



The *Gathered View*

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

Special Ed Can Be Special

By Faith Weaver

Our son William Harlee Weaver was born in April 1996 and was diagnosed with PWS when he was just over 2 months old. At that time it just meant he had a hard time eating and we had to take him several times each week to therapies so he could get caught up with every other "normal" child. The other realities we were told about or read about would never be a part of our reality, so we thought.

As William was nearing his third birthday, we were being guided toward the school system. Our baby, ready to start school? We were just sure that he would be trampled on because he was so small.

Well, cute as he was, from the very first day of the school year, he owned the campus. He strutted onto the campus each morning being greeted by his fan club, which included everyone from the students to staff to the custodians. There were no strangers to our William.

William was in an ESE {Exceptional Student Education} classroom. We felt he needed a smaller class size to better ready him to be mainstreamed like the "normal" child we knew he really was. The following year, we started seeing more and more signs of PWS: the food-seeking, coupled with the weight gain. We were no longer worried that *he* would be the one being trampled on. Yet at school he was always the same cute, friendly William that everyone knew and loved.

Things began to change in his kindergarten year, as we sold our home and moved farther south to Sarasota County, Florida so we decided to try mainstreaming. Our cute, well-known and much-loved little William became the "New Fat Kid" on

campus. I could never forget the looks he got from the other students that reached in and ripped out our hearts. We must not have been the only ones who noticed it: William soon starting losing his passion for school.

We had several meetings with school personnel addressing our concerns for William, as well as the IEP meetings. To make a very long story short, we had a year of abuse, neglect, headache and heartache. William started having accidents in his pants on a daily basis. The lack of self-esteem we were seeing in William was something we had never seen before.

As the end of the school year was approaching, word started circulating about summer classes. All children were going to be attending another school. This was a school I had only heard about, but I was thankful my child would never have to go to it. This was a school for very

special needs children, so I thought. Because William had more than 100 absences that year, we decided to sign him up. After all, it was just for 6 weeks.

Oakpark School is a Center School for students who have physical and/or mental challenges. It serves grades Pre-K to 12, up to age 21. It is a part of the Sarasota County School District. Designed to accommodate the county's challenged students, it has a wide variety of programs that offer opportunity for learning, socialization, skill development and personal accomplishment.



William Weaver rides horseback during hippotherapy.

William continued on page 17

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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA) unless so stated. Medical information published in *The Gathered View* should not be considered a substitute for individualized care by a licensed medical professional.

The Gathered View welcomes articles, letters, personal stories and photographs and news of interest to those concerned with Prader-Willi syndrome.

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA) in Sarasota, Florida.



Register Now for PWSA 2003 Annual Conference

July 2-5, Sheraton World Resort, Orlando Florida

Fulfilling The Dream: Joining Together to Secure Brighter Horizons

General Conference

Topics as diverse as behavior management, sibling issues, teaching social skills and how PWS affects the digestive system will be offered by a variety of presenters, many world-renowned. Some of the topics will include:

For parents of children age infant-5 years — sessions on sensory, PT, OT and speech by well known experts in the field, plus a session on infant and feeding issues. Presenters include:

Janice M. Agarwal, P.T., a parent who was a pediatric/neonatal physical therapist at a children's hospital in New York. Janice trained pediatric physical, occupation, and speech therapists as well as nurses in developmental aspects of children, with emphasis on children under 3 years old. She has her certification in Neurodevelopmental Therapy at the Bobath Center for Children in London, England and is writing a series on PWS and PT for *The Gathered View*. Kate Schuppert, P.T., will assist Janice with the sessions on Physical therapy.

Brynn Moritt Ferbin, is a speech-language pathologist. Brynn has had extensive experience in working with pediatric patients, specifically the birth-to-5 population. Her specialties include working with children who have feeding and swallowing disorders and motor-based speech disorders, including dyspraxia (apraxia) and dysarthria.

Dawn Oakley is an O.T. who currently heads up the rehab department at St. Mary's Hospital for Children in New York. She is a certified Sensory Integration Specialist. She is currently working on her Ph.D. in Sensory Integration.

Suzanne Cassidy, M.D., specializing in PWS, will give a medical overview for birth-to-5 families.

There will also be a time for sharing and meeting other families.

For parents of school-age children and teens — Morris Angulo, M.D. will address growth hormone therapy and other endocrine issues, and a medical experts panel will answer questions about your child's health issues. There will be a presentation on IEPs and how to advocate services for your child, as well as a session to train parents to Educate the Educators. Scott Stiefel, M.D. will present on social skills training, behavior management strategies, and how sleep disorders contribute to behavior problems. Janice Agarwal, PT will present "How Does Your Engine Run," providing an overview of sensory integration strategies for increased self-regulation. B.J. Goff, Ph.D. will address "Adolescent Dating and Sexuality." Speech dyspraxia will be addressed, as well as a session on "How to Handle Food Situations at School/Work/Home."

For parents of adults with PWS — sessions will be offered on "Teaching your Kids to be Cool – Developing Realistic Expectations in Relationships" by BJ Goff ; Dr. Scott Steifel, a pediatric psychiatrist, will be back by popular demand to present a session on "Understanding And Managing The Behavior Of A Person With PWS"; other sessions include Aging and Healthcare issues; Wills and Guardianship; Taking Care of Oneself and Building Support; How To Improve Communication Between Parents And Providers; and "Crisis Intervention and Prevention" by David Wyatt.

For program updates check the PWSA website at www.pwsausa.org periodically.

Scientific Conference

These sessions are designed for researchers and clinicians in the field of Prader-Willi syndrome. World-renowned scientists, medical specialists and other professionals will make presentations. The scientific sessions will cover topics on the genetic, medical, nutritional, endocrine, behavioral and

psychosocial aspects of the syndrome.

A limited number of parents will be

admitted to the Scientific Conference as observers only.

Professional Caregivers and Providers Programs

Special topics for providers and health care professionals will be offered, including an overview for health care professionals and a physician-led question-and-answer session.

This program is designed for all who work in homes, residential facilities, vocational and educational programs, health and human service agencies and other community programs that provide assistance and education to those with PWS and their families.

Youth, Infants and Adults Program

During the conference, there will be a Youth Infant Program (YIP) for PWS infants to age 5, and a Youth and Adult Program (YAAP) for those ages 6 to adult. The YAAP program will also have a separate program for siblings of children with PWS. The theme of this year's program is "Dream Weavers" and will be run by trained professionals and volunteers.

The YIP program run by Michelle Holbrook and Michelle Torbert will feature fun and safe activities held at the hotel. The YAAP program run by Tad and Gina Tomaseski, directors of Dream Team, will feature an offsite event on Thursday, July 3 at an area attraction and an indoor carnival and movie theater at the hotel.

Check Our Web Site for the latest Conference Information

www.pwsausa.org.

2003 Conference continued on page 14



Connected and Reaching Out to The World

By Lota Mitchell, PWSA (USA) President

Wow! Energy was flowing freely at the national board meeting in January in Sarasota. No shortage of power there! Unfortunately, there was a shortage of warm in usually warm, sunny Sarasota. Banish all fantasies of the board lounging on the beach.

Incidentally, we go at our own expense. Only \$500 is provided annually toward expenses for both the winter board meeting and the one at conference (although there is a fund to help those for whom this would mean financial hardship or inability to serve).

I want our membership to know what a terrific board we have, with directors who are committed, energetic, and contributing time, talent and treasure to the cause of PWS. Including our officers, we have parents, professionals, grandparents, providers, CPA, attorney, doctor, entrepreneur, financial types, computer expert, public relations specialist, social worker, family counselor, and physical therapist. All are working harmoniously and productively toward one goal — how to better serve our membership, both those with PWS and those who care about and for them.

There are so many programs in place now to help our members that it is awesome — Crisis Intervention, New Parent Mentoring, Bereavement Program, Medical Intervention program, ongoing publications updating and creation, to mention a few. Work is in full swing to prepare for the annual conference in Orlando. No other organization puts on as complicated a conference as PWSA(USA).

Our delegate to the International PWS Organization (IPWSO), Pam Eisen, gave such a sensitive and enthusiastic report that I could literally feel my horizons broadening as she spoke. With 54 countries now in IPWSO (Bolivia and Aruba just joined), Prader-Willi has truly become a global family, with every one of us a part of it. We have a common concern, we are connected, and PWSA(USA) is reaching out around the world with information and written materials. Talk about awesome!

At home we are so proud of our chapters. Twenty three of our 29 Chapters are in Good Standing, having sent in their minutes, financial report, \$35 yearly dues, and list of officers. (See box.) In addition, 18 chapters have provided financial support in 2001 and 2002 to national. (See box.)

We are so fortunate to have people who are willing to take on the responsibility of chapter president, and I would like to profile three more of them.

Although **NORTHWEST** includes Montana, Idaho, Hawaii and Alaska, 95 percent of its membership is in Washington state. The chapter is led by co-presidents

Susan Lundh and Joane Underwood. Susan is a secretary in an elementary school and loves it. She has also been on both the Seattle and state Special Education Advisory Councils. She says she has been an officer in her chapter “forever.” Son Peder, 15, is at the Woods School in Pennsylvania. An OB nurse, Joane works three days a week in Labor and Delivery. She likes to bowl and is on a team. Her middle child, Marisa, who has PWS, will soon be 18. They are looking forward to her birthday because at that time a residential placement is expected, just 15 miles away, in a PWS designated home.

The **KENTUCKY** chapter has a new president, **Frank Beck.** A telecommunications technician for the Jewish Hospital in Cincinnati, he is the father of Lauren, aged 3. He is in a radio-controlled airplane club, which is his hobby, and also involved with his son Brandon, aged 6, in Tiger Scouts, baseball and soccer. Thanks and appreciation go to past president Kim Settles.

The family of PWS truly is a wonderful one! Peace.

CHAPTERS IN GOOD STANDING

ARKANSAS
ARIZONA
COLORADO
FLORIDA
GEORGIA
MARYLAND/DC/VIRGINIA
MISSOURI
MINNESOTA
NEW JERSEY
OHIO
PENNSYLVANIA
UTAH
NORTHWEST
WISCONSIN
OKLAHOMA
OREGON
MICHIGAN
IOWA
CONNECTICUT
NEW YORK
NEW ENGLAND
ILLINOIS
CALIFORNIA

CHAPTERS PROVIDING FINANCIAL SUPPORT TO PWSA(USA) DURING 2001 & 2002

ARIZONA
COLORADO
CALIFORNIA
FLORIDA
GEORGIA
IOWA
ILLINOIS
KANSAS
MARYLAND
MICHIGAN
MISSOURI
NEW JERSEY
NEW YORK
OHIO
OKLAHOMA
WASHINGTON
WISCONSIN
PENNSYLVANIA

Respiratory Problems in Prader-Willi Syndrome

*By James Loker, M.D. Pediatric Cardiologist
PWSA (USA) Clinical Advisory Board Member*

Several recent articles continue to show that individuals with Prader-Willi syndrome are at risk for respiratory problems. In particular problems of central hypoventilation/apnea, and obstructive apnea in Prader-Willi syndrome have recently been investigated.

Central hypoventilation is a disorder of decreased breathing rate or depth particularly during sleep. This usually causes problems with daytime sleepiness and if significant can cause problems with elevated blood pressure in the lungs. Individuals with Prader-Willi syndrome may be at increased risk for this due to decreased muscle tone and mass, excessive obesity, and possibly decreased neural drive for breathing. Studies have shown some individuals with Prader-Willi syndrome have decreased depth and rate of breathing.

Central apnea means the complete cessation of breathing during sleep. There are several studies that show an alteration in the response of some individuals with Prader-Willi syndrome to chemicals that would normally increase breathing. Both receptors in the body and the area of the brain that is involved with breathing are being investigated. The clinical significance of central apnea is still under investigation.

Obstructive sleep apnea is well known to occur in Prader-Willi syndrome as well as in other syndromes with hypotonia (poor muscle tone) such as Down syndrome. It is seen in 2 percent of the normal pediatric population as well. This results when the individual is trying to breathe while asleep, but due to obstruction in the airway, no air enters the lungs. The obstruction can occur anywhere from the nose to the small airway passages in the lungs. These individuals usually have loud breathing and snoring associated with periods of quiet where no air movement is noted. Untreated obstructive apnea can have serious complications including death.

Other problems that can cause respiratory difficulties in the young are chronic stomach reflux and aspiration. Although the lack of vomiting is felt to be prominent in Prader-Willi

syndrome, reflux has been documented and should be investigated in young children with chronic respiratory problems. Individuals with obstructive apnea are at more risk for reflux as well.

The American Academy of Pediatrics has recently set forth guidelines for diagnosis and management of obstructive sleep apnea. The guidelines suggest that all children with a history of snoring or other evidence of airway obstruction be screened. Your physician may wish to obtain a sleep study if there is excessive sleepiness, significant obesity or before surgery. In those individuals with a positive history, a sleep study is performed where breathing patterns, heart rate, oxygen levels and air movement are recorded. If the test is positive, further evaluation may need to be performed to individualize the treatment. The primary treatment as suggested by the guidelines would include tonsillectomy and/or adenoidectomy or CPAP (Continuous Positive Airway Pressure), where the individual wears a mask at night to keep the airway open.

Frequently obstructive and central apnea may occur in the same patient. This is probably true in the majority of individuals with Prader-Willi syndrome with respiratory problems. Both obstructive and central apnea can be evaluated by a sleep study.

In summary, individuals with Prader-Willi syndrome are at risk for respiratory problems, most commonly obstructive apnea. If any child has symptoms of obstructive apnea, a sleep study should be obtained. The role of central apnea in Prader-Willi syndrome is under investigation.

Special thanks for their contributions to this article to:

- Daniel J. Driscoll, Ph.D., M.D. PWSA (USA) Clinical Advisory Board Chair
- Merlin G. Butler, M.D., Ph.D. PWSA (USA) Scientific Advisory Board Chair
- David M. Agarwal, M.D. PWSA (USA) Research Advisory Committee Member

Fund-raising for PWSA (USA): Who Do You Know?

As the old adage points out, "It's not what you know but who you know." The collective talents and generosity of the PWSA (USA) membership is staggering. PWSA (USA) is a member-driven organization in so many ways.

We are entering a year of expanding our services, reaching out to more people in crisis, while sustaining the well-being of our membership. We have made a commitment to building the PWSA (USA) Endowment Fund as well as continuing to raise funds that will support our numerous publications, Crisis Intervention Program, New Parent Mentoring Program and our growing Bereavement Program. In uncertain economic times, when we see corporate support

shrinking and modest investment returns, we look to our membership for new connections.

For those of you who love to entertain, we ask you to consider hosting a fund-raiser for us — it could be anything from a cocktail or pizza party to walk-a-thon or golf tournament. If you have corporate ties, we invite you to work on behalf of PWSA (USA) in developing relationships that could help us secure sorely needed corporate funding.

The bottom line for PWSA (USA) is that we welcome all legitimate efforts to raise funds on our behalf and we can provide a fund-raising packet to assist you. If you can host a fund-raising event, have ideas or personally have "connections," please call Diane or Janalee at 1-800-926-4797.

Prader-Willi Syndrome as a Model for Obesity

By Belinda Pinyerd, Ph.D., R.N.

Physicians and researchers from more than 20 countries met last fall in Zürich, Switzerland to discuss what is currently known about the obesity associated with Prader-Willi syndrome (PWS). The meeting was held in Zürich to honor the late Dr. Prader who, along with professors Alexis Labhart and Heinrich Willi, first described PWS in 1956 at the University of Zürich.

Other participants at the meeting included nutritionists, parents, and psychologists who are involved in the care of obese individuals. A book containing all the presentations is to be published within the next 18 months.

PWS was selected for discussion given the obesity features associated with the syndrome. In fact, researchers expressed a renewed interest in the syndrome from the standpoint that obesity is reaching epidemic proportions across the globe.

Intensive study of the special problems of obesity in PWS patients will not only be of great benefit to adults with PWS, but also to non-PWS obese individuals. Since PWS-obesity includes both severe appetite and metabolism problems, the hope is that with a better understanding of their obesity, researchers will simultaneously learn more about obesity in otherwise normal patients.

Presentations ranged from discussions on genetics and neuropeptides to behavioral manifestations common to children and adults with PWS. Specific discussions focused on the pathogenesis of human obesity, appetite regulation, carbohydrate metabolism, autonomic nervous system feedback loops, body composition, energy expenditure, and long-term medical management.

One of the most exciting presentations reviewed the new discovery of abnormally high elevations of ghrelin in those with PWS. Ghrelin is a recently described hormone that stimulates



Physicians and researchers discuss PWS and obesity in Zurich

appetite and seems to play a role in regulation of body weight. Therefore the abnormality seen in PWS may be important. However the group was in agreement that more research needs to be performed. Several investigators are focusing on ghrelin as well as the hormone leptin since they both seem to play key roles in body fat production and appetite regulation.

As the meeting closed, excitement and enthusiasm penetrated the audience. Plans for future meetings, collaborations, and exchanges were discussed among the participants. PWS is indeed a research priority to these worldwide leaders.

Belinda Pinyerd is a medical writer from Columbus, Ohio, and is vice president of the PWSA (USA) Ohio Chapter.

Ghrelin Hormone Found To Be Higher In PWS

By Edmund F. Funai, M.D.
Yale University School of Medicine

Ghrelin is a hormone that binds to a similar receptor as growth hormone. While it is not growth hormone, it may affect growth in humans by stimulating appetite. It is produced largely in the stomach, and may work on the brain.

Previous studies examined the effects of intravenous ghrelin on appetite and food intake, and found energy consumption increased 28 percent during ghrelin infusion (resulting in ghrelin levels approximately two times higher than fasting) compared with saltwater (placebo) infusion.

Ghrelin concentrations are higher during starvation and increase with weight loss. Therefore, ghrelin may signal conservation of energy to prevent further weight loss and restore usual body weight. It is known that ghrelin levels are higher in PWS adults.

Andrea M. Haqq and colleagues recently published a study in *The Journal of Clinical Endocrinology & Metabolism*

(88(1):174-178) that examined ghrelin in PWS children. While the study was small, involving only 13 PWS subjects, it found that fasting ghrelin levels were three- to four-fold higher in children with PWS, compared to both normal weight children and children with various reasons for obesity.

While some of the differences were not statistically different from each other, this study may provide a clue that obesity in PWS is at least partly related to excess ghrelin production.

Currently, there are no FDA-approved drugs that block the effects of ghrelin. However, the weight-loss industry is a multi-billion dollar business. If research continues to be promising, especially in non-PWS adults, we may see a ghrelin blocker from a major pharmaceutical company in the next 5-7 years, hopefully sooner.

Ongoing PWS Research Studies

Compulsive Food-Seeking & Food Motivation in Prader-Willi Syndrome

By Jamie Young, O.T.D. and Jennifer Zarcone, Ph.D.

Travis Thompson, Ph.D., the Institute for Child Development (ICD) at the University of Kansas Medical Center (KUMC), and Merlin Butler, MD, Ph.D., Chief of the Division of Genetics and Molecular Medicine at Children's Mercy Hospital (CMH), have embarked on a study of compulsive behavior in Prader-Willi syndrome (PWS).

The major purpose of this study is to determine whether food-seeking and excessive eating in people with PWS is related to compulsive behavior. People with PWS are often reported to engage in behaviors that are similar to people with Obsessive Compulsive Disorder (difficulty with changes in routine, engaging in repetitive behaviors, hoarding). Participants will perform a number of tasks that have been designed to test areas of the brain (orbital frontal cortex) associated with obsessive-compulsive behaviors. This study is funded by a grant from the National Institute for Child Health and Human Development.

Each study participant is evaluated with a battery of computerized tests and genetic tests. The tests will be conducted at the ICD and clinics in KUMC and CMH over the next two years. Participation requires approximately two days and involves parents completing several forms about their child's history and current behavioral characteristics. There will be no direct costs for families to participate. At the end of each person's participation, they will receive a written summary of results of testing, including standardized cognitive tests, laboratory results and newer assessments, not currently available.

Participants will receive \$50 for completing all assessments as well as compensation for travel, lodging, and meals.

For more information or to make a referral, contact Jamie Young, OTD, research assistant professor/project coordinator at jyoung7@kumc.edu or 913 588-5912.

Can You Help Us?

We need an inexpensive publishing company to publish the following:

- A children's book about two children with PWS (with color illustrations, about 36 pages)
- A cookbook (with color graphics, about 200 pages)

If anyone has a contact who is willing to talk with us, please e-mail us at national@pwsausa.org with a contact name and telephone number.

Please Accept Our Apologies

My name is Debbie O'Neal and I am the new business manager at PWSA (USA). Our sincere apologies to those of you who received dues renewals or reminders in error. As the result of a computer problem, renewals or reminders were mailed to members who already paid.

If you received one of these notices, please disregard it. If you are unsure if payment was made, please call Gilda at (800) 926-4797 to check your membership status.

Participants Needed for Yale University Neuropsychological Study

Dr. Robert Schultz and Dr. Anastasia Dimitropoulos, psychologists at Yale University, are seeking individuals with PWS (at least 8 years of age) to participate in an ongoing research study funded by the National Institute of Child Health and Human Development (NICHD).

The purpose of the research is to understand the developmental course, brain anatomy, brain function and neuropsychological and psychiatric characteristics of people with Prader-Willi syndrome, Williams syndrome and autism.

The study takes place over a 3-day visit to the Yale Child Study Center in New Haven, Connecticut. Lodging is provided and families are given an honorarium of up to \$210 for participation.

The study includes cognitive and educational assessments, psychiatric and emotional evaluation, MRI brain scans (functional and structural) and an EEG procedure. Parents receive individual feedback, a written report of the results, and recommendations.

For more information, please contact Elaine Melillo at (203) 737-4421 or elaine.melillo@yale.edu.

Dr. David Ledbetter's Genetic Research

Dr. David Ledbetter and his research group are conducting a study looking at potential chromosome factors that could predispose a deletion in the next generation. They are seeking blood samples from:

- 15 Women with a child with Angelman syndrome due to a deletion, and
- 5 to 10 men with a child with Prader-Willi syndrome due to a deletion.

The samples would be used for research aimed at identifying genetic mechanisms that may lead to the formation of causative deletions. Families are not likely to realize any direct benefit from participation, aside from contributing to a better understanding of why deletions occur.

Any family interested in participating should contact Patti Mills for information at the University of Chicago, telephone (773) 834-1070, or e-mail to pmills@genetics.uchicago.edu. The research group can provide a complete sample submission kit including informed consent documents.

**Special thanks to Pharmacia Corporation
for their major donations
toward the PWSA (USA) National Conference
and an
Unrestricted Educational Grant**



Our Healthy Siblings — The Neglected Population

By Janalee Heinemann

(Note: The following was written 16 years ago, but sibling issues have remained the same. Recently, this article was read by a couple of young mothers who did not know we had this information on siblings. They requested we reprint the article and also inform our readers of the sibling booklet Sarah and I wrote for younger siblings, Sometimes I'm Mad – Sometimes I'm Glad. It is primarily for ages 4-14.)

Last week, while going through old mementos, I came across a Christmas card from our daughter Sarah, written when she was in third grade. She is now 12 years old and a sibling to 13-year-old Matt, who has Prader-Willi syndrome. Included in the card was a list of jobs she would perform as a gift to us. Between the usual (1) I will clean my room and (4) I will take Lambi for a walk daily, was (2) I will help when Matt has a tantrum and (3) I will help keep food away from Matt. What seemed like a normal life to Sarah at age 8 was far from normal for the average 8-year-old.

Now that Sarah is 12, she is much more aware and sensitive to what her peers view as OK and not-OK, plus there is nothing more important to a 12-year-old than to be just like the other kids. When your cupboards and refrigerator are locked, and your brother's behavior is "weird" and embarrassing at times, it is hard to be comfortable in these situations with your peers.

Sarah recently told me of an incident on the bus, where a Special Ed school bus went past theirs. The boys on her bus began making fun of the children on the Special Ed bus and mocking them. Sarah said, "I was mad at them and wanted to say, 'Stop it! How would you feel if someone did that to you!' But I didn't because I was afraid they would turn on me and make fun of me because of Matt."

As a professional, I worked with families of children with cancer. Their sibling dilemmas and problems are very similar to our PWS siblings and most siblings of children with developmental disabilities.

For our next edition of *The Gathered View*, we are planning to resurrect an old column from the mid 1990's called *The Sibling View*. **We welcome writings from siblings.** These should be sent to the attention of Lota Mitchell at the PWSA (USA) national office, or e-mailed to her at ljcholism@juno.com.

The unique issues to our PWS siblings are the weight and behavior issues. Since Sarah and I wrote the PWS sibling book, *Sometimes I'm Mad and Sometimes I'm Glad*, five years ago and geared it as reading for younger siblings, I would like to focus here on the commonalties of siblings of all ages in situations of disabilities.

A myriad of feelings

I find that there are a myriad of feelings for siblings: resentment, guilt, love, jealousy, anger, a desire to protect, being left out and isolated, a fear of the disability being contagious or inherited, embarrassment, compassion and loneliness. Other issues I hear from siblings are that the parents love the disabled sibling more, seeing the sibling's disability as a stigma on themselves, and a desire to be "sick" themselves to get attention. (I asked Sarah if I missed any feelings and she said, "Sometimes you just feel downright miserable.")

There is frequently a mixture of all of these feelings, with some surfacing stronger at times. The strength of the feelings and how your child will overtly act or react is often age related.

Younger Children may be at risk because:

- They have a limited understanding of what is wrong.
- They are egocentric and wonder, Will I catch it? What will happen to me?
- They believe in magical thinking, i.e. It's all my fault because I said..., Did I cause it? Will God make it happen to me if I'm bad?
- Their parents are the most important people in their world, and their parents' attention is often diverted to the disabled child.
- In their great desire to please their parents, they may willingly take on too much responsibility.

Pre-teens and Early Teens are more focused on the following:

- They are much more aware of their siblings' differences and much less willing to be different themselves; thus they are more likely to be embarrassed or ashamed of how their disabled sibling looks or acts.
- They feel guilty for various reasons, e.g. because they are healthy and their sibling isn't; because they resent their sibling; because sometimes they wish their sibling was dead.

continued on the next page



Matt Heinemann, who has PWS (left), with his sister Sarah and her fiancé Chris

- They feel isolated, i.e. My parents don't understand me, my friends don't understand what I have to go through.
- They are acutely aware of their parents' double standard for their sibling on discipline, chores, achievements and tolerated behavior.
- They now may resent having to "take care of" their disabled sibling. I find that during this age period, they are the least sympathetic and understanding of their disabled sibling — but that's true in "normal" family situations also.

This is an all-too-long phase when you pray your kids will grow out of it before they kill each other! Even at this worst of ages though, siblings have a strong bond. The same 12-year-old brother — who, over a minor issue such as which TV program to watch, will shout, "I hate him, I wish he were dead!" — will also be the first to hotly defend his brother if a group of peers pick a fight or make fun of him.

Older Teens often begin to feel more comfortable with themselves and their situation, but a parent needs to be aware that:

- If the disabled sibling's problems cause too much home disruption and alienation from parents, this is the age when the sibling will "escape" by being away from home a lot.
- Or, it's an age when parents themselves see a way to escape and expect the teen to become overly responsible.
- Sometimes teens feel need to make up for their disabled sibling by being an overachiever.
- They may question more the justice of why God let this happen.
- They feel a need to protect their sibling from the world.
- They begin to become concerned about who will take care of their disabled sibling if something happens to their parents.

Avoiding guilt

I don't list all of the above issues to add *more* guilt to a population of parents who are already over burdened and guilt ridden. I only mention these potential problems to let parents know they are not alone and remind parents of the impact on siblings. As parents, we do the best we can, but often look back and feel that it wasn't good enough — that we made mistakes.

Some of the pitfalls we parents fall into are that we:

- Abdicate some of the parenting role to our healthy sibling. This may not be all bad as long as the burden is not on just one person. Spread the responsibility out. We don't have to apologize to our children for helping them turn into responsible, caring people. The problem comes when one sibling is taken advantage of. As overwhelmed parents, it is tempting to use the siblings to ease our own burdens.
- Say things we wish later we hadn't said because we knew they weren't helpful. What parents can honestly say they haven't made one of the following remarks: You should be thankful you don't have...! How would you feel if you had... Why can't you be more understanding of...? You shouldn't feel that way about....

Although it may be hard to believe at this point in your life, when it is all said and done and the siblings are grown, they will most likely become more loving, responsible and compassionate than the average adult.

- Give in frequently to our disabled child to avoid problems or to appease your guilt over the situation — and expect the siblings to give in also.

Forgiving ourselves

Besides forgiving ourselves for being human, and our siblings also, other steps we parents can take after realizing we have done or said something inappropriate are:

- Acknowledge to your child that you made a mistake
- Let your child vent his/her feelings and admit you also have some of the same feelings regarding your disabled child — or to the situation the disability creates, i.e. We don't hate Matt for the problems of living with locked cupboards and refrigerator, but we do hate the syndrome at times.
- Do some problem solving with your child regarding how you can both deal with the situation, i.e. We decided that although it wouldn't be fair to Matt to allow Sarah to eat in front of him, the compromise is to allow her to snack after he is in bed.
- Find some special time away from *all* your children, so you can come back feeling more refreshed and less sorry for yourself. Kids do not look kindly on parents who are martyrs.

Although it may be hard to believe at this point in your life, when it is all said and done and the siblings are grown, they will most likely become more loving, responsible and compassionate than the average adult. Although Sarah is still struggling with the ethical dilemmas of all 12-year-olds, I trust the day will come when she has the personal integrity and sensitivity that her grown brothers and sisters have.

Our healthy siblings' lives will be partly enriched and partly damaged by their situation. We can nurture the enriched part and minimize the damaged part by accepting them and ourselves with all of the normal faults and feelings that accompany the family of any child with a disability.

Candidates for the PWSA (USA)



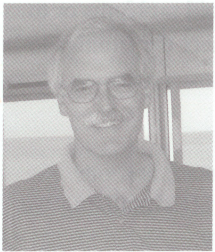
Lisa Graziano, M.A., MFT, Redondo Beach, California

It is no small undertaking to sit on PWSA's Board of Directors. Throughout the year I have been repeatedly impressed by the eternal dedication, unrelenting work, personal sacrifice and the overwhelming compassion and kindness I have witnessed each time I am anywhere in the presence of PWSA's staff, volunteers or Board members. Until my recent service on the Board, I had no idea of the enormity of PWSA's impact on the quality of life of individuals with Prader-Willi syndrome. Families across the world, much less in the United States, are far better off for the work of PWSA.

I am the mother of a 4-year-old son with PWS who has had the benefit of early intervention, and I am proud to say Cameron is doing magnificently, in every sense of the word. The reasons for his successes are multi-faceted, and he has benefited from opportunities united and organized as PWSA with the common goal to improve people's lives. All children with Prader-Willi syndrome must have access to the same opportunities – and more – that Cameron has had. This passion I bring to the Board.

I also bring to the Board my training as a licensed Marriage and Family Therapist. I currently serve as a PWSA Parent Mentor and am privileged to speak with and learn from families across the United States. I am also quite active in the PW California Foundation.

Should you choose to elect me I will be honored and dedicated to continue to serve you and your family.



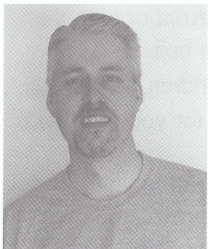
James G. Kane, Baltimore, Maryland

Jim Kane has been an active parent in various PWS causes for more than 10 years. Starting in the mid-1980s, Jim had positions in the national association including Treasurer, Board member and Chairman of the Board, and several committees.

Jim also was a founding member of the Maryland state chapter and currently serves as its vice-president. Jim's current passion is to organize the research efforts of PWSA (USA) to stimulate research into the many aspects of the syndrome, particularly the runaway appetite.

Jim's 21-year-old daughter, Kate, has PWS. Kate has graduated from Towson High School with her high school diploma and is currently living in a structured residential setting in Baltimore and looking for a good job.

Jim says, "As Kit and I look forward to the next chapter in Kate's life, we realize that we would not trade her for anything. She is a wonderfully sweet young lady whose talents are waiting to be tapped by the right situation. We've been through a lot and know we have a great challenge ahead of us and need all the help we can get."



Steve Lundh, Seattle, Washington

Steve & Susan Lundh are the parents of three sons. Their youngest, Peder (15), has Prader-Willi syndrome. Steve and Susan have both been active in the Northwest Chapter, and Steve was Chairman of the 1995 National PWSA Conference. He has served for the last 16 years as a leader in Boy Scouts and has worked with City Team Missions for the last 9 years.

Steve has been a member of the Board of Directors of PWSA (USA) for the last three years. He is co-chair of the Technology and Website committees, and he is currently on the Publications and Fundraising committees. Steve created and is Webmaster of the current IPWSO website, which is in the process of being translated into multiple languages.

As a gallery owner, Steve brings 30 years in sales, and more than 10 years of advertising and web design experience. Steve is looking forward to continuing his work on the board of directors for PWSA (USA).

2003 Board of Directions Election



Barbara McManus, Buffalo, New York

PWSA(USA) is "an Organization of Parents and Others...Who Are Making A Difference In the Lives of Those with Prader-Willi Syndrome," is the wording I added to the Prader-Willi Syndrome Association (USA)'s website. That is exactly how I feel. To make a real difference for our children, we need to pool our assets and talents for the betterment on all the people afflicted with PWS. When my granddaughter Jessika Dickinson was diagnosed in 1996 I had two choices, 1) feel angry and sad, or 2) do all I can to make her life better. My daughter Jeannie is a very good mother and doesn't have the time that I have to donate to the organization. I volunteered.

I am currently board member for the New York State Alliance of New York, the secretary to the board, assist the national office with their databases, including the conference database, initiated the eGroups for various age groups, monitor the eGroup for ages 6-12 years and work countless hours on the website.

Why do I want to become a board member? I believe that I can better assist all the members by being on the board as an elected member. I have a firm understanding of technology and its use for keeping all the members informed on the matters of this organization.

I own my own business, ProTech Computer Consultants, and work full time at the Multidisciplinary Center for Earthquake Engineering Research (MCEER) located at the State University in Buffalo, NY as a programmer/analysis. I am also on the Advisory Board of the Math and Science Department at Niagara County Community College and a member of the Zonta International Organization.



Mark Ryan, Newhall, California

Mark Ryan is President and owner Ryan Sales International (RSI), a worldwide aerospace marketing company, and Vertical Mind, a Web Design company.

Mark spent 4 years in the Air Force, earning his pilot's license in 1975. Mark and his wife Linda (who is vice president of Prader-Willi California Foundation) reside in Newhall, in Southern California. They have three children, Crystal (24), Danielle (21) and Trevor (13), who was diagnosed with PW at age 5.

Mark has supported the board during the last two years as Conference Committee Co-Chair. Mark will bring new and fresh ideas to the board from a business entrepreneurial view and marketing perspective. His hobbies include motorcycle riding, boating, computers and golf. He will be the Master of Ceremonies at the Orlando 2003 National Conference.



Mary K. Ziccardi, Cleveland, Ohio

Mary K. Ziccardi is completing her first term on the PWSA (USA) Board. She is currently employed at REM Consulting of Ohio, Inc. in Cleveland, Ohio, and has worked with people with developmental disabilities since 1985.

Over the past decade, Mary K. has worked extensively with people with Prader-Willi syndrome. She has developed and continues to provide oversight to four residential programs supporting people with PWS, as well as providing training and consultation services nationally.

While involved with the PWSA (USA) Board of Directors, Mary K. has co-chaired Provider's Day three times, including this year's conference in Orlando. She continues to be a resource to the national office staff for residential and vocational issues, and chairs the Crisis Intervention Committee.

Current areas of service, in addition to the upcoming Provider's Day, include assisting with the residential chapter of the third edition of the PWS Management book and coordinating the newly forming Advisory Board. The Advisory Board will create a forum for people with PWS to have representation of their interests and needs to both the Board of Directors and general membership in a coordinated manner.

In working with individuals with Prader-Willi syndrome, Mary K.'s motto continues to be "tomorrow's a new day!"

Prader-Willi Syndrome Association (USA) 2003 Official Proxy
Must be received at PWSA (USA) office by June 25, 2003

I hereby appoint _____ of _____ to
(print name of your designated proxy voter) (state of residence)

vote as my proxy at the PWSA (USA) Annual Membership Meeting in Orlando, Florida, July 2003.

Instructions to proxy voter:

☐ Please cast my vote as you see fit

OR

☐ Please cast my vote for the Board of Directors candidates I have marked below: (VOTE FOR 4)

I am a member in good standing of PWSA (USA)

Name _____
(please print)

Signature _____

Date _____

☐ Lisa Graziano

☐ Jim Kane

☐ Steve Lundh

☐ Barb McManus

☐ Mark Ryan

☐ Mary K. Ziccardi

☐

(This space provided for a write-in candidate)

Prader-Willi Syndrome Association (USA)
2003 Official Proxy for Second Family Member

This ballot to be used by
Family Memberships only

I hereby appoint _____ of _____ to
(print name of your designated proxy voter) (state of residence)

vote as my proxy at the PWSA (USA) Annual Membership Meeting in Orlando, Florida, July 2003.

Instructions to proxy voter:

☐ Please cast my vote as you see fit

OR

☐ Please cast my vote for the Board of Directors candidates I have marked below: (VOTE FOR 4)

I am a member in good standing of PWSA (USA)

Name _____
(please print)

Signature _____

Date _____

☐ Lisa Graziano

☐ Jim Kane

☐ Steve Lundh

☐ Barb McManus

☐ Mark Ryan

☐ Mary K. Ziccardi

☐

(This space provided for a write-in candidate)

Can Sneaking Ever Be a Good Thing?

By Vickie Fetsko

Absolutely! I surprised you with that answer didn't I? Let me explain how my family decided to look at the positive side of sneaking.

After school one day my 7-year-old Andy and 6-year-old Jon wanted a snack. It had been one of those days where I was constantly running behind. I told them to wait until I could get them something.

Well of course I forgot, and an hour later when I remembered I went to get some cookies and milk. I found the cookies open and several missing. Even though Jason (our child with Prader-Willi syndrome) was only 2½, I seem to be very aware of what food is opened and how much is left. I hit the roof, demanding, "Who was sneaking food?"

I went on to state that "sneaking is unacceptable in this house, especially sneaking food! Andy, I don't want you teaching Jason that sneaking is acceptable – it's not – ever!

Andy came to me and said, "I did it, but Mom you took so long, I thought I'd help and get it myself."

Then I asked myself, did I over-react just a bit?

After apologizing to my son for *my* behavior, I explained (not excused) my behavior to him, and why I was upset with the idea of sneaking.

I remembered a Rite Aid leaflet titled "Can Sneaking Ever Be a Good Thing?" There is a positive side to this word.



Jason, who has PWS, with big brother Andy

cleaning or behaving well or losing (even if just trying to lose but haven't yet) weight.

Do this with all your children, with your spouse, with your relatives and friends. Be creative and remember to be developmentally appropriate with your ideas. Make it simple.

Have fun as you figure out, "What can you sneak at your house?"

Vickie Fetsko and her family live in Grafton, Ohio. Husband Steve is president of the Ohio Chapter of PWSA (USA).

Dealing With Stealing: Make It A Sport?

Our son is 21 now and lives on a nice residence for special people. Yet he comes home at least once a week (well, Israel is a tiny country and it takes about an hour by train).

I must admit we didn't have much success with the money stealing problem that we confront like you. It is very much like the food stealing. Although we try to keep money out of his reach I still find some money in his things occasionally, or worse, the tracks of forbidden products that he had consumed.

What I did is to get in terms with *myself*, and stopped preaching him about the immorality of stealing, and how much it hurts us. It didn't work anyway.

So when ever I find money in his cupboard or pockets or anywhere (God knows where and when he found it), I just take it away without any fuss. He knows very well that he cannot complain, and I know that at least this time the money did not convert into calories.

The only question that we deal with is who is smarter and who is faster. Well, this can be some fun if you take it for a sport.

May you all have the strength and patience that it takes.

Urith Boger, from Israel

The Chuckle Corner

Our son Ian is 9 years old, and like many, his daily focus is breakfast, lunch and dinner. The other morning as we were getting ready for school, Ian asked what you got for breakfast in heaven.

I replied that you could have anything you wanted, that God provided for everything.

His next question was, "Does God fix our breakfast for us?"

Knowing my son, and that he lives for the day when he can fix his own meal without supervision, I answered, "No Ian, in heaven you get to fix your own breakfast and have whatever you like."

His eyes lit up like fireworks in the sky, and the next words out of his mouth were, "Yeah! And I'll bet they have a buffet too, huh Mom?!"

Jennifer Varner, Omaha, Nebraska



Please send your joke or funny story to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions.



Grandparents Needed

Grandparents, please consider attending and volunteering at the conference. We have many opportunities to volunteer at the registration desk, in the

Youth and Infant program or as a session facilitator. There will also be sessions for grandparents at the conference. For more information on volunteering, contact Kristin Gutierrez, PWSA Conference Planner at 407-688-0235 or pwsaconferenceplnr@hotmail.com

Registration

Please register as soon as possible. Online registration is available, with forms to be posted at www.pwsausa.org, so that you can register and pay by credit card from your computer. To have forms mailed or faxed, call PWSA (USA) at 800-926-4797.

Conference Grant Requests

Partial and full conference grants are available for a limited number of qualifying families. Please contact PWSA (USA) to obtain grant application. Call 800-926-4797.

Special Events

There will be a special banquet with entertainment for parents and a separate banquet for kids on Thursday, July 3. After the banquet, there will be dancing for all attendees. Tickets for the banquet are \$20 for adults and \$10 for children ages 6-17.

PWSA is pleased to offer a special July 4th event at Sea World to celebrate Independence Day! The event will include dinner, a Shamu show and fireworks. Special rate tickets that include both dinner and admission to all of the shows are \$50 for adults and \$27 for children ages 3-11 and including YAAP. Children under 3 are free.

The Sheraton World Resort (www.sheratonworld.com) is the headquarters hotel for the PWSA (USA) Conference. This recently renovated, year-round tropical style resort features three outdoor swimming pools, a fitness center and lighted tennis courts. PWSA (USA) has secured a block of rooms at the discounted rate of \$98 a night for up to four in a room.

To avoid any overcharge or problems with registrations, please make your reservations by contacting Globetrotter Travel at 800-322-7032 (press 2), or by e-mail to pwsa-usa@globetrottermgmt.com. Hotel reservations may also be made online by contacting www.globetrottermgmt.com/pwsa-usa.

All reservations require a credit card guarantee or a check deposit of the first night's room and tax. This deposit is non-refundable if canceled within 72 hours of the arrival date.

Tourist and Lodging Information

For more information on Orlando and all that it has to offer, log onto www.orlandoinfo.com (it has general information about Orlando and also talks about those with special needs) or try www.go2orlando.com. These web sites will have links to Disney World, Universal Orlando Sea World, and many other Orlando attractions.

Try www.disney.com, where you can order a free Walt Disney World® vacation planning video that will show you where to go, what to do, and how to stay right in the middle of the magic. Must be 18 years or older to order video, one per household. Offer expires 3/31/03.

Costs

Scientific Conference - \$125.00

The registration fee includes the Scientific Reception, daily lunches, and continental breakfast. Registrants may order the Gala Banquet on Thursday night and Sea World event on Friday for additional fees listed below.

Provider Conference- \$100 ~ Provider & General

Conference- \$250.00 ~ Provider & General Conference

(One-day Volunteer)- \$150.00 Professional Carers and Providers will have the option of registering for (i) the one-day program only, or (ii) the one-day program plus the General Conference. The One-day Program Registration Fee includes the Provider Reception (Tuesday night) as well as continental breakfast and luncheon on Wednesday. (For a listing of additional meals and events included in the One-day Program Plus General Conference Registration Fee, see the General Conference description below.)

General Conference- \$200.00 ~ General Conference (One-day Volunteer)- \$125.00

The registration fee for this program includes daily continental breakfasts and lunch on Thursday and Friday. Registrants may order the Gala Banquet (on Thursday night) for an additional fee listed below. Also, the event on July 4th at Sea World is an additional charge.

Youth and Adult Activities Program (YIP) age 0-2 - \$100.00 ~ age 3-5 - \$125.00 ~ YAP 6 and above - \$175.00

This recreation program for babies, children and adults who have Prader-Willi syndrome and their siblings is offered **only** during the General Conference sessions. All but the infant/toddler groups will visit one of the Orlando events as part of their program.

Additional Fees: Gala Banquet- \$20.00 Gala Banquet- PWS - \$10.00 Sea World Evening & Dinner - Adult \$50.00; Child & all YAAP \$27.00 (age 3 and under free).

Nancy Bowman

PWSA (USA) 2003 Conference Registrar

We look forward to seeing you at the 2003 Conference!

We Remember

How many hearts have had the healing balm of PWSA (USA) bereavement support? Thanks to our volunteer Bereavement Coordinator Norma Rupe, in 2002, 66 new families were supported with individualized booklets and calls, and all also received holiday packets. Norma spends a great deal of time looking for just the right poems and articles that will fit that particular parent and family before she creates their special booklet.

As an example of how much this program is needed and how much it means to our families, I would like to tell you about a call we received from a newly grieving mother, who said:

"I try not to show my pain and grief in front of my family. They tell me that my tears will upset others in the family and that I need to stop being so emotional."

"When I wonder what I can do to express my grief and sadness, I pick up my bereavement booklet from Norma, put my son's dog on a leash, get my stool and go to the cemetery. I sit there and read the poems and talk to my son. I can cry all I want and no one hears me but my son and his dog. My pain never leaves, but it becomes a little less hurtful."

Dear bereaved parents — **WE REMEMBER** — and our children with Prader-Willi live on in that shared memory. The following is a testimony to the lives of two of our members. We rejoice in who they were and the legacy they left — and if we could, we would sit by the grave and cry with you.

— **Janalee Heinemann, Executive Director**

Barbara Has Become a Real Angel



Barbara Harrison

My dear sweet sister, Barbara Ruth Harrison, died on January 23, 2003, at the age of 61. When Barbara was born, she was in a coma. The doctors told our mother that she would not survive, or if she did, she would have to be placed in an institution.

Were they ever proved wrong! With my mother's determination, Barbara not only survived, she thrived. However, PWS was yet to be identified in 1941 and it wasn't until many decades later that our family first heard about such a disorder. Somehow, it was a great relief to learn that Barbara's problems were shared by others and that, for a Prader-Willi person, she was normal.

Barbara was fortunate to have two healthy parents and four siblings to help care for her. She experienced all the usual PWS characteristics: mental retardation, constant food-seeking, poor muscle tone, short stature, small hands and feet, chronic bowel problems, obesity, skin-picking, obsessive-compulsive behavior, edema, rectal-digging, hypothermia and an absolute intolerance for being contradicted.

In later years, Barbara developed diabetes. After a short stint on insulin, we learned to manage it without medication by controlling her diet and being ever more vigilant in keeping food locked up.

Beginning about age 53, Barbara had to begin treatment for schizophrenia. Once the correct medication was found, that condition presented no further problems. Barbara had several mini-strokes (TIAs) and then, at age 57, she suffered a stroke that left her paralyzed on one side. She was never able to stand after that and was confined to a wheelchair.

In December of last year Barbara was diagnosed with metastasized ovarian cancer. It had spread throughout her body. She obviously had it for a long time prior to its discovery, yet the only symptoms up until then were headaches which became more and more frequent. They were not severe until the

very end. Barbara was able to attend an Adult Day Health program until one week before she died. She ate her last meal the day before she passed on, though she could barely speak, slept most of the time, and was very, very weak.

While this all sounds terrible, and intermittently it was, the majority of the time, life only got better. As she grew older, Barbara became very mellow and sweet. She was no longer argumentative or angry. She laughed frequently throughout the day, every day, and cheered up her caregivers. She listened to music, went to adult day-care, petted her pet rabbit, and played with her many games and toys. Barbara expressed interest and concern for the people around her. She continued to work jigsaw puzzles until the very end. Being in a wheelchair did not present a major problem because a hydraulic lift was used to move Barbara from bed to wheelchair.

When our parents became too old to care for Barbara, I took over her care. I was fortunate in finding an excellent adult family home for her. Over the years, the residents and caregivers there became Barbara's extended family. I lived close by and was involved in her day-to-day life. I supervised her care closely. Barbara and I had wonderful times together going to parks, picnics, movies, restaurants, the zoo, and on drives through the countryside to look for llama ranches and farm animals.

The night before she died I spoke to Barbara about what was happening to her. We talked about her going to heaven and named everyone we could think of who had gone before. I had trouble understanding her at times, but at other times, her voice was clear. At the end of our conversation she said she was "ready to go anytime."

By the next morning she was so weak she could no longer speak at all. She was not in any pain. She curled her little fingers around my hand. As she passed, the most remarkable thing happened: the lines fell away from her face and she looked like a young girl again. All the people who saw were stunned. She looked like the sweet angel that she was.

— **Jennifer Townsend, Seattle, Washington**

We Remember

Always in Love With Amy



Amy Nanzig

The back door banged open and five brothers scrambled through the back door and into the Nanzig kitchen, home from school for lunch.

"Hi, Mom. Is Amy in her crib?"

"Hi, Amy. It's 'Papa' Tom," cooed one brother.

The others took their turns, as well. Amy's daybed was a tiny, 6-month-size crib. She was a beautiful baby and each brother liked to see if he could amuse her. She almost always rewarded them with a smile.

Amy Elizabeth was born on October 4, 1964 in Grand Rapids, Michigan. Our family pediatrician had recently read an article describing Prader Willi syndrome in the *A.M.A. Journal*. Since Amy was observed to be a "floppy baby" and a poor suckler, she was immediately referred to Ford Children's Hospital in Detroit for an examination.

Yes, possibly it is Prader Willi syndrome, the Children's Hospital staff told us.

What should we do? "Take her home and love her" was the physician's recommendation.

Everyone did. Relatives, friends, doctors and nurses. Amy's father, an obstetrician-gynecologist, and her mother, a teacher, agreed that we must stimulate Amy as part of her development. Everybody encouraged and praised Amy's accomplishments as she grew up.

Amy became a good reader, speller, swimmer, angler and horseback rider. Amy's favorite mount, Phyllis, once threw her, resulting in a broken arm for Amy. Amy said that the horse had

apologized by nodding its head. When we asked Amy if she was a "horse whisperer," her eyes twinkled as she answered, "Maybe."

At Giggle and Grow, a day care center where Amy worked, supervisors told us that Amy was ever so gentle when she fed, rocked or read to the children in her care.

Amy was 4 feet, 8 inches tall and very soft spoken. She could also be feisty when she was irritated and, at those times, we had no trouble hearing her. The director of the group home in which Amy lived for some years explained to us that she often withheld money from Amy's check to reinforce some behaviors. It was also being put into Amy's bank account.

Some weeks later, Amy walked into the director's office with her check saying, "Well, here it is. You'll probably get it anyway!"

In later years a new supervisor at Amy's workplace wrote, "It was overwhelming for me to try to get to know the clients' habits. Amy made sure that I knew that Johnny needed his food cut up and that Sue was supposed to have her fluids thickened." The employee was amazed that Amy knew so much about the needs of her fellow workers.

And Amy's powers of logic were often shared with family and friends in humorous ways. Passing a Japanese restaurant, Amy asked her father why we never ate there. He answered, "Your mother doesn't really care for it."

Amy took a moment to count the cars in the restaurant's parking lot and remarked to no one in particular from her back seat position, "Well, they must be doing something right!"

Amy shared her moments of humor and frustration and love of life with us for 36 years. Some days were good, some days were, well, works in progress. In doing our best for our Amy, we trust we did something right.

Rose and Reinard Nanzig, Amy's parents, live in Grand Rapids, Michigan.

Running to Promote PWS Awareness Raised \$2,450

My friends Mary and Paul Hill gave birth to Oscar 2 years ago, and I suddenly became acquainted with the world of Prader-Willi. Mary and Paul have been tireless in their support of PWS organizations.

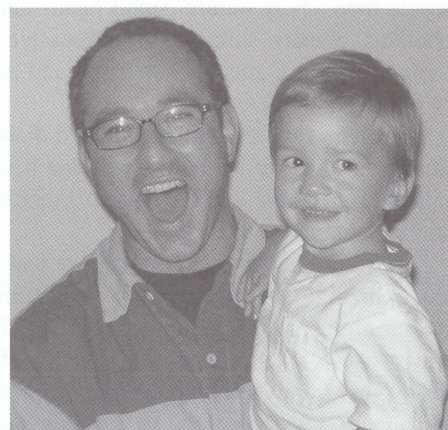
When I decided to run the NYC marathon, it seemed like a great opportunity to add to their efforts. I mailed out a letter to friends explaining Prader-Willi and the work that was being done by PWSA to promote awareness of PWS, support families and persons with the syndrome, and fund research.

The response was touching. More than 50 people contributed, and we raised \$2,450.

The marathon was my first, and I actually enjoyed myself. It's exhilarating to run through all five boroughs with throngs of people cheering you on. I recommend checking it out.

Thanks, also, to PWSA for creating an infrastructure and network to channel support for those fighting PWS. From what I hear, your existence makes a big difference to many people.

Marc Babsin, San Francisco, California



Marc and Oscar Hill, who has PWS

Would you like to raise funds for PWSA (USA)?
Call Diane at 1-800-926-4797 and ask for a free fund-raising packet.

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William - continued from page 1

William started attending Oakpark School and something amazing happened. His strut came back! He no longer had any accidents. Our Boy got his self-esteem back! He hated his school week to end, and all we heard each weekend was "Is it Monday yet?"

But this school wasn't for our son, or was it?

We found ourselves having to do some major soul searching. The question that kept haunting us was, did we want William mainstreamed because that's what's best for him or because that is what is best for us?

As each day passed and William would come through the door at the end of the school day, our answer became more and more clear. We met with the vice principal and asked him a series of questions about this, his "special" school. I cried. We believed that William would get everything he needed here.

At the end of the summer I called the school board and made all the arrangements needed to get William transferred.

For the first time in what seemed like forever, we feel good about sending William to school. He still gets O.T., P.T. and

speech and language therapy. But now he also gets aqua therapy as well as hippo therapy {for those of you like me — this is horseback riding}. His class has 7 children and 3 adults! What a GREAT ratio!

William is starting to read words and he wants to know how to spell everything so he can write words down. He brings home things he made in woodworking class. He loves his new school and each of his teachers. When we visit the campus we hear about his fan club from everyone we pass. Staff and other students alike slap him five or give him a hug. Again, there are no strangers to our William.

We remember our summer meeting with the vice principal, who told us that if William started there he would remain there. "We wouldn't want him anywhere else," he said. As of today, we believe he could be right!

Faith and William Weaver live with their children in Sarasota, Florida. Their son William has PWS.

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October 2002-January 2003

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Prader-Willi syndrome (PWS) is a birth defect first 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. The Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions.

