



March-April 2004
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The *Gathered View*

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

2004 PWS
Awareness Week
April 24 - May 1



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Five Years Ago Today...

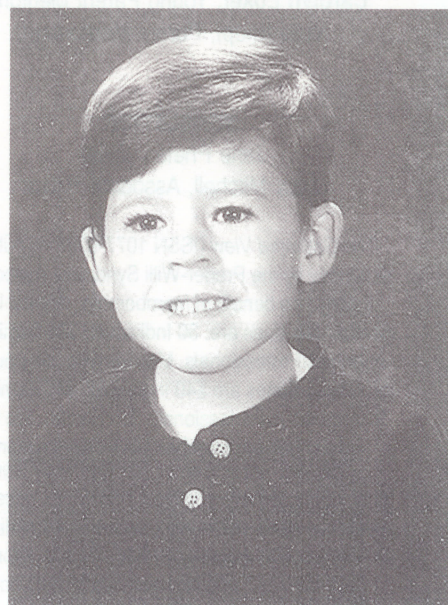
By Lisa Graziano

Five years ago today – January 21, 1999. I am lying on a recovery table after giving birth to my beautiful baby boy. He is just moments old and already I am so in love with him. I try to pull down the blanket he is wrapped so tightly in while still laying as prone as the nurse has advised me so that I don't become sick from the medication used during the emergency C-section. It is about 20 hours later that we have our first indication that something is wrong. The physician is worried that he is too lethargic, too sleepy, too weak to nurse. My husband and I hold on strongly to our belief that he just needs time to recover from his traumatic birth. Hours pass into days. It becomes clear our little boy is seriously ill. We begin the process of testing to determine the cause of his illness. We have begun our descent into hell.

Five years ago today. My memory flashes to various scenes with precision-sharp clarity. I ache to hold my baby in my arms. Just my baby, without all the tubes and wires attached to his little body. I remember the cruel irony of the mother next door who refuses to hold or nurse her baby. From another room comes constant laughter and new bursts of celebration with each new delivery of blue balloons. For me, there was nothing but unrelenting fear that my son would die and there was nothing that I or anyone else could do to save him.

Getting the diagnosis of Prader-Willi syndrome was for me almost a relief. For two weeks I believed my son would die – now I was being told that his death wasn't imminent, that there was hope. We were read a summary of PWS and the seemingly endless list of symptoms from pages photocopied from a book. I remember holding my husband's hand under the big conference room table, across from the social worker who looked pitifully at us as the physician read on and on and on. We nodded our heads that we understood. We didn't understand. We were numb and exhausted. We took our son home the next day, 13 days after his birth.

I savored the moments of normalcy being home with our baby, holding him in my arms, without all the wires and tubes, changing his diapers, dealing with the sleepless nights all new parents experience. I focused on all the wonderful parts of having a new baby, and there were so, so many. I tried to give myself permission to feel the overwhelming sad and terrified feelings that washed up — constantly. I reminded myself that my grief was normal and that the intensity of my feelings would pass. Three years later, I hid my nightly tears from my husband. How could I possibly explain the paradox of holding such hope for our son on the one hand while feeling intense fear for his future on the other?



Cameron Graziano, age 5,
who has PWS

Five Years continued on page 12

Prader-Willi Syndrome Association (USA)

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Our Mission: Through the teamwork of families and professionals, PWSA (USA) will improve and enhance the lives of everyone impacted with Prader-Willi syndrome (PWS) and related conditions.

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Report from the Board of Directors Meeting

Lota Mitchell

It was "that time" again, when a small army of the Board of Directors and officers of PWSA(USA) invade Sarasota for almost three full days of intense committee and board meetings to work on the business of PWSA(USA) — and maybe soak up some badly needed sun. "That time" came at the end of a frightfully frigid January for many of us. Although the first few days were overcast and rainy, nary a complaint was heard.

A week's worth of work lay ahead to be accomplished in those few days. On Friday the first committee meeting began at 9:00 a.m., and the last one ended at 10:30 p.m. Long day! We did get a dinner break for a buffet reception for all, including office staff, volunteers, spouses, a preschooler, a toddler, and a 5-month-old baby — a microcosm of the PW family.

While buckets of rain poured down outside, the board met all day Saturday. On Sunday we met most of the day; by afternoon the sun burst forth in all its glory. Ah, now we knew we were in Florida!

A major priority was Finance. While the bank accounts may look good at first glance, much of the money is in designated funds which can only be used for a particular purpose. Again in 2003 PWSA(USA) had an operating funds deficit. This must, underline "must," be corrected for us to survive over time. Two part-time development professionals have been hired. Francine Diemer is community development director and will help groups and individuals put on bake sales, walk-a-thons, etc. Mark "I-don't-do-cupcakes" Camille is corporate and government development director. He has laid out an ambitious program, but he needs the support of our members to supply him with more contacts. If you know people in key positions, please contact him at the national office.

The board voted to accept the challenge of an anonymous donor to support research, for the data base position. The donor will match, up to a total of \$25,000, all funds contributed by present and former board members and officers who contribute money in calendar year 2004, as long as 100 percent of all current board members contribute to the research fund for matching the NIH grant.

Another major priority was Research Advocacy. Jim Kane, past director and board chair, heads what he calls the RAT Pack. Its purpose is to stimulate research into PWS and help set priorities and direction of that research. PWSA(USA) voted to join the Coalition for Children's Health, which was formed to support Congressional interest in enacting comprehensive children's health legislation.

The Board reviewed the Strategic Plan for 2002-2006, approved the 2004 budget, and received reports from

1) Director Barb McManus, working with Janalee and Michelle Leightman on a new Teacher Mentoring Program; 2) Director/V.P. Carolyn Loker, whose Parenting Mentoring Program has served 410 families thus far; and 3) Crisis Counselor David Wyatt, that his crisis cases increased from 352 in 2002 to 496 in 2003. Publications showed off the new booklet, "Michael and Maria," beautifully done and useful for any teacher who has a child with PWS in her class to help classmates understand.

Also visited were plans for Conference 2004 in Ohio. Important! While child care is provided only up to age 9, programming is for parents of those with PWS of all ages, including adults. How can we emphasize that enough!

All that is the tip of the iceberg. We've all returned home with a long list of "action items" to be addressed before the next board meeting at conference. How fortunate PWSA(USA) is to have this group of people who dedicate their time and talents to getting it all done!

Chapter View

Sybil Cohen is the new **president of the New Jersey Chapter**. (Doug Taylor, past president, is now serving as executive director.) Sybil is the mother of Julia, 9, whom she and her husband adopted from China when she was nine months old, and Rose, 8, who has PWS and was born, severely hypotonic, three months after Julia's arrival in the family. Sybil teaches art in middle school, and husband Mike Burns (she kept her maiden name) teaches high school history. Before teaching, she was a freelance artist and jewelry designer. She is a parent mentor, involved in dragon boating (huh?), and on the Statewide Parent Advocacy Network. Rose is on swim team, doing well in regular classroom in second grade, a great reader but poor in math — and she loves exercise!

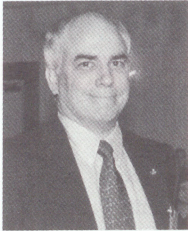
PWSA(USA) Chapters

Drum roll for our **15 Chapters and 3 Affiliates on Good Standing** who sent in all their required documentation by the deadline! Another 13 are still in the process of doing so.

**Arizona * California * Colorado * Connecticut
DC/MD/VA * Florida * Georgia * Michigan
Minnesota * New Jersey * Northwest * Ohio
Ohio Families * Oklahoma * Pennsylvania
Tennessee * Utah * Wisconsin**

PWSA(USA) Board of Directors Candidates (4 openings)

2 Current Board Members



Driscoll

Daniel J. Driscoll, M.D., Ph.D., Gainesville, Florida — Dr. Driscoll is a professor of pediatrics and genetics at the University of Fla.College of Medicine. He received his human cytogenetics training while pursuing his doctoral dissertation at Indiana University. He went to medical school at Albany Medical College. His pediatric residency and medical genetics fellowship were at the Johns Hopkins Hospital, Baltimore, Md., where he also received his training in molecular biology, particularly DNA methylation. He's had a long-standing interest in PWS and the phenomenon of genomic imprinting. His laboratory has made several important contributions to the field, including being the first (in collaboration with Dr. Robert Nicholls' laboratory) to propose and use DNA methylation analysis to diagnose the Angelman and Prader-Willi syndromes. His clinic closely follows more than 150 people with PWS from all of Florida and southern Georgia. He is board certified in Pediatrics; Clinical Genetics; Molecular Genetics; and Cytogenetics. He has served PWSA (USA) in a number of capacities including the Board of Directors, Clinical Advisory Board Chair, 2003 PWSA (USA) Scientific Conference Chair, and also serves on the IPWSO Medical and Scientific Advisory Board.



Lutz

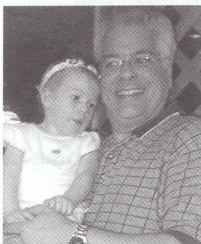
Robert Lutz, Bryn Mawr, Pennsylvania — The Lutzes' first child — Isabel — was diagnosed with PWS (Uniparental Disomy) 4 years ago at 5 months. She has a younger sister now, Natalie, age 15 months. "My family has benefited greatly from the PWSA(USA) since we first learned of Isabel's condition," he writes. "Attending conferences, reading PWSA materials, and connecting with other PWS parents has made a huge difference in our ability to understand the challenges we face and to give Isabel the best start possible... I came to deeply appreciate and respect the mission of PWSA(USA), and I would like to continue to contribute to that mission by remaining on the Board of Directors." For his past 3 years on the PWSA(USA) Board, he has chaired the Finance/Investment Committee and the newly reconstituted Fund Development Committee. He has an MBA and 10 years of finance experience in the energy/banking/and insurance industries. "I am hopeful that with sufficient financial resources and management of those resources, my daughter and every child/adult with PWS can achieve greater long-term happiness and independence than we can imagine today. If re-elected I would work diligently...and represent the interests of PWS families."

3 Prospective Board Candidates



Armento

Donald Armento, M.D., Huntington Valley, Pennsylvania — Dr. Armento is a retired urologist who was in private practice for 37 years in Philadelphia. College and medical school included Georgetown University, internship at Cleveland Clinic and residency at Henry Ford Hospital in Detroit. Previous board experience includes Holy Redeemer Hospital while president of the medical staff. He writes, "My 11th grandchild, Brooke (now 4), was diagnosed early as a "floppy child" and then with PWS.... Brooke is a very special angel from God, and I want to help her and her parents. Supporting them and the PWSA(USA) mission would fulfill those goals." He will attend the 2004 Conference in Ohio this June. He, Brooke and her mom attended the Orlando, Florida conference and experienced the PWS mission. He believes his medical education and experience will help to make significant contributions toward fund-raising and medical research for PWS.



Leightman

Stephen Leightman, Chery Hill, New Jersey — "In June of 2002, my life changed," writes Stephen Leightman. "Already the grandparent of one beautiful little girl, another child came into our family. To our surprise, she was admitted to the hospital and was diagnosed with Prader-Willi...." The Leightman family called PWSA(USA) for information. "I owe PWSA(USA) a great personal debt, and I hope to bring to the Board my dedication and skills so that I can make sure that others will always have support, information and research that has characterized this organization." His professional background includes an 8- year career in a private high school (4 as headmaster) and 27 years in the financial industry. Currently he is a vice president at PNC Investments, specializing in financial planning. He is in New Jersey Lions, the Philadelphia Estate Planning Council, and has been a member of the Endowment Committee of PWSA(USA). His wife Michele is also involved in the PWSA's efforts for grandparents' involvement and in training educators in the issues faced by children with PWS.



Heybach

John Heybach, Ph.D., Chicago, Illinois — Dr. John Heybach owns Bold Business Graphics & Systems, Inc. in Chicago. He earned an MBA from Kellogg Graduate School of Business at Northwestern University and a Ph.D. in Neuroscience, and did research and published in Behavioral Neuroscience and Endocrinology, often involving the regulation of food intake and body weight. He served on the Board of Managers for Marshall Square Boys & Girls Club in Chicago and is currently on the board of the Illinois Chapter of the Patrons of Arts in Vatican Museums. He and his wife Sue, an elementary special ed teacher, have been married for 33 years. Son Conor, 23, was diagnosed with PWS at age 15 (classic deletion, maybe Type II). Conor is currently living at home and is a junior

Heybach continued on page 12

Prader-Willi Syndrome Association (USA) 2004 Official Proxy
Must be received at PWSA (USA) office by June 21, 2004

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 Huron, Ohio, July 2004.

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 _____

- ☐ Don Armento
- ☐ Daniel Driscoll*
- ☐ John Heybach
- ☐ Stephen Leightman
- ☐ Rob Lutz*

☐ _____
(This space provided for a write-in candidate)

* Currently serving on the Board

Prader-Willi Syndrome Association (USA)
2004 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 Huron, Ohio, July 2004.

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 _____

- ☐ Don Armento
- ☐ Daniel Driscoll*
- ☐ John Heybach
- ☐ Stephen Leightman
- ☐ Rob Lutz*

☐ _____
(This space provided for a write-in candidate)

* Currently serving on the Board

West Meets East — PWS in Taiwan

By Janalee Heinemann, Executive Director
and Pam Eisen, IPWSO Parent Delegate for PWSA(USA)

On our way to Taiwan, we debated what we would do if no one met us at the airport, since we only knew one person in all of Taiwan, Dr. Shuan-Pei Lin, from Mackay Memorial Hospital. We laughed a little nervously about the reality that we were going to be further away than we have ever been from home, in a strange country, with only one contact.

We soon found out that we had nothing to be nervous about. We were met by not only Dr. Lin, but also his wife Grace, and Serena from the Taiwan Foundation for Rare Disorders. After that, we never ceased to be amazed at the time and effort all put into our visit to make us feel welcomed and comfortable.

Returning from Taiwan, Pam and I reflected that thanks to our work with Prader-Willi syndrome, we have met wonderful people from all over the world. But all of the people we met in Taiwan were special, not only the parents, but everyone — from professionals involved with the syndrome, superintendents at hospitals where we spoke, people who hosted the trip from the Taiwan Foundation For Rare Disorders (TFRD), to all the staff at hotels, and even strangers in the streets. Their warmth, graciousness, gentleness, and strong ethic of helping others shone in every person we met. Across Taiwan, we not only met with the heads of the four hospitals, but were given a gift by each. In fact, gifts were given, business cards shared and pictures were taken everywhere we went.

At the top of the list of caring and graciousness were Dr. Lin and Grace (her Americanized name). Although he is a busy and well-respected director of the Division of Genetics, and director of the Board for TFRD, Dr. Lin spent

We were very impressed by the leading role physicians played in seeing that families dealing with PWS had their treatment, educational and social needs met.... there is no doubt in our minds that Taiwan will be the leader in the Asian world regarding PWS.

most of the week taking us to hospitals to meet and speak to parents and medical staff in Taipei, Kaohsiung and Tainan. He also made sure we were able to see many wonderful sights and taste the delightful and varied cuisine of Taiwan. When he wasn't with us, Grace was. And someone from the staff at TFRD was there to guide and help us from morning until late at night. We've never been so spoiled!

PWS is PWS all around the world. The charming and lovable children with keen eyesight and quick hands for food may have different-shaped eyes and different-colored skin, but their personalities and stories easily connect us across the universe.



Janalee Heinemann and
Pam Eisen are welcomed
by the gracious people of Taiwan

We were impressed by the physicians' knowledge and their commitment to improving the quality of life for their patients and families, not only on a medical level, but a social level. They are advanced as to early diagnosis, but we could help them with PWSA(USA) educational materials and knowledge about growth hormone. We are willing and delighted to share our written materials, and articles we had already sent via e-mail had been translated in Chinese for the meetings at which we spoke.

It was exciting to see the follow-up articles from our presentations in four newspapers — not that we could read a word! Most exciting was that partially thanks to our visit, Serena Wu was motivated to secure an appointment to discuss approval for payment for growth hormone for children with PWS with Chen-hua Lee, M.D., vice president

and CIO of the Bureau of National Health Insurance for all of Taiwan. We attended this important meeting, and joining forces with us were three key

physicians, Serena, Welly Chan, Taiwan's IPWSO parent delegate, and his wife. We presented articles and before-and-after growth-hormone pictures. By the end of the meeting, Dr. Lee committed to presenting and doing all he could to support this cause to legislatures if Dr. Shaun Pei Lin got a consensus guideline statement in the next 10 days. The Taiwan PWS Association is fortunate that their national president is a parent who is a legislator with the People First party, Huei-Chu Chin.

Although we can offer a lot to other countries, we receive a lot from them. In Taiwan, we were fortunate to see

Taiwan continued on page 12

Effectiveness of Wellbutrin/Bupropion with PWS

QUESTION:

PWSA (USA) parent members from Canada wrote — A boy's doctor (of a family they knew) had prescribed Bupropion, and it soon worked like a miracle. The boy has lost a lot of his excess weight and no longer forages for food. Dr. ___ was impressed and wished to spread the word. Until now we have not heard of Bupropion. Our family doctor is hesitant to try it without knowing more. Has anyone there had experiences with Bupropion? Is there any further information available?

RESPONSES FROM OUR MEDICAL BOARDS:

Here at The Children's Institute, we have discharged selected patients using Wellbutrin. It is an effective antidepressant and is not thought to activate mood as do the SSRIs. It has some ADHD application as well. It does lower seizure threshold and can have liver toxicity.

Since our patients were already under the type of behavioral management and restrictions that would minimize food-seeking behavior or weight gain, we do not have an opinion on that issue.

Linda M. Gourash, M.D.

Bupropion is Wellbutrin. It's a well known antidepressant, and is also used to fight addictions, such as smoking (under the name Zyban). People do lose weight on it but I have never heard of someone losing a huge amount. The biggest side effect difficulty is irritability and jitteriness, which could be a problem with PWS.

Ivy Boyle, M.D.

Like most meds, it works for some people extremely well, for others it helps some, and for others it doesn't seem to be very effective. At least that's my experience.

Suzanne Cassidy, M.D.

We have not seen any better or worse effects than with Prozac, Zoloft, etc. It can elevate blood pressure in some people. It is worth a try, but sometimes it is just the changing of the medication that helps enforce structure, etc. We have seen that changing a medication can be helpful if a patient seems to have adapted and that the intrusive behaviors have reappeared.

Bryan Hainline, M.D.

My experience is much like the others. Wellbutrin is helpful to some patients and not to others. Although I have not looked at it specifically, I have the feeling that it has been most helpful in that group of patients who have some symptoms of psychosis. I continue to feel that the SSRIs are the most helpful to the most patients.

Jeanne Hanchett, M.D.

A number of my patients have been put on Wellbutrin by the psychiatrist and it seems to have benefited them, but for others it was of no benefit.

Dan Driscoll, M.D.

Yes, Bupropion is Wellbutrin. It's very commonly used here for ADHD therapy, although I am unable to find any effectiveness data. The medication is approved for treatment of depression. Interestingly, eating disorders (anorexia nervosa and bulimia) are contraindications to its use.

I have seen a few non-PWS kids with growth retardation who were on Wellbutrin, raising the possibility that it may have some similarities to the growth-retarding effects of Ritalin. For Ritalin, one theory has been that the linear growth deceleration is due to decreased appetite. However, most of the affected kids are normal weight, in my experience. It appears that Ritalin may also have direct effects on the GH/IGF system in some individuals.

I have not seen any PWS patients on Wellbutrin... however, I suspect that it will be as Dr. Cassidy suggested... effective for some, but not others.

Phillip Lee, M.D.

I would be glad to add my 2 cents, but my thoughts are already well reflected in the comments from my fine colleagues! We actually had relatively few people on it, and a variable response at best, with better luck with the SSRIs.

Elisabeth M. Dykens, Ph.D.

PWSA(USA) 2004 Annual Conference

June 30 - July 2

The Lodge At Sawmill Creek Resort
Huron, Ohio

**For the latest information and
a Registration Packet**

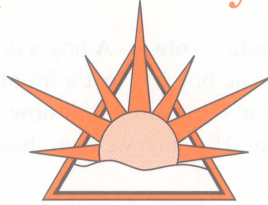
Check our web site: www.pwsausa.org

or call PWSA(USA)
1-800-926-4797

Registration packet online!

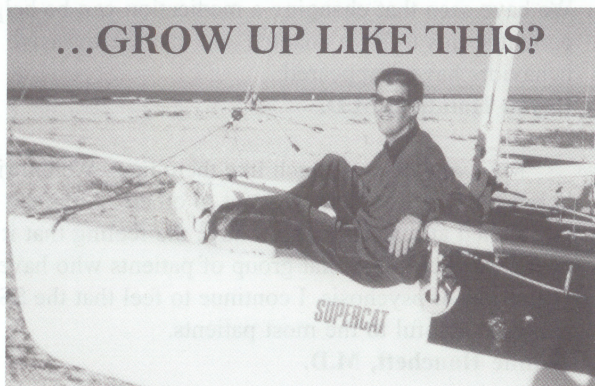
PWSA (USA) 2004 National Awareness Week

April 24 - May 1



Help Us To Shine The Light On Prader-Willi Syndrome

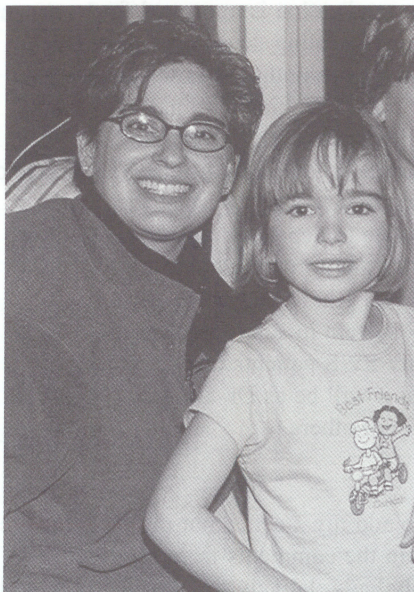
Will our children with Prader-Willi syndrome...



***YOU* Can Make The Difference**

Awareness ⇒ early diagnosis ⇒ intervention ⇒ education

= the keys to a happier, healthier life with PWS



They're Counting on You to Help!

HOW CAN YOU HELP?



Participate in PWSA (USA) National Awareness Week - April 24 - May 1

PWSA (USA) has made great progress in generating awareness by increasing early diagnosis from 20 to 50% in the last two years, but children with PWS are still dying from obesity-related causes. Prader-Willi syndrome is the most commonly known genetic cause of life-threatening obesity in children, and PWSA (USA) National Awareness Week is an opportunity for you to increase awareness in your community. Contact PWSA (USA) for a packet of flyers that can be copied and distributed for your theme day(s):

- Saturday, April 24 — **Exercise Awareness Day** – host a walk-a-thon, golf tournament, bowl-a-thon, work out day, etc.
- Sunday, April 25 — **PWS Outreach To Faith-Based Groups** – talks at places of worship, prayer vigils, a day of reflection for PWS. Hand out flyers (the day of this event would depend on your faith, e.g. Would be more appropriate on a Saturday for temple.)
- Monday, April 26 — **PWS Focus On Education** – projects that are aimed at both school students and teaching staff.
- Tuesday, April 27 — **Media Outreach Day** – activities that target local, state and national media to gain exposure about PWS. Media distribution information will be available. We need to get the word out that PWS is the window of opportunity to finding the cure for obesity.
- Wednesday, April 28 — **Health-Industry Outreach Day** – projects aimed at raising awareness of PWS in the medical and health-related professions.
- Thursday, April 29 — **Advocacy Day** – spend the day spreading the word about PWS to local, state and national governments and agencies.
- Friday, April 30 – **No Cookie — Cookie Sale Day** – have a table at your local stores or go door-to-door with your children to sell our delightful novelty box that will have items of value and information on PWS inside, but no cookies. It's a great way to involve your child. No Cookie Cookies include:
 - ♦ Chocolate Chipless ♦ Pretend Peanut Butter
 - ♦ Very Thin Mint ♦ Fantasy Fudge ♦ Weightless Wafers
- Saturday, May 1 — a second chance to host an **Exercise Awareness Day**

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Making Allies of Your Neighborhood Police Officers

By Tammie Penta

I was asked to write about something that we as families with Prader-Willi syndrome think about, but don't necessarily like to talk about: police involvement with your family.

I have been a police officer for the City of Tucson, Arizona for more than 15 years and have been the child abuse sergeant for more than 4 years. Most importantly, I

am a proud parent of a beautiful 10-year-old son, Victor, who has Prader-Willi syndrome, as well as mom to his brother Nick, who's 13, and sister Raquel, who's 8. In addition to being a mom, playing cop, and trying to be a good wife, I'm also current president of the Prader-Willi Syndrome Arizona Association.



Police Sergeant Tammie Penta with her son Victor, age 10, who has PWS.

Many years ago, before I knew what PWS meant, I was a young patrol cop working on Tucson's East Side. Periodically I would go to group homes with adults with disabilities. On one occasion I had the pleasure of meeting a young woman named Sunny. The staff had called me because she was "out of control." When I arrived, this beautiful young woman was sweet as pie and I thought the staff were out of their minds. I triaged the situation and walked away thinking the staff just didn't know how to deal Sunny. Yes, they told me she was manipulative. Sure they said she could go from sweet to not so sweet instantly, but I wouldn't have believed it. So this young officer left, never giving it a second thought.

About a week later, I received another call to this same residence. In my mind it was going to be the same scenario. Boy, was I wrong. When I arrived at the home, Sunny was out of control and was assaulting the staff. Doing what any police officers would do, my backup and I immediately went to control the situation by placing handcuffs on her. After a short struggle the worst was over, and I got a new-found appreciation for how strong someone who was less than 5 feet tall really was. Over the next several years I came to know and understand Sunny and PWS. Little did I know that 5 years later I would have a little angel born with PWS.

Why do I tell you this? Because no one wants to see the police come in and "handle" any situation involving any of their children. Unfortunately for people with PWS or any

disability, it is happening more often. Also, across the country there has been an upward swing of officer-involved shootings with mentally disabled adults. This cuts to the very core of the fear any parent has with a child with a disability who has a propensity for outbursts as a result of that disability. For me it's a double-edged sword, as I have had to respond to these very calls and make split-second decisions based on very little information. As a result, my agency, along with several others around the U.S., has mandated training for officers on how to handle cases involving disabled individuals.

In Tucson we have a program that allows officers to take a 40-hour course sponsored by both police and the Department of Developmental Disabilities. Together we train police what to look for and how to handle these situations. Beat officers then go back to their area as liaison for group homes in their sector. They learn who is in the homes and what their disabilities are. In fact, some officers have become so attached to some of the folks that they're on a first-name basis and go to lunch together occasionally. The officers and the community have embraced this program, which would not work without that participation.

Throughout the U.S., we are realizing the need to train officers how to respond to people who have special needs. Whether or not your community has a program like ours does not prevent you as a parent or caregiver from getting to know your neighborhood police officer.

Here are a few simple things that could make your life, the officer's life and most importantly, the person with Prader-Willi syndrome's life much easier in the event that those paths must cross.

- Find out what police agency is responsible for where you live. This is very important for jurisdictional reasons.
- Ask to set up a meeting with the beat officer or officers who patrol your area.
- If there is no beat officer, ask for a meeting with the division commander and ask if you could come into the patrol briefing to conduct a mini-training on PWS to include the dynamics of your child or adult with PWS. (They may run away, often call 911, etc.)

Contact the training academy and ask if there is a program like ours in Tucson. If there is and PWS is not a part of it, ask to be included as a guest speaker at training.

I have always found both as a parent and a law enforcement officer that if I had a personal connection with someone with whom I was in contact, we both felt more comfortable with each other. Police officers respond to numerous calls for service, solving multiple problems continuously throughout the day. If you can get to know the officer who would respond to your home, that officer will respond to the personal connection, making the situation less difficult for all involved.

The Sibling View

Special Sibling Says 'Volunteer for Special Olympics'

By Diane Spencer

Most of you have no doubt heard of Special Olympics; however, you may not know some of the details. Special Olympics, Inc. is an international organization that gives people of all ages with mental disabilities the chance to compete in many different sports at their own level. Athletes can begin training at any age, but they must be 8 years of age to compete in official competitions. The group depends on volunteers of all ages to support numerous sporting events, acting as coaches, scorekeeping, and teaching arts and crafts during free time, or just hugging a nervous athlete. This is where volunteer Kristin Lee Hamerski of Anchorage, Alaska comes in....

In March of 2001, Anchorage Alaska hosted the 2001 Special Olympics. More than 2,400 athletes from 69 countries competed for nearly 1,900 medals. They were greeted by capacity crowds and supported by more than 6,000 volunteers. Kristin worried about being able to communicate with so many different languages being spoken, but of all the lessons she learned at this marvelous event, the most important discovery was that "we all speak with the same smile."

At 18, Kristin is no stranger to volunteering, or to winning awards. She coached her little brother Erik in the 2001 Special Olympics Alaska figure skating competition, and Erik, age 8, won a gold medal! But this young man with PWS didn't come just to get a medal; he wanted to show the world that he could perform with excellence. Kristin says that winning isn't always walking away with a prize, true winning goes much deeper. Helping people to find the greatness in themselves is the greatest award of all.

Kristin is 2003 Miss Alaska Teen and a three-time Grand Champion winner in the Alaska State Fair. She has taken first place in the State Science Fair and is a National and Grand National award winner for National Junior Horticultural Association. She has received the Spirit of Youth Award for Participation in Business & Government and has won many awards in the areas of sports, dog showing, volunteering, citizenship, and the list goes on. She is also the owner/founder of her own company dedicated to helping people with need in the community.

Kristin urges all teens to get involved with Special Olympics. The Summer Games and Winter Games are held every 4 years, one in succession of the other, 2 years apart. To find out more about programs in your geographical location, go to www.specialolympics.org.

Diane Spencer is support coordinator at the PWSA (USA) national office in Sarasota.

We welcome writings from siblings and family members for *The Sibling View*: good experiences, bad experiences, we want to hear what you think. They can be signed or anonymous, whichever you prefer. Send them to the PWSA(USA) national office, Attention Lota Mitchell, Associate Editor, or e-mail to her at ljecholsm@juno.com.

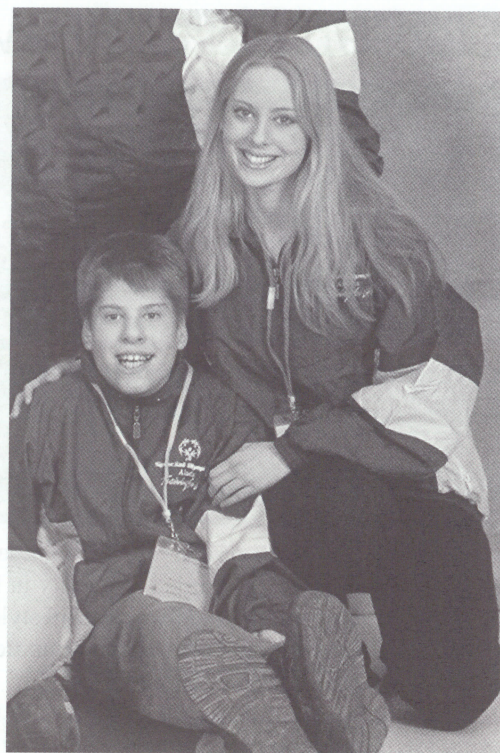


Photo by Digi-Pics
Kristin Lee Hamerski, Miss Teen Alaska
with her brother Erik,
who has PWS.

The Chuckle Corner

Saturday morning Ericka and Will woke early and were naturally fighting over which TV station they were going to watch. Sponge Bob over who knows what other cartoon?

Thinking I was going to allow myself some more much needed sleep-in time... I called Little Will into my room to lay with me and allowed him to watch TV as long as he kept it low. He insisted we turn to channel 3-7. I had no idea what cartoon I was about to watch.

To my BIG surprise, he didn't want to watch any cartoon, he wanted to watch the Food Network! I don't know how he found this even existed. Soon announced was that next would be "Cooking with Emeril Lagasse."

Will's eyes got REAL big as he said to me, "He is a really, really cool guy!" I watched Will totally mesmerized as Emeril made pasta dishes.

Only in our PWS world would a 7-year-old pick Emeril over Sponge Bob. I had to laugh... or maybe I would cry.

Faith Weaver, Sarasota, Florida



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.

Step Up Florida! travels across state with a message



Members of the PWSA(USA) national office are ready to participate in the Siesta Key "leg" of the state-wide public health walk, Step Up Florida. From L-R: Janalee Heinemann, David Wyatt, Diane Spencer, Debbie O'Neal, Mark Camille, and Gilda and Eric Hilton.

Photo by Eric Michael Hilton

Step Up Florida! a program of the Florida Department of Health, focuses on the burden of obesity in Florida by promoting a healthy and physically active lifestyle and awareness of the many physical activity opportunities available to citizens and visitors throughout Florida.

County by county, from the Florida Keys to the state capitol in Tallahassee, the flag was carried by runners, walkers, cyclists and kayakers, arriving on Siesta Key at

1 p.m. on February 9. The PWSA(USA) national office staff joined the cyclists and escorted the flag through Siesta Key. It was a sunny day and it was great fun to have Florida State Police escort us along our two-lane roads. The Step Up Florida events will end March 2 in Tallahassee. We arrived back at the office (without the escort) slightly sweaty and wobbly-kneed, but well-satisfied with our participation and with creating additional awareness for PWS.

— **Diane Spencer, Support Coordinator**

Taiwan - continued from page 6

and admire the fortitude of two wonderful people who, due to their own children with rare disorders, began TRDF: Serena and Min-Chieh Tseng, Ph.D. In five years, they founded and built this national organization to a staff of 18 serving rare disorders. Although we have wonderfully committed physicians on our two medical boards here in the U.S., in Taiwan, we were also very impressed by the leading role physicians played in seeing that families dealing with PWS had their treatment, educational and social needs met. Although they are at the beginning of the learning curve in some areas, we do not doubt that Taiwan will be the leader in the Asian world regarding PWS.

Taiwan's accomplishments seem to far exceed its physical size. They are a warm, generous people, steeped in tradition and strong values. Although the parents appeared to be shy, these are people who listen carefully. Now that they will have our shared material, we believe they will quickly adapt our experiences to their culture. Even though we saw (and enjoyed) how much the Taiwanese love to eat and entertain, we also witnessed their routine inclusion of

good health and exercise as a way of life. With practical information on controlling diet and, we hope, government payment for growth hormone, PWS children and families will have a much brighter future.

Five Years - continued from page 1

Five years ago today. If I allow myself, I can still experience those feelings as raw as they were back then. Five years' experience has taught me, however, that so many of my early fears have been pointless. I've shared with many new parents and I hear the same words from other more experienced parents, "If I had known then that my child would be doing as well today, I could have saved myself a whole lot of tears."

Five years later, my tears now usually spring from an overwhelming sense of pride and awe while watching my son sing — loudly and stridently — in the preschool choir. Or watching him carry on a beautiful conversation with a soccer teammate when they're both supposed to be paying attention to the coach. Or while listening to him read all by himself from his beginning reader Bob Books. Or when out of the blue he says after great contemplation that he wants to be a coach when he grows up, or "no, Mom, maybe a teacher." And I am overwhelmed with the knowledge that he is already a great teacher.

Happy fifth birthday, son. I am more proud of you than words can possibly express.

PWSA(USA) Board Member Lisa Graziano lives with husband TJ and Cameron in Redondo Beach, California.

Heybach - continued from page 4

majoring in Criminal Justice at Northeastern Illinois University. Daughter Michelene, 26, has been involved in the siblings program at national conferences and as a caretaker for PWS attendees. "Given this background," Dr. Heybach writes, "along with personal characteristics of dedication, hard work, and the motivation to understand and improve the lives of individuals with PWS and their families, I think I might be a useful board member."

Richard Simmons Works Out for PWS Awareness

By Janalee Heinemann, Executive Director

Fitness celebrity Richard Simmons is 2004 spokesperson for Prader-Willi Syndrome Association (USA) Awareness Week, April 24 to May 1. Richard's empathy for children with PWS, the most common known genetic cause of life-threatening obesity in children, began before he had even heard of the syndrome. Graduating from high school at 268 pounds, Richard knew intimately what it was like to have a life of social isolation and low self-esteem.

After turning his life around and becoming the fitness guru, Richard did a feature program on compulsive eating, and had a child with PWS on the show. He then began receiving letters from others with the syndrome. His heart was touched by their stories and their loving nature; thus Richard has kept in touch with many of the children as they have grown into adulthood. Since many children with PWS die of obesity-related causes before reaching adulthood, his goal is to inspire them that even with the syndrome and all of its challenges, if they work hard enough at it, they can not only survive — but can thrive.

As spokesperson for PWS Awareness Week, Richard Simmons hopes to encourage awareness and understanding of this little-known syndrome. An estimated 15,000 children are living with PWS in the USA, along with 500,000 worldwide, who could survive and lead a higher quality of life if they receive an early diagnosis and early intervention. Many children with PWS become prisoners in their own bodies of fat unless food is controlled and a significant exercise routine is established.

Although most people have experienced hunger, they cannot comprehend the constant hunger (due to a wrong message to the brain) that a person with PWS must live with. As one young man with PWS wrote, "I could feel



Richard Simmons enjoys a dance with 3 ½ -year-old Maria Christine Vucci, who has Prader-Willi syndrome.

sharp teeth tearing at my stomach like piranhas — and still do." A person with PWS also gains weight on much fewer calories than the average person — some must live on less than 800 calories a day. Weak muscle tone and short stature also make the battle against obesity that much harder for people with the syndrome, unless they get growth hormone treatment. Exercise is difficult for a child or adult with PWS, but essential. To focus on the importance of exercise in the lives of all people, April 24th of PWSA(USA) awareness week is Exercise Awareness Day.

For more information or a press release about PWS, or to learn other ways you can help, call 1-800-926-4797.

Kayla Rose would really appreciate some friends **PW POST OFFICE**



Hi my name Is Kayla Rose and i am 13 years old. I have Prader-willli syndrome. I am really fat and i never get to wear any pretty clothes and I don't have many friends because I am fat.

And many kids at my middle school call me fatso because of it. This has been going on for along time. Ever since Elementry school. About two years ago my family heard about a place in pittsburg that people like myself can go and get help to lose weight and also learn how to handle pws. I want to go there. I want to lose welght,-very bad-

I need friends. my mother says we can't afford to go. It Is hard for me to understand why we can't go. I want to grow-up and become a special education teacher to help children

that need extra help. I have had great teachers In special ed. Who have told me I can do what ever i set my mind to. my cousin danyelle is skinny and i couldn't understand why I didn't look like her. But No matter what we still love each other very much. I weight a lot I weight 270 I want to fit In Jeans that will fit me.

I want someone to be my friend. I want to go to a dance and have someone dance with me. I want the people that have not been very nice to me to see that I can lose weight. Look all i am asking is one thing and that Is it. Help. I need help desperetly. Does anyone care how i feel? Yes Those who have pws. And a few in my family. I know if i don't get help I will get heavier and die. Please help. I don't want to die. I have to much to do. I hope you can help me. Can anyone help me?

Editor's Note: Answer Kayla c/o PWSA(USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242

We Remember

Each of our young people with PWS had something special to offer this world — and we, along with their families, want to share who they were and what they meant to the people who loved them.

Dawn Karen Lucia Ficarro

Dawn Karen Lucia Ficarro passed away October 28, 2003. Dawn didn't find out that she had PWS until she was 38 years old, mid 2001. She went through her life with difficulty; attended school through college and had many other accomplishments, working diligently to overcome her disability, which was still unknown to her.



Dawn Ficarro

It was such a relief when she was diagnosed and we could all understand why she had such a struggle and so many health problems. One of her favorite things was to care for people, especially children. She was accepted as a Foster Parent and spent many hours creating crafts and activities for the children in her care. Dawn did marry and tried to maintain her own life until she became too ill.

The blessings she received through PWSA were invaluable. Among them were the education and understanding of her condition and meeting other people with PWS so she didn't feel so alone. We were able to make a donation of brain tissue to help with further study to help the children Dawn was so fond of. In all things, Praise God. ASAP means "Always Say a Prayer."

— Dawn Lucia (Dawn's mother), West Covina, California

In Memory of Mathilde Budner

10/18/18 – 4/12/03

In September of 2002, I wrote an article In Memory of Harriet Budner and her very special mother, Mathilde Budner.

Mathilde devoted her life to finding out the cause of her daughter's difficulties, and finally, at age 30, Harriet Budner was diagnosed with PWS.

Mathilde gave us the gift of all the records and videos that she had kept on Harriet through the years.

As frequently happens here at our PWSA national office, the voice on the other end of the phone becomes

more than a mere caller. Mathilde and I talked several times a month, and we exchanged pictures and stories about what was going on in our lives.

Sadly, in May 2003 I received an e-mail from a niece of Mathilde informing me of Mathilde's death. Shortly thereafter, we received notification that Mathilde Budner had given us another gift... she remembered PWSA (USA) in her will. We will be ever grateful for her generous gift of \$45,314.

— Diane Spencer
Support Coordinator

Joyce "Joy" Catherine Tighe

Joy was born in Calgary, Alberta on September 26, 1981, a very special child to all who knew her.

She was very lovable and kind and always had a smile on her face. Joy was in and out of the hospital until the age of 2, but she amazed everyone including the doctors and family when she started walking at age 3. At 15, Joy lost her hand in a freak accident. She had to learn how to write all over again with her left hand. At that time she gained a lot of weight, so was put on a very strict diet and lost 53 pounds, thanks to my mother's hard work.

Joy's favorite times of the year were Christmas, Halloween and Easter. At Christmas, a fire truck would come up the road and she would stand there all day waiting for it.

The fireman always had a gift to give her. She was the only child who would wait for him every year. She also had a love for animals; she had a dog named Whimper whom she loved with all her heart.

Joy was presented with a new bike from the Nova Scotia Power Corporation after she had lost her hand. Joy used to take her pet rabbit Peter in the basket of the bike for a drive every day and he never moved the whole time.

In the last two years of Joy's life, we noticed a big change in her. Her weight increased significantly, and she no longer wanted to go outside and play or ride her bike. A couple of months before Joy died, she didn't do anything at all. I don't think anyone in our family really thought Joy was as sick as she was. Her birthday was that week, and we went out and got all the decorations, cake, and everything to have a birthday party for her in the hospital. They put the decorations up the night before she passed away, and she was just lying there watching everyone put them up. Joy at least got to see her balloons and banners, but she was tired of the pain and suffering. Joy died on her 22nd birthday. We will always wonder if maybe the doctors were more educated, if she would still be alive today. I guess we will never know. But we try to remember Joy in her happy times, when she was smiling and doing the things she loved to do.

— Bernice Tighe (Joy's sister) and Kathy Tighe (Joy's mother), New Victoria, Nova Scotia, Canada

Contact PWSA(USA)'s Volunteer Bereavement Coordinator Norma Rupe, who lost her own daughter. We offer bereavement support materials for our members, along with contribution envelopes.



Joy Tighe and her mother Kathy



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will be listed in the next *Gathered View*.

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Because of space limitations, additional donations will be listed in the next *Gathered View*.

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.

