot Lunchers. In school for lunch each day, they put their name under "packing" or "hot lunch."

~Pam Siefert
Dayton, Ohio

Power Up With The Stepping Out Running Club

Can you imagine a person with PWS loving to run? Can you imagine a whole group of individuals with the syndrome running 5Ks and 10Ks all summer, cheering each other on and even forming a Running Club? This actually happened at Stepping Out - a small company in Hastings, MN that provides services to 14 individuals with PWS. This April on the first Saturday of the month, The Stepping Out Running Club will kick off their 5th season with a Celebration Breakfast. The spring and summer agenda of 5Ks, 8Ks and 10Ks will be passed out and discussed. There's been some rumbles lately about ½ marathon training. That will also go on the table for discussion. New shirts will get passed out and any new members will get introduced and high fived. Then the "runners" will head to the trail and barring a spring snow storm The Stepping Out Running Club will "Power Up" and do their first group training run of the season.



Running is loosely defined in this club. Essentially if you can walk reasonably fast you are in but there are some fast runners too. Vince Sumner for instance came to Stepping Out in 2001 when he was 12 years old. He was 4', 7" and weighed 265 pounds. The growth plates in his knees had been crushed due to his weight and he came in a wheel chair. Five surgeries and many hours of exercise later, Vince typically runs a 9 minute mile and a 30 minute 5K. On the other end of the speed spectrum are the serious walkers who are just as much a part of the club and earn as much respect and kudos as the runners.

Run Club started the summer of 2006. Stepping Out residents jog or walk for 30 minutes first thing in the morning, five times a week. It is part of their rigorous exercise program. After one of these morning walk/runs



someone saw a poster announcing a local 5K. "Why can't we do that race?" they asked. It was a bit worrisome to consider due to the proliferation of treats at the end of all races but it seemed worth a try. It was decided though that anyone who wanted to do a 5K needed to "train". Training consisted of stretching, hill repeats, speed work and most of all pep talks. From those first ideas and that first 5K a well organized club has evolved. Members run fast or walk. They help each other and cheer for each other. Sometimes at a race they will all go back and bring in the slowest walker. The enthusiasm they generate is infectious. At the end of the season The Running Club has an Awards Banquet at a local restaurant. Families and friends attend. Speeches are made. Awards are presented and everyone gets giddy and full of pride.

The club members are celebrities in this small town, getting their pictures and stories in the local paper regularly. People in Hastings know about Prader-Willi Syndrome and the challenges these runners and walkers deal with daily. Every one of the club members has a story and they love telling about how they came to their present healthy state.



More than the inspiration the club generates is the healthy lifestyle it encourages in its members. Who could have guessed that they would spend the whole winter working out to stay strong for Run Club. It has made them proud to be who they are. They have pushed the limits that PWS placed on them and achieved something wonderful. ■

~Bonny Bates
Owner/Operator
Stepping Out, Inc.

Chapter View

Colorado Derby Day May 1

PWSA of Colorado's Derby fundraiser annual event is a community awareness and fundraising gala held on "Kentucky Derby" day. In 2010 it will happen on May 1 in Denver, Colorado.



All funds raised directly benefit individuals with PWS. This family-friendly day brings people of all ages together to watch the race and participate in a variety of fun activities.

Hundreds of attendees enjoy placing bets on the horses using "Prader-Willi dollars", participating in silent and live auctions, watching the race (on TV) and enjoying delicious food and drinks. It is a wonderful way to spend the day and support a great cause.

For more information, contact Lori Harry 720-933-7009 or lori.harry@gmail.com. You may also visit the website: www.pwsderby.com.

Prader-Willi Association of New York announces that their 20th Annual PWANY Conference will take place April 30th - May 1st, 2010, in Albany, New York. For more information contact Linda LeTendre, lindaLeTendre@CLASInc.org

PWSA of Ohio has a full calendar of events: PWSA of Ohio Benefit dinner at the home of Tom and Sandy Guisti in Columbus, April 23 and 24; Awareness Day, Cleveland Metropolitan Zoo, May 22; Jazzy's Walk to Benefit PWS, DeWeese Park, Dayton, May 29; Recreation Unlimited Summer Camp for PWS, June 7-11.

PWSA of Pennsylvania plans a mini-conference July 31-August 1 in State College. Speakers: Drs. Linda Gourash and Jan Forster.

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

PWSA (USA)'s NEWEST EDUCATIONAL FORUM – THE WEBINAR

To date, we have made three webinars available to our members. The first, held October 25, 2009, was co-presented by Barbara McManus and Janalee Heinemann. They discussed the Medical Survey results and gave tips on surviving the holidays. One of the participants had this to say:

"I thought the webinar was very informative and much needed. I have a 22- year-old son. I have a better understanding right now of why he does the things he does. I wish this material was available when he was just starting out in life. Kudos to you!"

On November 19, 2009, our second webinar, "The Truth About Consequences", was co-presented by Evan Farrar and Mary K. Ziccardi, who shared behavioral management strategies with their audience. Two of the attendees provided this feedback:

"I thought the presentation was excellent… I look forward to more presentations."

"All of the PWSA support is MUCH appreciated! Thank you. I know I am one of many that would be lost w/o this support! SO thank you!! "

The first webinar for 2010 was held February 28. Dr. Suzanne Cassidy presented "Prader-Willi Syndrome: An Overview for Parents of Young Children". One family had received their diagnosis just two weeks earlier

PWSA (USA) is proud to provide access to such quality information to our families, as well as to individuals in Spain, Chile, Brazil and Canada who participated in the webinars.

Details about upcoming webinars will be available on the PWSA (USA) home page.

Counselors Corner

An ongoing advocacy goal of PWSA (USA) is to have PWS added to the Social Security Administration's list of Compassionate Allowances. Inclusion on this list would speed up dramatically the approval time when people with PWS apply for social security benefits. On February 11, 2010 the Commissioner of Social Security, Michael J. Astrue, announced the addition of 38 new conditions to the list but did not include PWS. While this is not the good news we were hoping for, ***it is still good news*** because this marks the first time the list has been expanded – which means it is possible to include PWS in the future.

When announcing the expansion, Commissioner Astrue said, "There can be no higher priority than getting disability benefits quickly to those Americans with these severe and life-threatening conditions." We agree! This is why we cannot give up in our effort to have Social Security recognize PWS as one of these severe and life threatening conditions deserving of compassionate allowance. To do that, we need your help! Please take a moment to send an e-mail to Commissioner Michael J. Astrue, Commissioner of Social Security at Compassionate.Allowances@ssa.gov and ***include*** in your communication at least these three points:

1. Your appreciation for the list expansion.

2. Your disappointment that PWS was not included.

3. The story of your loved one with PWS as an example of why PWS should be included when the list is expanded in the future.

If you have questions about what to write, please contact me at efarrar@pwsausa.org

~ Evan Farrar
Director, Crisis Counseling

From the Home Front

Stained Glass

It's hard to believe that it's been 6 years since Justice was born. Every year at this time I tend to become a little sad as I think back to the day she was born. With my other four kids I only have fond memories of their births. With Justice there are so many memories of grief and despair. The picture that was painted for me of PWS was so dark I wasn't sure how we would go on. (The unknown is so scary.) She wouldn't eat, she couldn't open her eyes and close her mouth at the same time. She was unable to even lift her arms or hands off the bed. She lay there lifeless with such shallow breaths, I sometimes would have to put my head near her chest to ensure she was still breathing.

She was so fragile and helpless, and for the first time as a parent I was unable to fix it. I couldn't make it all better by a kiss or a band aid. I had to come to the realization that we were now on a journey, a journey that would show us a whole new world that I had been able to pretend didn't exist.

Now Justice is a thriving, smart, beautiful 6-year-old with a vivid imagination. She is a joy to be around and can bring a smile to anyone. The picture that was painted of PWS that was so dark and scary is no more. I now see it more like a stained glass window. When it is first started, there is no color or light, only darkness and so much work ahead. Every new thing Justice accomplishes is like a splash of color added to our window. We now have the most beautiful, unique piece of art in her, and she radiates her own light.

Our journey is far from over, but I am no longer fearful. This new world has introduced me to people who are amazing and made me realize that I am stronger than I ever thought possible. I know that we can make it through anything now.

~Kristi Rickenbach
Blaine, Minnesota

A Parent Recommends

My husband I decided to buy Cole "YOUR BABY CAN READ" from an infomercial on television. This is a early language development system invented by a Dr. Robert Titers. I'm very skeptical of these kinds of things, but we bought it anyway. It included 6 videos, 6 books, tons of flashcards that have the word and then open up to the picture; it all corresponds to each other. We started it in September of this year.

I cannot even tell you the difference it has made in Cole's speech and cognitive skills by putting these videos on every day and doing the books and flash cards. He is a completely different child. He talks along with the video when identifying pictures and WORDS! He talks around the house, identifying actions and objects, and has started putting 6 to 7 words together already.

Because most children with PWS children learn best from repetition and memorization to put into long term memory, this video does the trick! Just wanted to share this information in hopes that maybe it could help some other people out.

~Tracey Lombardi, mom to Cole (PWS UPD), age 3
Ocean, New Jersey

Contributions

Thank you for Contributions in December 2009 and January 2010

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

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

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

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