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

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

Prader-*WHAT?*

by Jodi O'Sullivan and Lota Mitchell

In the past, typical responses when we talked about our children were "Prader-what?" "Did you say, uh, Willy-Pradder?" "Prader-Willi's syndrome? Never heard of it!"

Thanks to a lot of hard work on the part of a lot of dedicated people, the responses are sometimes getting better: "Prader-Willi syndrome. I think I've heard of it." Or even "Isn't that the eating disease?"

That's what the PWS Awareness Month of May is all about—moving toward "Oh yes, I know about Prader-Willi syndrome!" So many have worked to educate others about what our children and adults with PWS experience and to increase understanding of what parents and family and caregivers go through. And perhaps knowing what a serious problem it is will motivate more people to give monetarily, either toward research, programs or operating expenses of PWSA (USA) so that we may continue to provide a wide range of services to help those who are affected by this difficult birth defect.

The Awareness Month of May was jam packed with family members, friends and chapters, all helping to create that awareness which is so important. And they did it in lots of ways!

Some Highlights

Michael Paul of Georgia, 23, who has PWS, threw out the opening pitch on May 29th for the Rome Braves baseball game and was then relieved by John Smoltz, Atlanta Braves pitcher who was in Rome for rehab from injury. Thanks to the Paul family, it was officially PWS Awareness night at the stadium.

Zak Bassel, 3, who has PWS, was poster child for YAI's Central Park Challenge in New York City on May 31st. Approximately 6,000 people attend. Zak and his parents appeared in a Public Service Announcement. Additionally, Zak's dad, Jamie,

Zak Bassel rang the opening bell for the New York Stock Exchange on May 30th

shared that Zak rang the bell for the New York Stock Exchange on May 30th.

Nina Roberto in New York, mom to Sonny, 5, who has PWS, wrote to her Assemblyman regarding a resolution. It was approved, thus May was officially considered PWS Awareness Month in the entire state of New York! Nina also made a video and put it on YouTube. You can view it at www.youtube.com/watch?v=IpmSjDoLKRM.

Jenn Jones wrote: "A story about our little Gavin was published in the May 10th issue of 'The War Cry,' a Salvation Army national publication. They weren't aware when they assigned the story that May is PWS Awareness Month, so that is an added bonus!"

In The News

Many stories appeared both in print and online

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USA
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Still hungry for a cure.

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Lota Mitchell, Editor

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

Executive Director's View

Photo by Eric Hilton

Craig Polhemus

Saving Each Other

Every day, the phone rings at PWSA (USA).

- *"We just received the diagnosis . . . "*
- *"My insurance company won't cover . . . "*
- *"The police arrested him for stealing food . . ."*
- *"My child is running a fever. Should we go to the ER? . . ."*

Do any of these sound familiar?

More than a thousand times last year, families called PWSA (USA) Crisis Intervention Counselors at (800) 926-4797 or (941) 312-0400. Here are some of their reactions:

"Once again thank you and your organization . . . At the time I contacted your group we were having a very difficult time with our son. As it turned out he was over medicated by a doctor who didn't understand a Prader-Willi patient. Using information from the Primer we found a Psychiatrist who changed his medication and our son is back to his normal self. I took the liberty to give both his primary care physician and his psychiatrist a copy of the documents you sent me. Both doctors were more than pleased to have the information and feel it will be helpful in caring for our son in the future."

"I would like to extend a heart-felt 'thank-you' to everyone who had a part in securing the waiver for my brother. He smiled for the first time in weeks when I told him the good news."

"Thank you very much for helping my youngest sister get her growth hormone approved by the insurance company. It was very stressful for my parents, especially my mother. . . We feel very fortunate that we have someone like you."

"Just to let you know my daughter finally saw a psychiatrist and was given drugs to help her! She is so much calmer and feeling a hundred times better!"

"I was so pleased with the turnout of the meeting and it helped me a great deal in feeling positive about [our son's] schooling going forward (especially after a very tense parent-teacher conference with [our son's] current school the same evening). Thank you so much for all you have done to help us, and your willingness to go out of your way for us. We are extremely grateful!"

"Thank you so very much. I tell you every time I think life is sailing smoothly I'm thrown a curve. But that curve ends up in teaching a lesson for me or someone else. You were very thoughtful and considerate and a God-send for us."

"I appreciate your e-mails, your calls to the doctor and just knowing you were there for us when I needed someone."

"Once again thanks for your help. You have given us a light at the end of the tunnel."

How do we provide these services? Through your contributions and fundraisers.

PWSA (USA)'s Crisis Intervention Program was initiated by Alterman Crisis Counselor Emeritus David Wyatt with financial support from the Alterman family. Today, David continues to assist as a volunteer along with the current Alterman Crisis Counselor Kate Beaver and Crisis Team Leader Evan Farrar. On behalf of the Alterman family foundations, PWSA (USA) Board Member Michael Alterman recently announced an increased donation to $15,000, nearly a quarter of the program's cost.

For the first time in history, families of those with PWS also have access 24 hours a day, 7 days a week, to emergency medical counseling and referral through a pilot project launched last year. So far, we have almost half the dedicated contributions to support this program throughout 2008.

Crisis Counselors turn frequently to volunteer medical and other professionals, including Mary K. Ziccardi, a PWSA (USA) Board member with REM Ohio. With support from Lois and Steve Willett, we are able to provide training across the country for teachers and schools when all other attempts at mediation and education have failed for children with PWS, to finance transportation for emergency medical and behavioral intervention, and to help cover legal costs in exceptional situations.

The crisis programs, like New Parent Mentoring, the Package of Hope, National Conference family sponsorships, medical education, research, and awareness initiatives all rely on – you. Families interested in helping each other through generous donations, fundraisers, and volunteer work

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Medical View

BLOOD DRAWS: QUESTIONS AND ANSWERS FOR FAMILIES AND PERSONS WITH PWS

By Shawn McCandless, M.D. **-** Assistant Professsor, Department of Genetics, Case Western Reserve University

What are some instances where my child would need blood work other than the genetic testing?

Children and adults with PWS, like anyone with complicated medical conditions, may need blood tests for a variety of reasons. Most blood tests look only for one piece of information, such as a blood count, or to measure sodium or potassium in the blood. Although all the blood may be placed into a single tube, or a few tubes, the sample is separated in the laboratory so that the technician can have enough of the sample to complete the test ordered and, if needed, repeat it to confirm the result. Each individual test uses a different instrument or procedure, so more tests require more blood. Many blood tests have been developed to work on small amounts of blood, so that, on average, most blood draws can be less than two teaspoons of blood.

Children on GH need regular monitoring of blood to be sure that the dose is correct. This testing measures insulin-like growth factor 1 (IGF1) which is part of the information the doctor needs to tell whether the dose of growth hormone is too low, too high, or just right. At the same time, the doctor may need to monitor the blood count or measure the output of the thyroid gland. Any time a person has surgery, the doctor will likely request blood tests to confirm that the blood clotting factors are normal and that there are no unexpected abnormalities of electrolytes (salts and minerals in the blood) or blood counts that would increase the risk of problems during anesthesia or surgery. At the time of puberty, doctors may need to evaluate the body's hormone production to understand why outward signs of puberty are occurring earlier or later than expected. Blood tests may also be used to evaluate causes of seizures, to monitor drug therapies, to help identify the cause of infections or fevers, and to evaluate heart or kidney function.

It is important that you know what tests are being ordered for your child.

Does the higher body fat content in a person with PWS contribute to the difficulty of blood draws? If so, why?

The process of drawing blood, called "phlebotomy", is complicated and always difficult. Individuals with PWS tend to have extra fat in the front of the elbow, where it is normally safest and easiest to draw blood. This makes it harder to see or feel the vein, making it more difficult to get the needle into the vein. Some phlebotomists may prefer to draw blood from the back of the hand, where the veins may be somewhat easier to see, although they are usually smaller than the veins in the front of the elbow.

Some people are better at drawing blood than others. If there have been problems in the past, don't hesitate to ask for the most experienced person for pediatric blood-drawing available. It is worth asking your doctor for recommendations about finding individuals with a lot of experience drawing blood from children. Often this may be a nurse who has worked in a neonatal intensive care unit or it may even be the doctor (or not!).

My son is fine with getting shots and the pinch of needles, but holding him still seems to upset him almost to hysterics. Why?

Children with PWS are known to have increased tolerance to pain, and many parents note that their child with PWS doesn't seem to be bothered by needles for blood drawing or shots. For all children (and adults, too) the anticipation of the needle is worse than the actual event. This is especially true for our children with PWS, who have a natural tendency to "obsess" about upcoming events. Because young children don't understand that they can't move their arm when blood is being drawn, they usually must be held. If your child is able to be still, based on your past experience, let the phlebotomist know. Also it may help if you offer to hold your child, because many children with PWS, like most children, don't like to be restrained by strangers. Actually, neither do I.

Our children take many cues about how to behave from us. If we appear to be frightened, upset or anxious about an upcoming blood draw, our child will likely be frightened, upset or anxious. The most helpful thing that a parent can do is to remain calm and to be firm that having the blood draw is not a choice (having already asked the doctor what the blood test is for and why it is needed), and to not increase the child's anxiety by making comments that are likely to increase it.

What is EMLA cream? Are there any other ways to numb the skin so the needle doesn't hurt?

EMLA stands for "eutectic mixture of local anesthetics". It is a combination of topical anesthetics blended into a cream that is applied to the skin, providing anesthesia at the surface of the skin. The cream takes 30 to 40 minutes to reach its full benefit so it may need to be placed in multiple sites, in case there is trouble drawing blood from the first site tried. Care must be taken to see that the child doesn't accidentally eat the cream and that the total dose applied is not excessive. Too much of these prescription medicines, whether they get in through the mouth or the skin, can have dangerous effects on the heartbeat. This is usually not a big problem, though.

Besides taking a long time to work, there are several other drawbacks to EMLA cream. First, it is expensive, and insurance doesn't always pay for it. Second, it only numbs the surface, and sometimes the more significant pain from a blood draw is caused when the needle moves around under the surface of the skin where it is not numb. Most important, the medicine also may cause the blood vessel to constrict, making it more difficult to get the needle into the vein.

There are other methods of numbing the skin, but most are either not effective or interfere with the blood draw, so they are less useful. EMLA is most useful for children who have severe anxiety before the blood draw. But because most needle pokes actually are quick and hurt very little, the EMLA cream really doesn't do much. Children who are anxious are likely to still be anxious, and the EMLA just makes them have to wait longer and have more time to worry before the blood draw. If your child has problems with anxiety about blood draws, and using EMLA significantly reduces that anxiety, then it is safe and reasonable to use it. Unfortunately, it is fairly rare for it to make that much difference, especially in children with PWS, who generally find the waiting and the being restrained the worst parts of the blood draw.

What can I do, as a parent, to minimize the trauma associated with blood draws?

The most important thing the parent can do is to remain calm and collected so that the child doesn't sense parental anxiety. Don't hesitate to ask questions about the purpose of the blood test. Also, sharing with the phlebotomist what has worked well for your child in the past (e.g., distractions, being held by parent, not being held, putting the tourniquet over the shirt sleeve) can be a big help and is usually better received than trying to tell them how to do their job. If you are becoming upset because the blood draw is difficult, suggest to the phlebotomist that you all take a short break. During that time you may be able to tactfully suggest that another provider be called to try, preferably one with even more experience. The phlebotomist will likely be thinking the same thing, but it may be easier for them to ask someone else if the request comes from you. Certainly talk to the doctor if you think that EMLA cream may help. It is essential to always be an advocate for your child and to work with your healthcare providers to ensure the best possible care.

> *"The most important thing the parent can do is to remain calm and collected so that the child doesn't sense parental anxiety."*

More questions and answers about blood draw can be found in the Members Only section of the PWSA (USA) website. Others may reproduce this article but only with the following credit line: Reprinted from The Prader-Willi Voice April– June 2007 issue, published quarterly by the Prader-Willi Syndrome Association of Ohio.

Your Dollars at Work

PWSA (USA) CONTINUES TO SPREAD AWARENESS THROUGHOUT THE MEDICAL COMMUNITY

In April, along with endocrinology nurse Kathy Clark, I had the opportunity to present to all attending the national PENS (Pediatric Endocrinology Nursing Society) meeting for 1½ hours and also to do an awareness booth. In June, we did an awareness booth at the major Endocrine Society conference, and in October we will have a booth at the National Society of Genetic Counselors. At these major conferences, we hand out a vast amount of free educational materials to thousands of medical professionals and answer hundreds of questions from specialists in the field. There is no better way to spread the word about the proper management of Prader- Willi syndrome. Thank you for making this possible!

- Janalee Heinemann, Director of Research & Medical Affairs

Growth Hormone Approved in Australia

Yesterday morning I was notified (verbally from Pfizer) that Growth Hormone for PWS was passed here in Australia. I wish to thank you for all the data you supplied to us here in Australia; I believe that if not for this data we would not have GH passed here. It has been a long battle, and after 9 years we have got there finally.

Thanks Again. Best Wishes
Barry Greensmith, President, PWSA of Australia

Research View

PWSA (USA) Recent Research Grant Awards

By Janalee Heinemann, Director of Research & Medical Affairs

As announced in the May-June Gathered View, PWSA (USA) has recently awarded four more grants (two in Dec 2007, one in March, and one in April 2008) totaling $344,211. Adding these awards to grants approved earlier in 2007 makes total awards $540,721. I have abstracted some of the key points of the awarded grants below.

We want to thank all of our members who have donated or hosted fundraisers to make this important research possible.

RECENT GRANTS AWARDED:

Development of a Microsphere Suspension Assay for the High Throughput Screening of Prader-Willi Subjects – Principal investigator is Heather Newkirk, Ph.D.

Expected Significance

The researchers have designed a novel assay for the detection of genomic copy number changes called quantitative microsphere hybridization (QMH). Current PWS testing has limitations in identifying some of the genetic subtypes. This research has two major aims. The expected significance of each specific aim includes the following:

Aim 1) Development of a high-resolution, high-throughput, low-cost assay for screening PWS subjects to distinguish different types of deletions including IC (imprinting center) defects. The assay could ultimately impact clinical delineation and description of the syndrome as well as genetic counseling and management of the syndrome. The QMH (quantitative microsphere hybridization) platform could be readily introduced into the clinical setting as a cost-effective, rapid screening method for PWS. No such assay currently exists for identification of IC mutations in subjects with PWS.

Aim 2) Development of a panel of unique sequence probes for use in FISH analysis for typical PWS type I, type II and IC deletions, which currently cannot be distinguished or in some cases even detected using commercial probes.

Genetic Underpinnings of Restricted Repetitive Behavior -- Principal investigator is Soo-Jeong Kim, M.D.

Expected Significance

Despite its clinical significance, little is known about underlying neurobiological mechanisms of restricted repetitive behavior (RRB) in PWS. RRB is an umbrella term used to describe a wide variety of maladaptive repetitive behaviors, such as stereotypy, self-injurious behavior (i.e., skin picking, nail biting, etc.), obsessions/compulsions, rituals/insistence on sameness behaviors, and restricted interests. The majority of individuals with Prader-Willi syndrome (PWS) suffer from clinically significant RRB that is impairing and often serves as focal points of interventions.

RRB is also a diagnostic feature of Autism Spectrum Disorders (ASDs). Increased rates of ASDs have been reported among individuals with PWS. As PWS is caused by a structural or functional absence of paternally inherited genes in the 15q11-q13 region, specific genetic variants in this region may play a critical role in the clinical manifestation of RRB in individuals with PWS. In addition, abnormal serotonin (5-HT) neurotransmission may contribute to RRB in PWS, as selective serotonin reuptake inhibitors (SSRIs) have been used to treat certain RRB features with moderate degree of success.

The researchers have hypothesized that specific genetic variants in the 15q11-q13 region contribute to the risk of specific forms of RRB, and that interactions between genes within the 15q11-q13 region and the 5-HT system genes would increase the susceptibility to specific forms of RRB. They will also be investigating genotype-phenotype correlations, and examining gene-gene interactions.

Findings from this research project will lead to new treatment for this debilitating clinical condition (RRB) in individuals with Prader-Willi syndrome (PWS). This study will also generate data that may help to understand underlying genetic mechanisms for ASDs whose prevalence rate is significantly high in PWS. In addition, this project will provide an opportunity to test the hypothesis of gene-gene interactions among the 15q11-q13 region, SLC6A4 and TPH2. We believe the new knowledge from

this project will ultimately benefit the scientific and clinical community of PWS.

Autistic Symptomatology in PWS: Examining Behavioral and Neurobiological Similarities between PWS and Autism Spectrum Disorders – Principal investigator is Anastasia Dimitropoulos, Ph.D.

Expected Significance

Current findings suggest individuals with PWS exhibit behaviors characteristic of autism, including deficits in social relatedness. Examining the PWS behavioral phenotype in relation to other neurodevelopmental disorders biologically linked to the 15q – q13 region (such as autism) is critical to uncovering the genetic mechanisms involved for PWS. Understanding the behavior and biological similarities and differences between PWS and autism will also aid in illuminating a probable genetic pathway to autism. The PWS phenotypic evidence also suggests that over-expression of maternal genes in the 15q – q13 region (m-UPD) may be associated with increased social impairment as compared to other causal mechanism of PWS. This could have profound implications on the treatment of children with both PWS and autism.

Expression of Four Genes Between Chromosome 15 Breakpoints BPI and BP2 in Subjects with Prader-Willi Syndrome and Impact on Cognitive and Behavior Measures -- Investigators -- Douglas C. Bittel, Jennifer Zarcone and Merlin G. Butler

Second year approved. Abstract on progress report on first year follows:

Prader-Willi syndrome (PWS) is a complex neurodevelopmental disorder resulting from a paternal chromosome 15q11-q13 deletion in 70% of subjects, uniparental disomy 15 causes PWS in 25% of subjects, and the rest are due to imprinting defects or chromosome 15 rearrangements. The deletion can be classified as either a large typical Type I (TI) deletion involving breakpoints BP1 and BP3 or a smaller typical Type II (TII) deletion involving breakpoints BP2 and BP3.

The researchers are working to quantify the expression of the four genes NIPA1, NIPA2, CYFIP1 and GCP5 and correlate with neurodevelopmental parameters (behavioral, cognitive and visual integration measurements) previously reported to differ between the two deletion subtypes in Prader-Willi syndrome individuals. This project allows the investigators to expand their pilot data and analysis.

Preliminary analyses of their new data tend to support their hypothesis that changes in expression of these genes, whether due to genetics, epigenetics or chromosomal deletions, result in alterations in the behavioral and cognitive parameters of individuals with PWS. They hypothesize that the size of the deletion should also be determined by using, for example, aCGH technology on each subject with the typical deletion to further characterize the size and type of the deletion. The enhanced gene expression patterns will then be correlated with behavior and clinical outcomes (and deletion size) in individuals with PWS. The gene expression patterns will also be compared with maternal disomy and comparison subjects.

Prader - WHAT? – *continued from page 1*

newspapers and TV, written from different angles, but all raising awareness of PWS in the public eye.

The NJ.com Sports with the Star-Ledger in Jersey City, NJ on May 20, 2008 carried an article, "A coach and her team find motivation to give" by Sean Reilly. It reports how Red Bank High School softball team coach Tracey Lombardi and her team are giving back to the Ronald McDonald House. It tells how Lombardi benefitted from the Ronald McDonald House when her son, Cole was born 18 months ago and hospitalized, eventually to be diagnosed with PWS. It notes how Cole is an inspiration to the team.

Find many more examples of PWS in the news in the Members Only section of the PWSA (USA) website under "Current News."

Blogging

Lots more people are blogging about PWS and PWS Awareness Month and getting the word out!

Here are two blogs you can check out:

www.berrypatches.blogspot.com/2008/05/prader-willi-syndrome-awareness-month.html

www.theknopfcrew.blogspot.com/

Let's not forget the numerous events that occurred through May. Some are highlighted on the fundraising page in this issue of the Gathered View. Others will be featured in future editions.

PWS awareness is great in May, but also any time of year. Let's keep awareness going!

Visit the PWSA (USA) website and click on "Events/Conferences" to learn more about PWSA activities.

ASK THE PROFESSIONALS

STEM CELL RESEARCH and THERAPEUTIC APPROACHES FOR PWS

QUESTION from a mother

Hi Janalee, I spoke to you about doing stem cell research to find a cure for PWS. As I mentioned, (in theory) we could cure PWS using stem cells. We know the exact portion of dad's DNA on chromosome 15 that is missing, most dads are alive and well and available to give their DNA (via blood, skin cells, etc), and many of us younger parents have saved our children's cord blood (ample stem cells). Technically, we could use genetic engineering techniques to "slice" that portion of dad's DNA into the child with PWS's own cord blood stem cells. The new genetically engineered stem cells would be given to the PWS child and thus, a CURE!!

I really feel that this is the way to go to find a cure for PWS. Using stem cells engineered with dad's missing portion of chromosome 15 could provide a cure for the insatiable hunger now and allow our children to live more normal lives.

ANSWER from Robert D. Nicholls, D. Phil., Children's Hospital of Pittsburgh and member of PWSA (USA) Scientific Advisory Board

Most scientists will agree that the specific approach suggested is impossible, which today it is, as there are a lot of difficulties that may prove difficult or insurmountable. For example, PWS is complex and does not involve just one gene but rather an entire 2 megabase (Mb) region of over one dozen genes which are likely to play roles. The techniques for genetic engineering of a 2 Mb appropriately regulated chromosome domain are not currently available. Additionally, even in the event it was possible to engineer the necessary genetic information, it is likely that these genes need to be expressed in specific types of neurons. Therefore, one would have to use stem cells to differentiate these into the correct neuronal cells, which would then have to be transplanted to the correct sites in the brain (or other tissues) at the correct developmental time. Currently, we don't know what types of neurons and which sites are important in PWS, or what stages of fetal, neonatal or childhood development may be critical. All these basic questions need to be answered in order to even start to consider therapeutic approaches based on genetic engineering and stem cells.

In terms of future potential genetic engineering approaches, perhaps some good news related to the ideas discussed in the Question is that dad's cells and/or genetic information will not be needed. Although a few functional polymorphisms in some of the genes from chromosome 15q11.2 may occur and be specifically inherited in different individuals from either parent, given the small overall genetic contribution of 15q11.2 (12-15/25,000 genes) to an individual, if it were possible to use genetic engineering approaches to modify stem cells for a PWS therapeutic approach, the more practical and cost-effective (of a likely very expensive process) approach would be to use a single "designer paternal chromosome 15q11.2 domain" that had been chosen or engineered to have and maintain the correct genomic imprinting and gene expression pattern. Another small bit of potential good news for such a futuristic approach is that none of the PWS gene products are known to be located on the outside of cells, so expression of the PWS genetic domain in transplanted neurons derived from stem cells of an individual with PWS may not contribute to potential immune recognition.

In addition to the above considerations, it is also important to consider alternative therapeutic approaches that may be possible for the person with PWS. These possible approaches are based on:

(1) Modification of genomic imprinting, with activation of the silenced maternal allele directly in cells from PWS individuals – the main difficulty here will be specificity as current approaches that might achieve this would be very toxic to other genes across the genome and likely lead to bad clinical side effects. In addition, one would also have to ensure that the activation of PWS genes on the maternal allele in neurons would not silence the Angelman's Syndrome gene and lead to AS-like neurological symptoms [the current hypothesis in the literature would suggest that this might indeed occur, although this hypothesis is unproven and other potential mechanisms and outcomes may occur];

(2) Replacement of specific PWS genes or PWS gene products (RNA or protein) when the genetic pathways in PWS are better understood (this could be a direct PWS-region gene, or downstream genes or gene products based on an understanding of the function of PWS genes); and

(3) Replacement of end products of genetic pathways in PWS, such as hormones, in essentially the same way as currently done with growth hormone. Currently, this latter prospect is the most amenable if the basic understanding of what causes PWS were improved.

Many laboratories are using stem cells and/or genetic engineering ("gene therapy") to try to find

cures for many genetic diseases, but it is important to realize that at this time, there is no cure for any of those genetic diseases. Unfortunately, in the fields of stem cells and gene therapy (especially for complex diseases) the hype typically vastly exceeds the reality. PWS is a complex disease in every sense of the word: clinically, behaviorally, developmentally, genetically, and at the genomic level. Breakthroughs in science and medicine do sometimes come by chance in laboratories working on other systems, but more likely will come from painstaking work by laboratories devoted to understanding the complex system under study. Therefore, although many consider PWS a rare disease and not of high general interest which affects funding from NIH and other national agencies and which is an area of priority for non-scientists in the realm of PWS research, I am certain that continued research on understanding PWS will not only be significant for the PWS community but will continue to make breakthrough discoveries of importance for all of genetics and medicine.

FUNDRAISING
EVENTS TO REMEMBER

By Jodi O'Sullivan, Rachel Elder and Diane Spencer

It takes as much energy to wish as it does to plan.
~ Eleanor Roosevelt

Congratulations, Losers!

The 6th Annual PWSA (USA) **Lose-A-Thon** wrapped up at the end of May and helped raise nearly $10,000 for PWSA (USA)! Thanks go to our four incredible teams and 21 individual participants who worked hard to reach weight loss goals and support PWSA (USA) during the past six months. You all did a wonderful job! Keep working toward your goals!

We'd like to highlight Team Gillian, led by participants **Rick and Caryn Segall**, parents to **Gillian**, 7, who has PWS. The Segalls created a team of 13 members and so far have raised nearly $3,500. "Gillian has been the light of our lives and our inspiration," Rick said. "The key is keeping her on track with exercise. Now we do exercises with her, so it's a family thing, not just something Gillian has to do by herself."

Rick and Caryn even made laminated wallet size photos of Gillian for the team members and on the back Gillian asks them three questions to keep them on track: 1. Am I really hungry? 2. Is my brain tricking me? 3. Is it healthy to eat?

A Night to Remember – A Quest for a Dream

We always remember our loved ones who have PWS, and so occurred the **2nd Night to Remember: An Evening of Cabaret** on April 26th in Philadelphia, PA. Co-chairs **Stephen and Michele Leightman** are grandparents to 6-year-old **Josilyn** who has PWS. They along with their hard-working host committee, parents to 8-year-old **Isabel, Deb & Rob Lutz**; parents to 5-year-old **Mikhel, Maria & Martin Sinclair**; parents to 8-year-old **Brooke, Davis and Anina Pfeiffer**; parents to 9-year-old **Adam, Mitchell and Staci Sklar**; parent to 5-year-old **Ashley, Suzanne Tate**; and parents to 13-year-old **Rose, Sybil Cohen and Michael Burns**, netted $31,000 for PWSA (USA). About 150 people attended the event. Steve Leightman said one of his favorite parts was the final song, "To Dream the Impossible Dream" from Man of La Mancha because, "it expressed our determination in our quest to beat PWS against the odds and achieve our dream together." The host committee thanks the many volunteers and guests for such an unforgettable night of dreams.

If You Want Something Done, Ask a Grandma!

Dorothy Morse, grandmother of **Roxy**, 6, who has PWS, started attending garage sales eight months before her second Texas **mega-yard sale** from May 2-3. She filled numerous garages and storage rooms and drafted her two sisters from Houston to help sort and price. PWSA (USA) received $2,000 from Dorothy's hard work.

Barbara Emmons, grandmother and guardian of **Andrew**, 9, who has PWS, did a **Fun Day at the Moose** on May 18th in Indiana. Barbara's group prepared food along with a silent auction and games, and clowns entertained the kids. A check for $1,081.39 was given to PWSA (USA) to support conference grants and research.

Casual Day and Pretzel Day for the Twins

Heidi Metcalf, mom to identical twins **Justin** and **Joshua**, age 5 who have PWS, planned two special days at Electronic Data Systems (EDS), where she is employed, to raise awareness and funds for PWSA (USA). EDS sponsored a **Casual Day** and two days later a **Pretzel Day** specifically for PWS. "The boys always light up the office when they come by, so it was warming to reach out to everyone at EDS," wrote Heidi. Together, the EDS Casual Day and Pretzel Day raised $522 for PWSA (USA).

A Jeans Casual Day, Sponsored by Auntie Deb

Deb Whiting said this 3rd annual fund raiser in May was "the best ever." Deb put up flyers

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A SURVEY OF THE VOCATIONAL STATUS OF ADULTS WITH PRADER-WILLI SYNDROME

By Marjorie H. Royle, Ph.D., and Joan Gardner

In 1987 Louise Greenswag surveyed 232 persons with PWS. She found 35% were unemployed, 3% did volunteer work, 46% were employed with 70% of those in sheltered settings, 4% were competitively employed, and 2% worked at home. In 1991 Anna Marie Saporito surveyed 173 adults, finding 68% in sheltered workshops, 9% in supported employment in the community, 16% in day programs, and 4.5% receiving occupational training.

In 2003, the most recent effort, a brief survey inviting "members to share information about the vocational placements and problems of individuals with PWS" was placed in The Gathered View, posted on the web site, and mailed to parents or other caregivers known to the authors. The authors stated that "because of the method of survey administration, results are not a random sample of the population of adults with PWS and cannot be generalized to all adults with PWS in the United States. Instead, they provide a description of a wide variety of vocational experiences of adults with PWS whose parents are active in the national organization." Following are some interesting points from that survey.

Completed surveys came from 52 families in 24 states. Ages ranged from 19 to 51, with females about double the males. Most had had some type of vocational training, with about half the caregivers rating it as excellent or good.

About 17% were not working, 29% were in sheltered workshops, 30% were in supported employment settings, and 15% were in competitive employment. This may or may not be an improvement over 10 years earlier, or an over-representation of those in successful job placements. Still, a significant number were working outside sheltered workshops in a variety of jobs. Most of those not working were in day programs with some vocational training or component.

Types of jobs included typical assembly work (usually in sheltered workshops), cleaning and clerical jobs, working with children or animals, making and selling crafts, and landscape maintenance.

The most frequent answer to what adults with PWS liked about their jobs was money. However, there were many other answers, such as the sense of responsibility or accomplishment they got from it, having a "real" job, liking to work with children or animals or some other aspect of the job. What they didn't like was that they were under-employed and wanted more, or the job was too easy and they were bored, or they really wanted to work in the community. Other common reasons for dissatisfaction were issues with supervisors or the work itself. However, people tended to stay in their jobs—in this sample from just starting to 23 years, and 3 or more years for most.

The three job settings—sheltered workshops, supported employment, and competitive employment—represented three different situations with different factors associated with success in each:

Sheltered workshops: About half need the close supervision that sheltered workshops provide. Most like the social aspects, but find the work boring or not enough to keep them busy. One creative and successful use of a sheltered workshop was to utilize the person as an assistant to the staff, able to perform some higher-level supervisory tasks but still provided with close supervision (in essence, supported employment positions within a shelter workshop).

Supported employment: Job coaches are key to making this work—designing the job with strengths and limitations of the person in mind, training the person to do the job, training the employer and other employees about PWS and necessary accommodations, and being available to trouble-shoot problems. Accommodations included limiting access to food, developing reasonable job expectations, providing the person their own work area, and allowing the coach or training "buddy" to assist. Behavioral problems rather than food were more likely to result in failure of the placement.

Competitive employment: This option is probably not suitable for the average person with PWS. Those in competitive jobs had more education, a higher functional level, and fewer

severe behavioral problems than those in more restrictive settings. Accommodations, including limited food access, space provided for the person to work, and reasonable job expectations, are difficult unless the employer is very willing and, usually, the setting small. Written procedures and rules for the person with PWS are helpful, in addition to having supportive co-workers who want to make the placement work.

People with PWS were reported to have job skills that can make them good workers. They want to do a good job and they are motivated and willing to work hard. Their sociability can make them good coworkers, and their small motor skills are an advantage for many tasks. They are persistent, thorough, and good at job specifics.

As to be expected, the two most common reasons for leaving previous jobs were food access and behavioral problems. The next two most common problems, moving away and having the job end, had nothing to do with PWS. Other reasons given probably related to PWS.

The authors felt that the survey indicated two specific areas that might improve the vocational life of persons with PWS. First was the importance of vocational staff. A very important factor in making job placements successful is employer and co-worker knowledge about PWS. Training and supporting staff could do much to improve employment opportunities for people with PWS.

Second is increased use of volunteer opportunities. Many qualities that people like about their job such as a feeling of responsibility and sense of accomplishment can also be found in volunteer jobs.

SAVING EACH OTHER – *continued from page 3*

raising awareness and funds.

Like many nonprofit charities, PWSA (USA) faces special challenges in a weak economy. Over the past 5 years, we generated net income of nearly a million dollars in net income, almost nearly half a million dollars in 2006 alone. But as the economy weakened in 2007, donations dropped for crisis support, for research, and for the Angel drive. So far, despite some very successful grassroots events, 2008 looks even worse.

What is the answer? As always, we need to look to ourselves, to work together to raise funds to maintain and continue expanding our services to families struggling with PWS. Please call or email me (cpolhemus@pwsausa.org) for more information.

This parent's message was meant for all those who support our programs: "I don't know how to thank you but I said prayers for you and your family!"

Our Young People Can Also Be Entrepreneurs!

Bring To Light Candle Company was formed by three adults with PWS who wanted to break the barriers of conventional day programming by creating meaningful employment. Jen, Scott and David live at group residences run by Advocates, Inc. in Massachusetts. They formed the candle company last year and recently began selling their candles online. Through months of planning, dedication and creativity Jen, Scott and David have developed a company that they can be proud of, a company that they founded with the intent to create jobs for people with PWS and to work in an environment that is safe and supportive of their unique needs. You can visit their website at www.bringtolightcandles.com. For more information contact Patrice Carroll at pcarrol@advocatesinc.org.

View From The Home Front

SHANE AND MITCHELL FIND A HOME

Vince and I married in 1994, knowing that we wanted children. We also had dreams of one day adopting children. We were blessed with three beautiful daughters by birth. Our youngest was a preemie, diagnosed with cerebral palsy at four months. We were told that she would probably never walk or talk. We immediately began advocating for her needs. She saw many specialists and therapists. We also did therapies in home with her for hours. All the hard work paid off, and Quintessa flourished.

We knew then that we would begin our dream of foster care and adoption, as we had realized that we were being called to parent children with medical needs through our work with Quin. Seven years later, we have helped 24 children...but most important, we were blessed with the adoption of our two boys, both of whom have PWS.

Shane was first. Born on January 10, 2003, he spent his first four months in the NICU. When he left the NICU he went to a foster home. They began seeking an adoptive home for him when he was almost one, after the foster mom decided that she was not going to adopt him. The agency received many homestudies for our little boy, so when we found out that they had chosen our family, we were elated!

We drove to Kentucky to meet Shane, 15 months old, and his team of therapists. We were told that he had PWS and was blind. Our little guy was so weak that he could not hold his own head up. He was fed through a g-tube. And he was a chunk, too!

We brought Shane home in April 2004 within a few weeks of our initial visit. Within four days of being at home and with lots of stimulation, Shane began tracking. Although he had never eaten by mouth up to this point, we got him sucking on a cleft palate bottle with a Haberman nipple and thickened formulas after his first week at home. We were able to remove his g-tube by July 2004. We also got Shane started on growth hormone. Hard to believe that he has been with us almost 4 years already!

Shane started walking at almost his third birthday (after using a much hated stander). He started food seeking at about 3½. Today, Shane is five years old. He still food seeks, so our kitchen is locked. He has been on an 800 calorie diet since he started eating by mouth and he looks wonderful! He is a delightful little boy when he is not tantruming, which is a good bit these days. His speech is still really delayed (even with speech therapy three days a week) so he easily becomes quite frustrated. We are now beginning to use an assistive technology device to see if that will help curb his frustrations.

Shane will be transitioning to an MDS classroom in the fall for kindergarten, so we will have a new adventure there! He still has blond hair and blue eyes with the PWS deletion, but I always find it interesting that he is of Iraqi descent.

His diagnoses at this time include PWS, Fetal Alcohol Syndrome (which creates many of the behaviors, as well as the extreme cognitive delays as he functions at a 15 month level), seizure disorder, sleep apnea, dysphagia, autistic spectrum disorder, scoliosis and hip dysplasia. We utilize both a TSS and BSC for him in the home and at school. While he is not an easy child to parent, he is an easy child to love!

We actually found out about our second son, Mitchell, when his foster mom posted about him on the PWSA e-mail support group! Mitchell, born May 26, 2005, was placed into the foster system in Florida and remained in the NICU for two months before joining his foster family. Mitchell was having problems breathing on his own and had a hole in his heart. Of Korean descent, he, too, has PWS by deletion.

About two months later his foster mother posted on the PWSA e-mail support group that he was now going to become available for adoption. We immediately emailed her with much excitement and interest! Mitchell's foster mom was great, and we learned so much about him through her. Unfortunately it was almost a year before we got to meet Mitchell and bring him home, but we were thankful that he was in a good home getting therapies and growth hormone.

Mitchell was never tube fed, but sure did not like to eat when we first met him. He is a little squirt still! He has now been home for almost a year, and we can not imagine our lives without him. He and Shane are night and day of each other - but both bring so much joy to our home! Mitchell is doing outstanding in his therapies, walked at 22

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View From The Home Front

Michele Kennedy, 35, Gainesville, FL, shown with her grandmother, has been walking for the March of Dimes since 1995. She's raised as much as $800 one year but never less than $500.

The Best Mom

A few weeks ago we were at the orthodontist. They are always having drawings and things like that for the kids for ipods and stuff. This particular week they had a contest where the kids fill out a paper telling why their mother is great; if they win, their mother gets a certificate for free spa services. They handed Lindsay one to fill out. I told Kristy, the receptionist, that Lindsay isn't able to write (unless you spell it out for her). But Lindsay didn't know that so she filled out this form oblivious to the fact that no one would be able to read it. She handed it in with her name (legible, but barely) and pretty much scribbles, but you can just make out the word mother. Lindsay was proud of what she wrote. Kristy thought it was so cute and put it in the box.

I got a call a couple days ago that they picked Lindsay's as the winner! I appreciate so much when others can see the beauty in my child. Lindsay knew what she wrote even if no one else did and they "got it." Now I get to go and get a pedicure, and I'm going to take Lindsay and get her a pedicure, too, and have them paint her toenails cute.

She can be such a sweetheart (even if she WAS a bear this morning).

~ Pamela Rauch,
Mom to Michael (11) and
Lindsay (9-PWS deletion)
Stansbury Park, UT

From a Proud Grandma

Well another year has passed and our Josi [Josilyn Levine, almost 6, with PWS] is at another dress rehearsal for another ballet recital. Last year she danced to "What a Wonderful World". I questioned if it truly was. This year she is dancing to " ONE " from " A Chorus Line ". The next words are " a singular sensation". She truly is sensational. She stands there trim and beautiful in gold sequin shorts. She knows all of her steps. She is doing well. I could not have imagined all of these wonderful moments would be ours. I have trained myself to enjoy all of the "nows" and not dwell on the tomorrows. Maybe tomorrow it will be ....a wonderful world. In the meantime she IS a singular sensation !

~ Ronnie Levine,
Cherry Hill, NJ

Luke and Me

Luke (5) has done it again! During the 30-minute car trip to his school, we've been practicing simple math out loud. I make him math sheets, and as he does each equation, he says "1+1 equals 2, so write the 2." Now he's making his own math problems and solving them, like 4+4, 0+3, and even a few we haven't done like 8+8.

Just for perspective – In 1976 when I was his age (5) and in kindergarten, I was unable to open my milk carton (he can since 4), couldn't zip my zipper (he can), and was just beginning to learn about colors, shapes, and songs and then later in 1st grade began the alphabet. As well, I was struggling with the just half day kindergarten. And I didn't have PWS. Luke really amazes me. He has already surpassed me.

~ Lisa Ranieri, mom to
Luke, 5; William, 3; and
Mallory Lynn, 1½ years,
Hoover, AL

Chuckle Corner

Her school aide discovered a piece of pizza of unknown origin in Rachel Forster's lunch box. It did not belong there, so she quietly removed it without comment. When Rachel discovered it was gone, she promptly went to the school principal and reported it stolen!

-John and Donna Forster,
Pittsburgh, Pa.

The International View

Lost in Translation — Found in Sharing

The following e-mail is just one example of how we are sharing around the world. Two things made me smile when I read this: 1) the disparity between the mindset of parents of the young child and those of the older child is an issue worldwide; and 2) the translation issue.

— Janalee Heinemann, Director of Research & Medical Affairs

Dear Janalee,

I have just finished to read the article you wrote about how to deliver bad news to the families. It came in the most miraculous timing. Last week a very good (to my view) [television] program from England was aired here in Israel and aroused a very intensive and "loud" discussion in our parents forum in our web site.

The program 50 minutes long was about three youngsters with PWS in not the best condition. (That is understatement.) It is called "My Child Can't Stop Eating." Our new families were so angry at what was there (unpleasant truth in families that seem as if they have never heard of PWS organization in their lives.) On the other hand our [parent] "veterans " are impatient (understatement) with their "hopes" that this is all history and the future of their children will be different.

Some weeks ago I asked the parents to discuss the way they think PWS should be published but they didn't response what so ever. So from heaven came your essay ("Giving Difficult News to a Family," November-December 2008 Gathered View) and I am going to translate it into Hebrew right away. The only thing I need your help is to explain what does it mean "not to read beyond the tabs." I guess it is some expression because the translation of tab in my dictionary did not make sense.

Urith Boger, President, Israel PWS Organization:

Another Letter from Israel

Hello to all! The November/December Gathered View looks great and is full of informative and interesting articles. You do such a great job for all of us out here in the world and I continue to admire your initiative and dedication. I send special regards to Janalee who visited us on Kibbutz Ein Hashofet many years back, and I still dream about getting to a Conference one year to meet you all.

Guy is going on 15, life flows relatively well when everything is in place, great school, incredible aide who is now with us for a third year, supportive environment and financial backing from the private and public sector. He is so typically PW that sometimes I think that I could have written all the manuals! But he is also very Guy, bright, reads his newspaper every day and up on all the news, musical, continues to take singing lessons and is working on a disc. Of course this is Guy, so he insists that he is a soprano! Unfortunately his scoliosis has worsened and he is due to be operated on at the beginning of February, I am trying to be as calm as possible but it's a worry, not just the operation but his behaviour before as the tension rises.

The years have flown by, it seems like yesterday that I wrote an article for The Gathered View and began my association with such a wonderful group of people.

Best Regards,
Margot Finks
Israel

SHANE & MITCHELL – *continued from page 12*

months, loves to dance and is quite the little jokester. He seems such a typical two year old to us, outside of the speech delays.

Obviously there are many challenges with our boys. And things are certain to get harder in the future, especially with Shane. However, we can not imagine our lives without these little guys. And our girls love them, too! They have become very compassionate children (they are 7, 9 and 10) and are so good with their brothers. We are involved with the different PWSA e-mail support groups and read daily about the good, the bad and the ugly...knowledge is power! And we were able to attend our first PWS event this past January with the Pennsylvania chapter.

- Pam and Vince Vizzini from Johnstown, PA

If you are the sibling of a person with PWS, or if you have PWS, email your story to gatheredview@pwsausa.org for possible publication

FUNDRAISING – *continued from page 9*

announcing a Casual Day at the Madison County Department of Social Services in Wampsville, NY. For $3.00 the employees were allowed to wear jeans for the day. Everyone who participated received a brochure about PWS, so it was a great Awareness Day, too. Nephew Grant, 2, who has PWS, will one day know how lucky he is to have a very special Aunt Deb. In all, PWSA (USA) received $350 from this special effort.

A Golden Wedding Anniversary Gift

Ken and Carol Ceppos celebrated their 50th wedding anniversary this year and did so in a very special way. Along with a party, the couple requested that in lieu of gifts donations be made to PWSA (USA). **Suzanne and Rich Ceppos**, parents of **Chelsea**, 19 with PWS, were very grateful for their aunt and uncle's generosity. "It was a big party, with more than a hundred guests, but we never imagined they'd raise $5000! That's incredible, and we are so thankful to everyone who donated—especially to Uncle Ken and Aunt Carol, who also made a large donation themselves—for being so thoughtful and generous," said Suzanne. "At the party Rich got up on stage and introduced Chelsea, who always likes to take a bow. Chelsea loves to dance, dance, dance!"

Rich and Suzanne served several terms as co-secretaries for PWSA (Michigan). Suzanne also edited the PWSA (USA) Handbook for Parents.

Did you know you can donate to PWSA (USA) through GoodSearch and GoodShop?

GOODSEARCH - Go to www.goodsearch.com. Where it asks, "who do you GoodSearch for?", type in "PWSA" in all capital letters and then click on "Verify." Then select "Prader-Willi Syndrome Association – PWSA (Sarasota, FL)", the first one listed. Then use this site as you would any other search engine when searching the internet. Once you make your selection, it should show automatically every time thereafter. Each search gives a penny to PWSA. Sounds small, but it adds up.

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

GOODSHOP - Go to www.goodshop.com. You can also get there from www.goodsearch.com. At this online shopping mall, choose PWSA (USA) the same way described above. Then select the retailer(s) where you want to shop and a percentage of your purchase will be donated back to PWSA (USA). Retailers include more than 500 name brand stores, such as Target, BestBuy, Staples, iTunes, Barnes & Noble, Walmart, Bloomingdale's, eBay and Amazon.com.

Announcing The Counselor's Corner!

This corner will feature information about our crisis response program. We will let you know what kind of services we offer, share insights into the level and scope of our work, and offer tips and resources for handling (and preventing) crisis situations in the lives of people with PWS.

For example, for families with children nearing 18, new information on the best tactics for applying for SSI is now online at www.pwsausa.org/ssi.htm. This information was based in part on a December 5 hearing where Executive Director Craig Polhemus testified before the Social Security Commissioner on ways to improve the disability determination process for those with PWS.

The Counselor's Corner is written by members of PWSA's Extended Crisis Team. Members of this team include staff that respond to crisis situations and provide family support. I serve as the Crisis Team Leader so if you have questions you would like us to consider or information you would like us to share, please e-mail me at efarrar@pwsausa.org We look forward to serving you in the Counselor's Corner!

- Evan Farrar, Crisis Intervention Counselor

Contributions

Thank you for Contributions through May 2008

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.

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