

The Gathered View

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

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

Linda had an Idea....

By Diane Spencer, PWSA (USA) Support Coordinator

“Han-nah, Han-nah, Han-nah” the football fans yelled as the Johnson family walked onto the field Oct. 31 to receive a \$224,575.59 (replica) check from Eastside High School for PWSA (USA). The check, raised from the school’s week-long fundraising events, will help PWSA (USA) provide crisis and support services for families affected by PWS.

It all started last February around Valentine’s Day. I received a call from Linda Johnson, whose daughter Hannah is two with PWS. Linda wanted to talk about an idea she had.

Each year several Greenville, South Carolina, high schools participate in Spirit Week, a full week of numerous fundraisers that benefit a specific charity which is selected by a committee before the end of the school year. During Spirit Week, the high schools compete with each other to see which school can raise the most money. Linda asked me for some help to put a presentation together. We knew that we would have to select a cause within our organization that would capture the heart of a high school student. Many discussions ensued, and a final selection was made. Linda prepared a letter to read aloud and packets of information to give to the committee showing how the funds would be used. On May 21st, Linda Johnson and little Hannah went before the Eastside High School Spirit Week Committee. Two days

later, Linda’s doorbell rang, and a representative of the Student Council told

her that PWSA (USA) had been selected.

This high school has been doing this event for 30 years. PWSA (USA), one of 18 charities that had applied, was selected because they wanted their funds to help real people and provide awareness (rather than help build an addition on a building), and because Hannah’s story inspired them.

Each of the 40 members of the Student Government was in charge of an event or food. They contacted every business listed in their yellow pages, asking for donations, services or products to auction. They went door to door to ask for support. This year for the first time they contacted past alumni for donations. Planning begins in May for the seven days of Spirit Week during which events are held morning, noon and night.

Linda called me every week after everyone was back in school to let me know how the plans were taking shape. Finally, during the week of October 24th to 31st the hours and weeks of planning events came to fruition. The teens were running from dawn to dark, from fundraiser to fundraiser. They were on a mission to help those with PWS and nothing could

Linda, continued on page 13



left to right: Linda and Archie Johnson; Hannah Johnson; Selvy Miros, Spirit Week President; Ryann Kroske, Senior Class President; Katie Henson, Student Body President; Olivia Johnson, Hannah’s big sister

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

8588 Potter Park Drive, Suite 500
Sarasota, Florida 34238
800-926-4797 ~ 941-312-0400
Fax 941-312-0142
info@pwsausa.org
www.pwsausa.org

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

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

E-mail Support Groups:

We sponsor nine groups to share information.

Go to: www.pwsausa.org/support

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

Executive Director's View

Photo by Eric Hilton



Craig Polhemus

Help Us Build a Better Bullhorn

Though PWS is classed as a rare condition, the energy and commitment of families, friends, and colleagues have led to some impressive successes. Recently, we created, posted on our web site, and provide through our Crisis Intervention Counseling program what a high federal official called "incredible information" to ease and ensure accurate eligibility determinations for SSI (and hence also for Medicaid) when those with PWS turn 18.

Diane Braunstein, Director of the Social Security Administration's Office of Compassionate Allowances and Listing Improvements, asked us for a copy of these new materials, which may ease and shorten what has often been a lengthy and difficult process for families needing to prove that their child with PWS qualifies under the federal disability criteria. In turn, I asked her for the SSA draft of a parent guide to the eligibility process. "I really don't think anything we can come up with will be better than what you already have," she said, and indeed the draft she provided did not mention PWS or highlight the key aspects of the condition that make eligibility most evident. SSA's openness to our new materials to ease the eligibility process came about in large part because we were able to generate hundreds of letters and online comments about the problems our families have encountered in this process.

Utah PWSA Chapter President Lisa Thornton notes that 'a couple

of our Utah families have sailed through the SSI process using the forms that you all created'.

We also helped cause Senator Charles Schumer of New York to pull back from the Senate floor calendar a bill, designed to combat abuse of growth hormone by professional athletes, that threatened to further obstruct access to growth hormone for those with PWS. We need to make growth hormone more accessible, with affordable copayments, for all those who would benefit from it. Thanks to thousands of calls, emails, and letters from those in the PWS network, Senator Schumer's staff is now working with PWSA (USA), the Foundation for Prader-Willi Research, and the National Organization of Rare Diseases to develop a bill that will not harm, and might even improve, such access.

And sparked by Jessica Howard, mother of 3-year-old Thomas, who has PWS, "Fight Obesity With a Cure for PWS" came in 16th among 1190 proposals in the American Express Members Project. Though the "expert judges" did not select this project to advance in the 2008 competition, we demonstrated that while PWS may be rare, sincere commitment among those who know about it is both common and vocal! This year, we can shape a project more targeted on the aspects now shown to be favored by the judges, hoping to win a share of \$2.5 million in funding.

Until now, PWSA (USA) has not had a systematic approach to identifying, prioritizing, and taking action on public issues. With 2009, we are launching a new system that, if you support it, will make major changes in how the PWS network tracks and acts in public policy.

You can now join an electronic task force, the **Advocacy eGroup**, to help impact those policy issues that most affect your family. The list of likely issues is broad, including school issues, research funding, community support, housing options, employment, tax policy, mental health parity, health care coverage, law enforcement, nondiscrimination, guardianship, insurance, and a host of public benefit programs.

What do you need to join this group? An interest in shaping the future for our children. Although the Advocacy eGroup will include some experts, most important are families, friends, and colleagues who will be willing to speak up – to call or write government officials, to visit your elected representatives in Washington or in their local offices, to contact the media and explain why an issue is important and how it might affect your family or others. The glory of democracy is that it responds to public sentiment; a weakness of the system is that "the squeaky wheel gets the grease." We need to pick the right issues – and then squeak as loudly and effectively as we can.

To join, just email info@pwsausa.org with the word "Advocacy" in the subject line. We hope this will be an active, growing group representing all ages, all parts of the country, and all the variety of problems faced by families affected by PWS. If you want to talk about it first, please give me a call at (800) 926-4797 or (941) 312-0400. ■

A handwritten signature in black ink that reads "Craig". The signature is fluid and cursive, written in a professional style.

Production, printing and mailing of this newsletter was underwritten by a generous grant from Pfizer

Medical View – Ask The Professionals Dental Problems and PWS

By Dr. Tom Hughes, DDS

Orthodontist, Treasurer PWSA of WI, Inc and Parent of Sara w/ PWS

Most dental problems with PWS are related to decreased salivary flow and mouth breathing. These two concerns combined promote tooth decay, periodontal disease and crowded arches. What can be done?

Make sure the child or adult has either a fluoridated water supply or fluoride tablets (1 mg /day to help fight tooth decay). Have them brush with a fluoride toothpaste after each meal and before bedtime. Parents should check their teeth after brushing, especially at night, so that they don't leave food along their gum lines. This leads to decay and periodontal disease.

Persons with PWS also have a tendency towards dry mouth because of their mouth breathing, leading to thicker saliva. Normal saliva is thin and washes the teeth clean, while thick saliva sticks to the teeth and harbors bacteria that cause tooth decay and periodontal disease. (Many parents report the use of Biotene toothpaste has been helpful.)

As a result of mouth breathing during their early years, those with PWS have a greater chance of developing narrow arches which cause crowded teeth. Getting orthodontic care early (age 6-9) to help develop the arches to a more normal shape can make it easier to keep the teeth clean and can also help to reduce the tendency to mouth breathe, both of which would decrease tooth decay and periodontal disease. Professional dental cleanings every 3 to 6 months also assist in keeping the teeth and gums clean and healthy.

Ask the Dentist

Dr. Hughes has provided some

answers to some common questions regarding dental issues for persons with PWS.

QUESTION 1: Sealants are often used in protecting a child's teeth from the formation of cavities. Is this something an adult with PWS could have done? **Yes, an adult can have this done but this only protects the biting surfaces from decay. Along the gum lines is where most decay due to dry mouth and thick saliva occurs. Only proper brushing with fluoride toothpaste and topical fluoride rinses or varnish is effective.**

QUESTION 2: Is it true that chewing gum after meals helps to prevent tooth decay? If so, is there any special gum that helps more than others? **Chewing gum could help clean the teeth, but you have to be careful. Use sugar free gum and only let them chew one piece. This can last from breakfast to lunch or lunch to dinner or dinner to bedtime. Many people with PWS will try to chew many pieces either at a time or one after another as the flavor goes away. If they chew many pieces of gum containing sugar, it can have the opposite effect and cause cavities and weight gain.**

QUESTION 3: Are there foods that may contribute to the development of cavities that should be avoided? **Any food that is soft, sticky and sugary (raisins, "gummy anything", candy) should be avoided.**

QUESTION 4: It is often common to see white crusting on the sides of the mouth in persons with PWS



- what causes this and can anything be done to prevent it? **This is dried saliva from mouth breathing. If your child has crowded**

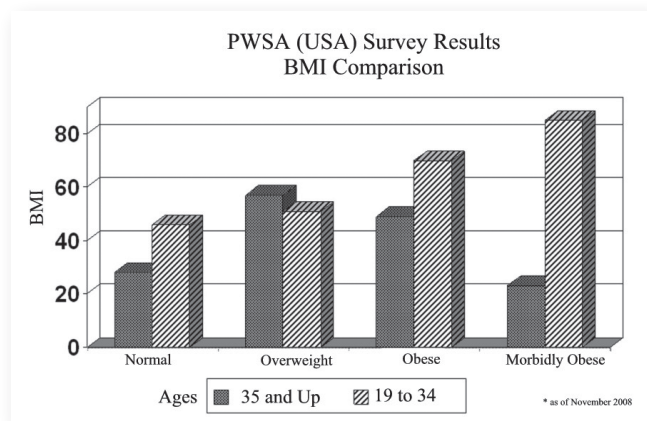
teeth and narrow arches (a dentist must assess this), having orthodontic treatment to widen the arches might help with their ability to breathe through nose instead of mouth. Also have tonsils and adenoids checked because if they are enlarged this causes mouth breathing also.

QUESTION 5: Are there any special considerations that parents and dentists need to be mindful of when considering orthodontia for a person with PWS? **The biggest problem is keeping the teeth cleaned. Parents will have to help their children keep their teeth cleaned during orthodontic therapy. ■**

Why Do Our Statistics Show A Big Drop In Morbid Obesity In PWS With Age?

We were amazed at the dramatic decrease in morbid obesity with age in our survey of people with Prader-Willi syndrome. Of those that responded, 400 gave us both height and weight so we could calculate body mass index (BMI) and how many are over age 19.

In reflecting on the reasons for the drop in morbid obesity, my conjecture is that: 1) People with PWS who are morbidly obese often die in early adulthood. 2) Many of our young adults go into supportive living where food access can be more controlled, thus a decline in weight. 3) Dr.



Dan Driscoll has reported there may be a decrease in appetite in PWS as a person ages.

If we compare obesity in France to the USA, French adults with PWS have significantly higher rates of obesity than adults in the USA, but growth in French children with PWS is similar to the USA. Most French adults with PWS live at home, which helps confirm my rationale regarding supportive living management being a major factor.

Barb McManus and I continue to work on compiling the data from the medical surveys (actually, Barb does most of the work) that members have filled out. The second survey is now available on our web site by going to www.pwsausa.org/ population or by calling Barb at 800-926-4797. As you can see from the chart above and from the abstract on scoliosis (see article below) that was presented at conference, the information you provide is important to parents, medical staff, and researchers. If you have not done so, please update the original medical questionnaire and fill out the new form. We will continue to include information gleaned from the surveys in future newsletters and plan to work on getting the information published. ■

Janalee Heinemann

Director of Research & Medical Affairs, PWSA (USA)

Scoliosis and Prader-Willi Syndrome: Results of the Latest PWSA (USA) Survey

by Harold van Bosse, MD and Barbara McManus, Janalee Heinemann, Jamie Bassel, DC, PC

Introduction: Spinal deformities are estimated to occur in 40-90% of children with Prader-Willi syndrome (PWS). Approximately 15% of all children with PWS will require treatment, either bracing or possibly surgery. To understand the factors influencing these spinal deformities, the

membership of the PWSA (USA) was queried by a mailed survey.

Methods and Materials: A general survey was mailed to the membership families of the PWSA (USA) in 2007. Of the 1603 responses, 639 indicated they had a child with a spinal deformity. A more specified questionnaire was sent to these families, resulting in 210 responses, of which 200 stated that their child had been diagnosed with a spinal deformity. This report summarizes the results of these surveys.

Results: There were 113 patients eighteen years or younger at the time of the survey (date of birth on or after January 1, 1989). In the 0-5 age range, 16% of children had a spinal curve. In the older child, 6-18 years, the prevalence was 35%, both for children with uniparental disomy and chromosomal deletion patterns of PWS. Age at curve detection for this group was 5 years old.

There were 87 patients older than 18 years -- 80 indicating they primarily had scoliosis, 7 primarily had kyphosis--for an overall prevalence of 46%. The average age of curve detection was 11 years old. Thirty-four patients required bracing, of which 19 progressed to surgery. Of the 15 who were braced and did not progress to surgery, 8 were on growth hormone (GH), 2 started prior to the diagnosis of a spinal deformity, the other 6 after diagnosis of the curve. Of the 53 patients who did not use a brace, 11 had surgery. Twelve of the 42 patients who were not braced and did not have surgery used GH, 6 started prior to the diagnosis of a spinal deformity, the other 6 after diagnosis. Compliance data was available for 31 of the 34 braced patients -- 15 were fully compliant, of which 11 needed surgery; 7 were mostly compliant, of which 2 needed surgery; 7 were sometimes compliant, of which 3 needed surgery, and 2 were never compliant, neither needing surgery. Six patients used a Milwaukee brace; 19 used a Boston/Wilmington style brace.

Thirty patients of the group older than 18 years needed surgery, at an average of 13 years and 10 months. Curve magnitude ranged from 30° to 90°, with many around 70°. Six patients required a second procedure, and one patient required 5 procedures altogether. All had posterior spinal fusions, except one who apparently also had an anterior procedure.

Conclusions: Spinal deformities are very common in children with PWS. Of patients older than 18 years of age, 46% were diagnosed with a

Scoliosis, continued on page 6

Medical View

Scoliosis –

continued from page 5

curve, and of those 52% required treatment (17% bracing, 13% surgery, 22% bracing and surgery). From the data available, we are unable to determine what effect GH has on the development or progression of spinal deformities in children with PWS. We are also unable to determine the efficacy of bracing. Until more data is available, the recommendations should be that patients with PWS be screened yearly for scoliosis with radiographs. Once diagnosed with scoliosis, they should be followed every 3-4 months radiographically. At this time, we still recommend bracing for curves over 20° to 25°, although this may change upon further study. The data at this time does not support discontinuing GH in the face of scoliosis. ■

The First International Conference on Hyperphagia

Sponsored by: The Prader-Willi Syndrome Association (USA)

June 4 & June 5, 2009

Baltimore, MD, at the Hyatt Regency Inner Harbor

QUESTION: What do these disorders have in common?

**Prader-Willi syndrome *Alstrom syndrome *Bardet-Biedl syndrome
*Fragile X syndrome *WAGR syndrome *Albright hereditary osteodystrophy*

**ANSWER: A constant hunger and/or a driving hyperphagia
(excessive, sometimes insatiable, appetite)**

THE PURPOSE OF THE CONFERENCE:

*for attendees to learn, collaborate, share, strategize and help
all individuals suffering from hyperphagia and obesity.*

THOSE WHO ARE EXPECTED TO ATTEND:

- international research scientists focused on these unique disorders
- representatives of other syndromes that struggle with hyperphagia
 - experts on hyperphagia and obesity
- pharmaceutical researchers interested in obesity and hyperphagia
 - representatives from the Office of Rare Diseases and other NIH representatives
 - a limited number of parents.

For more details visit <http://hyperphagia.org>.

Research View

Long-acting octreotide treatment causes a sustained decrease in ghrelin concentrations but does not affect weight, behaviour and appetite in subjects with Prader-Willi syndrome

Jean-Pierre Chanoine, et al

A 56-week study funded by a grant from PWSA (USA) has now been completed, and the full report can be found in the European Journal of Endocrinology (2008) 159 381-388.

Ghrelin is secreted primarily by the stomach and circulates as acylated and desacyl. Only the acylated form stimulates appetite. Both types are elevated in Prader-Willi syndrome (PWS), suggesting that ghrelin may contribute to hyperphagia and overweight in these subjects.

However, sustained decreases in acylated and desacyl ghrelin concentrations for 16 weeks

following Octreotide administration did not affect weight, appetite or compulsive behaviour towards food in subjects with PWS. It was noted that this does not completely rule out a role for ghrelin in the pathophysiology of appetite in PWS. ■



Combined Federal Campaign

PWSA (USA) is included in the Combined Federal Campaign. If you work for the Federal government and its agencies, use CFC ID No. 10088 to designate PWSA (USA) to receive donations. Questions? Call PWSA (USA) at 1-800-926-4797.

Visit our newly improved web site for more pictures, regular updates and more...

www.pwsausa.org

2009 and 2010 PWSA (USA) Conferences

In response to the challenges facing PWSA(USA) and our members in the current economic climate, we are taking a new approach to conferences and educational opportunities in the near term.

- In 2009, we will offer expanded conference programming for scientists and providers, but no general family-focused conference.

- In 2010, we will offer a family-focused conference in Orlando, including a Youth and Infants Program (YIP) and a Youth and Adults Program (YAP), as well as traditional programming for scientists and providers.

- We are also developing a new webinar education series for families, scheduled to begin in Spring 2009.

The PWSA (USA) Board emphasized that this decision has not been made lightly, as it postpones in-person networking at a national family-focused conference until 2010. The Board felt this plan represents the best effort to serve the needs of our PWS family while making fiscally responsible use of available resources. The YIP and YAP programs at the 2010 conference will serve our children and adults

with PWS well - entertaining them and keeping them safe, while inspiring them to identify and nurture the best qualities in themselves.

Meanwhile, the Board is excited about offering webinars beginning this spring as a new way to share information and experiences with each other nationwide.

WEBINARS

Beginning Spring 2009

A four-part educational series on topics of interest to all age groups, available via the web for a minimal participant fee

2009 SCIENTIFIC, PROVIDER, AND HYPERPHAGIA CONFERENCE

*June 3-5, 2009, in Baltimore, MD
Focused on expanding scientific and provider programs and accelerating a solution to hyperphagia*

- **Wednesday, June 3rd:** Clinical and Scientific Advisory Board Meetings and Professional Providers Day
- **Thursday, June 4th:** PWS Scientific Day and beginning of hyperphagia conference
- **Friday, June 5th:** Multi-disorder, collaborative meeting on

hyperphagia (see page 6).

Parents may register to attend as observers to the PWS Scientific and Hyperphagia meetings.

2010 CONFERENCE

Summer 2010, in Orlando, Florida

Traditional conference format with educational programming for the entire family

2 days of youth and adult programming (YIP/YAP) including a Gala Banquet geared toward children and adults with PWS. Scientific Day, Professional Providers Day and Chapter Presidents Day are also planned.

HOW YOU CAN HELP

Registration fees for Conference and YIP/YAP programs don't begin to cover the actual costs of putting on a family-focused conference. If you'd like to see these programs continue, please consider holding a fundraiser and/or donating to PWSA(USA) to support them.

Planning and financing conferences are monumental tasks, requiring hundreds of hours of staff and volunteer time. Please consider volunteering for our conference committee and/or volunteering your time at a conference. ■

Research Studies by the Pacific Graduate School of Psychiatry

These two research studies, funded by PWSA (USA), consisted of a study focusing primarily on the parents and family system and a study focusing primarily on the sibling. Twelve mothers and 13 siblings were recruited from June 2007 through April 2008. The majority of mothers were in their mid to late 40's. Healthy siblings when interviewed ranged from 12 to 19 years of age. Eight were female and 5 were male. Eleven siblings were older than the child diagnosed with PWS.

The small sample size necessitated caution when interpreting the results. However, because 1) PWS

has a low base rate in the population; 2) participants represented a fairly wide geographic and socio-economic range; and 3) the severity of PWS in the diagnosed child varied, results would likely generalize to a larger sample in the same population.

Quality of Life and Caregiving in Families of Children Diagnosed with PWS

Mary M. Mazaheri, M.S.

Pacific Graduate School of Psychology

The study aimed to identify the psychological and health related quality of life (HTQoL) effects

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Research View

Research, continued from page 7

across the areas of 1) maternal distress and HRQoL; 2) the overall family functioning; 3) the healthy siblings' HRQoL; and 4) the relationship between the mothers' reaction to the diagnosis of PWS and the siblings' perception of caregiving.

First, the mothers in this group appeared to be experiencing significant behavioral distress symptoms, with higher than average levels of depression, feelings of isolation, anger and worry. Second, the mothers reported difficulties in overall family functioning, including problems with communication between family members and an increased number of conflicts. Third, when the PWS mothers were compared with a sample of mothers of children diagnosed with cancer, the PWS mothers viewed the healthy siblings' HRQoL as poorer than mothers of children diagnosed with cancer. Further, the mother's perception of the healthy child's HRQoL was significantly lower than the sibling's self-report would indicate. The parent and sibling reports of HRQoL were significantly different across multiple domains (school, social and overall functioning). Finally, the results of this study revealed little correlation between the mother's reaction to diagnosis and the mother's ability to provide care to the healthy sibling.

The Impact of PWS on Healthy Siblings' Perceptions of Caregiving Availability and Psychosocial Adjustment

Raazhan Darleen Rae-Seebach, M.S.

Pacific Graduate School of Psychology

(1) Moderate to severe levels of post-traumatic stress reaction were reported by twelve siblings, one sibling reported mild symptoms of post-traumatic stress reaction; (2) the siblings' post-traumatic stress reaction symptoms were strongly associated with experiences of unresolved attachment; (3) the siblings' perceived loss of caregiving availability and unresolved attachment were significantly related to their psychosocial adjustment; and (4) siblings' unresolved quality of attachment and psychosocial-emotional and behavioral functioning were significantly correlated with mothers' self-reported levels of stress. Some positive benefits were also reported. Siblings stated that they are more aware and understanding of the needs of individuals who are disabled. Parents commented that having a sibling with PWS enabled siblings to develop increased empathy.

Suggestions made by siblings identified ten predominant themes: allowing time to learn and grow, being open to learning from siblings with PWS, coping with reactions from friends and social interactions, going on family outings, self care for healthy siblings, talking to others about feelings, managing feelings of frustration, sharing tips on caring for siblings with PWS, developing a positive long term perspective, and being open minded to learning from the child with PWS.

Conclusions

These studies reaffirm that chronic illness affects the entire family in multiple ways and will hopefully lead to increased awareness among PWS parents about their own psychological needs, the importance of social support, and the needs of healthy siblings. Talking about feelings is one way that can be helpful in reducing stress and the effects of trauma associated with living with a child diagnosed with PWS. Both parent and siblings can be encouraged to understand PWS and the potential impact it can have on the family, as well as the diagnosed individual. Sibling support groups focused on chronic illness and developmental disability in general can be supportive if a group focused on PWS is unavailable. ■

Change in Dues and Membership Categories

PWSA (USA) has kept the cost of dues the same for 14 years while the Consumer Price Index increased more than 45%. To help us help you, the Board has voted to increase and change the structure of dues as of April 1, 2009. Domestic dues will now be \$50, with the three prior classes of full membership consolidated into one. (International dues will be \$60.) Domestic dues for individual membership were previously \$30; for family memberships \$35; and for organizations \$40.

Each full membership (which may be for an individual, a family, or an organization) will now have one vote. Auxiliary memberships remain \$15 domestically or \$25 internationally. When paying their dues, PWSA (USA) members can also donate sponsored memberships for those who cannot afford to pay dues. Membership is never denied parents for financial reasons. ■



Crazy Mixed-up Rhyme for the 4th Annual Lose-A-Thon

- 1** *for the money* — **Join Lose-A-Thon**
- 2** *for the show* — **Get a plan because no plan is a plan for failure**
- 3** *to get ready* — **Set a series of small weekly goals**
- 4** *to go* — **Contact your friends and family to set up your support base and fund raising group**

Ask yourself, "Do I need to join Lose-A-Thon to better my health and physical well-being?" If the answer is "yes" or "maybe", don't do another thing until you have signed up. Go to www.pwsausa.org/fundraising/lose-a-thon You might even put together a team of people so that you can motivate and support one another.

With the program you have five months to establish a new healthy eating and exercise habit that can stay with you forever. We will help you with weekly suggestions. A registered dietician will be available to answer food and nutrition questions, a personal trainer will be on call for fitness questions, and a former participant will share his methods for success.

You will be able to share your experiences, too (there are no failures here, just opportunities to begin again), on our own personal Yahoo e-mail group. And there are **PRIZES** this year for several categories. See the Lose-A-Thon website for more information.

Newcomers and alumni are welcome! Call Diane at 1-800-926-4797 for further information and/or questions. Sign up today! ■

A Heartfelt Thanks

Thanks to everyone who participated in the 7th Annual Valentine Research Fund Campaign. You put your **hearts** into supporting research and helping our **loved ones** with PWS have a hopeful and bright future. Thank you from the bottom of our **hearts!** Because of your efforts and the **love** you put into this campaign, we can continue our search for a cure and treatments for PWS.

The campaign runs from January 1, 2009 until **Valentine's**

Day. You can keep it **pumping** until the end by reminding family and friends to donate. Don't forget, if we raise a **heartly** \$37,500 we'll receive a match from Josilyn Faith's Foundation for \$7,500!

For more information, check our Valentine Research Fund Campaign headquarters on the PWSA (USA) web site at www.pwsausa.org/Valentine.

Thanks again! You warm our **hearts** by such tremendous efforts! ■

Tips for and by Parents *Improving Walking, Standing and Sitting*

~by Diane Spencer, Support Coordinator

Some ways to combat (not cure) hypotonia, suggested by Jennifer Deau, an exercise physiologist, are simple.

Walking –

- **Discourage** compensatory movements such as "waddling" instead of walking.
- **Encourage** lifting knees up and forward while walking instead of stepping side to side with no knee bend.
- **Encourage** use of shoulder joint movement by swinging the arms forward and back.
- Try to make at least 50% of the exercise routine weight-bearing in nature. Swimming and stationary biking are great, but the foot strike done in walking helps to **build bone density**.

Standing –

- **Discourage leaning** on walls; **encourage standing tall** with shoulders back. This also improves respiratory function and uses more muscles, which burns more calories.

Sitting –

- **Encourage** sitting in chairs correctly with butt against the back of the chair. Sitting with the butt in the middle of the seat and slumped over invites back pain and increased respiration rate.

Be ready to give gentle reminders about posture and walking; appearance is important!

Hearing Voices

In the fall of 1992, when my daughter Maggie was 13, she started asking if I had said things that I'd never even thought of – were we going to give her up for adoption? Did she have a twin? Was I sure we loved her, or had we just been talking about how awful she was?

By Christmas Maggie had gone beyond “hearing” things to “remembering” things. She went up to kids she'd never seen before and accused them of being mean to her at camp last summer. She approached people in restaurants who were “talking about her.” The therapist Maggie was seeing brushed it off, suggesting that I needed treatment to stop overreacting.

Early in January, Maggie's therapist, looking alarmed, said, “Maggie just asked me about her birth parents and was very upset that I ‘refused’ to tell her about them. I think Maggie is having a psychotic episode. She needs to see a psychiatrist and get medication as soon as possible.”

Thus began an eight-month quest in those still early days of genetic testing that ended in our finally getting a diagnosis of what was wrong with our little girl. Her psychotic episode was the result of her desperate attempt to hold her life together as all her friends at her special school for students with learning disabilities started to grow up and she didn't. Why wasn't she maturing the way they were? Why was she not “outgrowing” her learning problems and moving ahead like they were?

Why? Because she had Prader-Willi syndrome, UPD, masked by her 90-95 IQ and

strong ability to read and speak fluently.

Unfortunately, PWS does not immunize anyone against mental illness. As parents and often legal guardians, we face incredible challenges in getting accurate diagnoses and treatment for our children with mental illnesses, one of the last but greatest of the medical stigmas that still haunt our culture. What, exactly, are we up against?

First, many psychiatrists do not want to see people with PWS. Either they've seen one who was very challenging, or they aren't interested in working with people with developmental disabilities, or they don't feel qualified to work with a relatively rare genetic problem.

I spent years looking for one who was knowledgeable about psychotropic drugs and willing to take on the kind of medication experimentation that PWS often calls for. Finally I found a university-affiliated child psychiatrist at one of the PWSA conferences who shepherded Maggie through the process of getting into the medical school treatment system. Maggie now sees an annually revolving staff of psychiatric residents working under that psychiatrist's supervision.

Second, most people are not familiar with the symptoms of mental illness. Several times over the past 15 years since her diagnosis, I have had staff tell me that my daughter's recurrent delusions were “normal” for people with PWS—or accuse me of making excuses for her strange behavior and claim there was nothing wrong with her that better mothering wouldn't cure. I think that laypeople simply

haven't seen much mental illness so they tend not to recognize it when they do see it.

Third, most people are not up to date on psychoactive medication, its benefits and liabilities. Recently, the head of residential services and the social worker at my daughter's agency became distraught when I told them I thought Maggie needed to get back on anti-psychotic meds. They said that she would become dysfunctional, “drugged out,” and unable to lead a life that was at all normal.

This may have been the case 25 years ago, but not anymore. Because so many people suffer from episodes of serious mental illnesses, drug companies have invested millions of dollars in research and experimentation to develop new kinds of drugs. Fifteen years ago, if you suffered from clinical depression, there was only Prozac, itself a major breakthrough. Now there are perhaps eight or ten drugs designed to address depression, all of which work in slightly different ways.

...if we learn enough, demand the right research and services, and work on being there for one another, we can help our children with PWS grow, mature, and become successful citizens of the world in their own unique and often beautiful way, regardless of what additional diagnoses we find they face.

Voices, continued on page 11

Voices, continued from page 10

The same is true of drugs for bipolar disorder, psychosis, affective disorders, and other life-altering and often life-threatening illnesses. Every one of them can have side effects – just as growth hormone or hormone replacement therapy can have. But the side effects are usually not bad enough to discontinue treatment; and if one drug has side effects, others do not. Often, side effects do not appear at all.

How can you, a parent or guardian, know if your loved one with PWS *does* have a mental illness? We are all well aware that many challenging behaviors are common aspects of PWS. I also know, though, that human beings – especially, perhaps, moms – have a sort of sixth sense when something is going seriously wrong.

My first advice, therefore, is to watch yourself, your own reactions – and when you sense that something is wrong, pay

attention and start gathering data. (This is especially true if there is any mental illness in your family, or alcoholism or drug abuse, which are often attempts to self-medicate mental illness.)

Next, educate yourself about what might be wrong. I recently took a free twelve-week course called “Family to Family” sponsored by the National Alliance on Mental Illness (NAMI). I barely made it through the course, it was so painful. I heard other people’s stories that were much worse than mine; some made PWS look pretty benign!

But I *did* make it through, and I gained the precious insight that Maggie suffered not from depression, but rather from bipolar illness. She could be down for months, but when she was up, her thoughts were racing, she managed to go through incredible amounts of money, made grandiose plans, and called me ten, twenty, even thirty times a day, starting at 5 a.m. until close to midnight.

Since then, after four months of working with her psychiatrist, Maggie is slowly (the key to new meds seems to be to go very slowly) but surely reducing her antidepressants and replacing them with a mood stabilization drug that should, over time, buff out both her extreme lows and her extreme highs.

Our world stigmatizes people with mental illness, whether they are otherwise “normal” or not. Facing up to mental illness may be even more challenging than facing up to a genetic defect. But if we learn enough, demand the right research and services, and work on being there for one another, we can help our children with PWS grow, mature, and become successful citizens of the world in their own unique and often beautiful way, regardless of what additional diagnoses we find they face. ■

~ Flor Pinero

[Ed. Note: see “A Pilot Study of Psychotropic Medications in PWS”, *The Gathered View*, May-June 2008]

Counselors Corner

“A young man with PWS is arrested for taking a sandwich and soda out of an unlocked car.”

“The police are called when a young woman with PWS is caught taking a bag of candy that belongs to someone else.”

Encounters with law enforcement are particularly scary for people with PWS and their families. To help minimize these potential crisis situations, we recommend the following:

- Prevention is a key step in crisis management so educate your local police department before a crisis happens. Visit the police in your local precinct and share with them PWS educational materials. Consider creating a one page sheet specific to your loved one, including a picture and tips on what might be helpful in a crisis situation (i.e., don’t touch). If you have a school age child, include school police resource officers as well.

- Keep on hand a supply of PWSA (USA) resources such as our Statement for Law Enforcement (long and wallet size versions) and the article “When Stealing is not a Crime.” Both can be downloaded from the Members Only section of the PWSA (USA) website.

- If an incident with law enforcement does occur, contact a crisis counselor at PWSA (USA) right away (800-926-4797) along with your local PWSA chapter. It is essential that police, public defenders, judges, and district attorneys understand as quickly as possible how PWS contributed to what appears to be an incident punishable by law. This moves the discussion from criminality to disability.

Our goal is to discourage having behaviors related to PWS criminalized.

See you next time in the Counselor’s Corner! ■

Evan Farrar
Crisis Intervention Counselor

Stress Managing Strategies

by Lisa Graziano, M.A., MFT

We know it intuitively, but research by PWS experts Janice Forster, M.D., Linda Gourash, M.D. and Marjorie Royale confirms it: *stress is significantly higher among parents and other caregivers of people with PWS than it is in the population at large.* It's imperative, then, that we reduce and manage our high stress levels in order to have adequate energy to sustain a calm and neutral response to our child with PWS, to be emotionally available to *all* of our children and spouse, and to stay healthy and enjoy the same high quality of life we work so hard to provide to our family.

We tend to think of "stress" as an evil to be avoided. Stress, however, is an unavoidable fact of life, caused by sad, fearful and worrisome events, or exciting and wonderful ones--anything creating change or demand.

We can't prevent stress, so we must learn effective ways to manage it.

Physiological Reactions to Stress

When the brain perceives a stressor (demand), it signals the release of the chemicals epinephrine and norepinephrine, and then the release of cortisol and other hormones. The body is put on alert for a change in behavior (i.e., fight or flight). Afterwards, the body returns to its pre-stress state.

Chronic stress, such as typically experienced by care providers of persons with PWS, sensitizes the stress system,

making it *more* responsive to stress. Result? The system *overresponds* to new stressors, trapping us in a vicious cycle of perceiving any new stressor as SEVERE--so we're more likely to attempt to manage it utilizing a familiar but often unhealthy stress-reducing strategy--which ends up placing *more* stress on our body. Long-term potential outcome? A multitude of physical and emotional disorders, even an acceleration in the aging process.

Emotional Reactions to Stress

Some people are perpetual Worry Warts who feel more anxious the calmer things become. Others remain unruffled even in the midst of an obviously sinking ship. While everyone has an emotional reaction to stress, the degree is individualized and dependent upon various factors including the complexity of our care-taking responsibilities, quality of our support network, demands of our daily responsibilities, and our physical health. Whether you're a Worry Wart, a Cool Cucumber, or somewhere in between, your first reaction to a stressor will probably be fairly consistent and marks a starting place to begin improving your stress management techniques: Do you tighten up, experience back pain, tummy aches, headaches? Get irritable, impatient or angry? Experience a steady stream of negative thoughts? Tend to cry, ignore or avoid the problem, or just give up? Reach for a cigarette, drink or some other drug? Eat when you're not hungry? None of these strategies is necessarily inherently "bad" or unhealthy--unless it's the *only* strategy used to manage stress.

How To Manage Stress

Following is a list of stress management strategies. Some won't be a good fit, some may work only occasionally, and some will work very successfully. Give yourself a pat on the back for each one you already utilize, and consider adding a few more.

• **Controlled Breathing:** A favorite in-the-moment stress-reducing technique is slow, measured breathing. Breathe in through your nose and exhale slowly out of your mouth to a count of four. Relax your shoulders. Repeat 4-5 times and notice your mind and body begin to relax.

• **Thought Management:** Another effective technique to use during those "I-can't-take-this-anymore-or-I'll-explode" moments is to tell yourself to "Stop. Breathe. Relax. It's ok. I will get through this" or "Stop. Breathe. Relax. There's nothing I can do about this. I'm doing the best I can." **Keep things in perspective. Maintain realistic expectations. Don't sweat the small stuff.** Guided Imagery can be used anytime you have even two minutes: control your breathing, relax your body, and imagine relaxing, calming scenes. Long-term tools include meditation, yoga, and Tai chi.

• **Time Management:** My son's Karate teacher tells his students that the best defense to an attack is to move out of the way. The best defense to stress is to avoid it! Prioritize. Avoid overscheduling whenever possible. Don't over commit or overextend yourself. Give yourself plenty of time for transition or travel.

Stress, continued on page 13

Stress, continued from page 12

• Personal Boundary

Management: Having a child with PWS challenges us to think ahead and anticipate potential problems. Assertively (*not aggressively*) protecting our personal boundaries is healthy, even and especially when interacting with our kids. It's ok to share that today you're feeling extra tired and therefore need extra quiet time. It's ok to tell your friend that you really can't help out today because you've made other commitments (to yourself!).

Limit the amount of time you spend with people who stress you out. Know your limitations. If you're not good at calmly helping your child with her homework, have someone else do it.

• **Exercise & Diet:** A top strategy is regular physical activity. Exercise releases wonderful chemicals in your brain that restore and heal mind and body. Fifteen to twenty minutes a day for 3-5 days a week

will make a huge difference in how you feel. Incorporate a daily walk; or wake up 20 minutes earlier in the morning or go to bed 20 minutes later so that you can work out to an exercise DVD. Get creative; you'll find plenty of opportunities for physical activity. Maintaining a healthy diet gives your brain and body the fuel they need.

Adequate consistent sleep is vital to a healthy body and managing stressors. For many, especially those whose child awakens several times during the night, it is very difficult to get the recommended seven to nine hours of sleep necessary to recharge the brain and revitalize the body. But without adequate sleep, we are less able to calmly manage even the tiniest stressor.

• **Support:** If you're lucky enough to have a good support system, use it! People with a healthy support network have fewer stress-related symptoms and manage stress better.

• **Therapeutic Intervention:** It takes intelligence to recognize when we've done all we can and it's just not enough. It takes courage to ask for help. If you don't have the luxury of a good support system and you're overwhelmed with stress, find a good professional. Many psychologists, psychiatrists, social workers, marriage and family therapists, even some clergy are trained in stress management techniques. Counseling can be brief or longer-term, depending upon the need.

In the midst of stress we tend to forget any potential new management options, so until they're automatically incorporated into your daily life it may be helpful to post some of these stress-managing options on your fridge or in your car. I wish you successful stress-managing strategies that carry you throughout your lifetime! ■

Linda, continued from page 1

stop them. When it was all over, there was Hannah standing in the middle of the football field with a very, very large check.

After all the funds were raised, the student council committee in charge of Spirit Week went into a huddle and gave their thanks for having a successful fundraiser, not because they won the competition between their school and another high school, but for being able to have a successful event that will provide help to children like Hannah with PWS.

It is with utmost gratitude that we thank these young folks with such big hearts, this wonderful family and a mom who dared to



The Spirit Week team, with Hannah Johnson in the front row and big sister Olivia in the third row

dream. And it all started with "I have an idea." If you have an idea, help it grow! If you read about something, think about something

or want to share your thoughts, get started by calling us at PWSA (USA). You can make a difference just by having an idea. ■

Emails to Heaven

By Janalee Heinemann

Director of Research & Medical Affairs—and
Pam's forever friend

"I wish I could send her emails in heaven."

– from a young mother in India

On November 19th, our dear international (IPWSO) president, Pam Eisen, from Wormleysburg, Pennsylvania, lost her ten-month battle with pancreatic cancer. During those months, Pam made several trips, including to Germany to speak and organize the first international providers' conference. She also spent much effort preparing her children for her death, especially Gabriella, her 28-year-old daughter who has PWS.

Pam and I traveled together to educate many countries on PWS and communicated weekly. Like many other people, I will miss her both as professional and as a dear friend. She was known and well loved throughout the PWS world for her volunteer work for IPWSO. I have 58 pages of emails to Pam through me since her diagnosis, which I'm sharing with her family so they can appreciate her importance to the world of PWS. Here are a very few:

I remembered our meeting, your cheerfulness and kindness, your charming smile, your inexhaustible energy, your keenness and devotion to the noble idea - help to patients. (Romania)

I feel privileged to have met and worked with a person like you. The time we spent working and talking together enabled me to... observe, with awe and wonder, that obstacles and difficulties were not words in your vocabulary and just challenges overcome more often than not. (Israel)

As a parent dedicated to helping other parents, you have set an example of how to live a remarkable life filled with compassion, purpose, guts, determination, and supreme gentle grace. (USA)

Pam, you are one of the most beautiful butterflies I know. Your gentle nature leads you to communication and cooperation, as opposed to confrontation and conflict... And, once I got to know you, I knew your strength. I know many of life's obstacles that you have had to overcome. (Canada)

Although we can't help feeling a deep anguish... what emerges is a wide smile remembering her and the sweetness she was communicating... Meeting her was a feast..she was always available to help everybody even the smallest and the poorest. I think we all received a sign from her. Pam: you'll always be with us. We love you very much. (Venezuela)



Pam Eisen, middle, surrounded by Janalee, three children with PWS in Thailand and their teacher

We all knew and loved Pam, wonderful person, sweet and determined... committed as we are to a battle for the spreading of rare diseases knowledge, Prader-Willi syndrome

in particular. To helping families to better manage the disease, getting them out of isolation, providing them a genetic diagnosis, even in most disadvantaged countries.

We all shall remember Pam forever, worldwide solidarity ambassador, encouraging, advising, comprehending, building a collaboration network between association, patients, physicians, researchers.

The Italian traslation of the "Medical Alert" published by BIRD Foundation is dedicated to Pam. (B.I.R.D.Italy)

From Chile we wish to share with each one of you the happiness and the privilege we had knowing and meeting Pam, the deep pain that brought us her death and our firm belief she will continue taking care of us... Pamelita will always live in our hearts, inside our strength and daily work.

MANY THANKS PAM!! Rest in peace.

A strong hug (PWSA Chile)

At PWSA (USA) we have set up a designated fund in Pam's memory for international efforts, and her sons will be setting up a foundation for international PWS work in Pam's memory as Pam requested. Yes, Pam, rest in peace. We grieve your death and celebrate your life. The difference you have made will live on for generations to come. ■

Good News!

We are glad to announce that Dr. Merlin Butler, Chair of our Scientific Advisory Board, is resettled and now able to take patients with PWS again.

Merlin G. Butler, MD, PhD, FFACMG

*Professor of Psychiatry, Behavioral Sciences and Pediatrics
ABMG Certified Clinical Geneticist and Clinical
Cytogeneticist*

**Departments of Psychiatry & Behavioral
Sciences and Pediatrics**

Kansas University Medical Center

3901 Rainbow Boulevard, MS 4015

Kansas City, Kansas 66160

Phone: (913) 588-1873

From the Home Front

A Father's Advice

[excerpted from an online message from Mark Brosso to the mother of Abigail, 8 months]

Our son Luke is 23 months old, walking, long and lean, very happy. He gives and receives lots of love. This is a far cry from the doctors' prognosis.

I still remember the Medical Geneticists telling my wife Maureen and I that Luke has PWS and saying words forever seared into my brain. "He will never live independently...he will be morbidly obese...he will have small hands, feet and have underdeveloped sexual organs...he will be cognitively impaired." Anyone who offers you anything close to that is relying on one page in a 20 year old Pediatrics textbook.

Here is what we have learned since that time...

1. You found out that Abigail has PWS, not a degenerative neuromuscular disease like SMA, Muscular Dystrophy, etc. Be very thankful.
2. Remember that the doctors can give you a diagnosis but they cannot give you Abigail's long term prognosis.
3. Remember that "hope" is NOT a four letter word! I remember many doctors saying that "it's good to have hope but..." As if "hope" was false hope. As if the anecdotal reports from many parents who are pursuing current treatments are not seeing actual results in their own children. A couple of days of web surfing will tell you that the prognosis for these kids is changing rapidly and greatly. Don't be afraid to tell those doctors that they are woefully behind the times with respect to current treatments and outcomes for PWS.
4. Understand that Abigail has two prognoses that you can control. When people ask me what the prognosis is for Luke, I tell them that "he will be loved." That is 100% certain. Additionally, remember that hope is not enough. Action is important. So

aggressively pursue all of the treatments that are available. Get her on treatment and your hope will be rewarded with development.

5. Find the right doctors for Abigail that have CURRENT experience with PWS. You will need to see Endocrinology (for the Human Growth Hormone treatments now and other treatments along the way), Ophthalmology (for screening), Orthopedics (for x-rays of spine and hips), Pulmonology, Sleep studies, Orthotics, etc.

We have established criteria for doctor shopping. (1) Does the physician treat the patient irrespective of his particular focus and practice specialty? You don't want an orthopedic surgeon who is treating the spine. You need one who is treating Abigail, (2) Does the physician refer to Abigail by name and see her as a person? (3) Does the physician have experience with PWS and understand all of the implications? (4) Is the physician progressive in his research and application of treatments? If not, will he refer you out to other physicians?

6. Listen to other parents. They are a tremendous source for progressive treatments that the medical community may know about in another 5 years.

~Mark Brosso

Malvern, Pennsylvania



"My daughter Tressa, 7, left our home one time at 2AM, went next door to ring the doorbell of our 82-year-old neighbor, and told her 'MOM NEEDS COOKIES'. I borrow an egg or cup of milk once in a while to avoid a full blown drive to the store, and she picked up on it."

~Mary Pringle

Cape Coral, Florida

Contributions

Thank you for Contributions in October and November 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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