



May-June 2007
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Our 32nd Year of Publication

The *Gathered View*

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



Mackenzie Rose Beverage
Australia

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Donations for Research

As of 3/31/07:

\$93,899

A Life Less Perfect

By *Lisa Peters*

Before my son Nicholas was born, my life was perfect.

I ran in an invisible race with neighbors and friends. A race to see who had the greenest lawn, the smartest kids, the whitest teeth. I was a member of an elite group, devoted to raising elite children. We spent our time at barbecues and soccer games, tallying our points in the quest to grab that glittering gold ring of perfection.

As we admired our children and our lawns, we never stopped to realize that on our faces we wore rose-colored glasses and in our hearts we felt an emptiness that searched for a deeper meaning to our lives.

On January 18, 2002, like a thin layer of glass, my perfect life came shattering down by the purest sound of six horrifying words... "Your son has Prader Willi syndrome."

And suddenly I could not breathe.

I sobbed for my poor, weak, little child.

I sobbed for myself.

I sobbed for the perfect life we would never have together.

There were no flowers, no cards, no congratulatory notes from family and friends. My son entered the world in silence. No smiles, no laughter, no fanfare. No one welcomed him. Everyone was sad.

Where in a perfect life would this little child fit? It was as if his very existence threatened to tarnish this utopian world we had created. My tiny son was a giant monster of truth that threatened to expose the meaninglessness of a life built out of playing cards. And all who lived in these fragile card houses could not understand how to celebrate the birth of this little child.

My son lay limp upon his bed. A yellow feeding tube was taped to his cheek and traveled up his nose and into his stomach. Taped to his tiny skull another tube pumped antibiotics into his fragile veins. Around his floppy body a brace made of thick straps and stiff velcro held his weakened hips in place. IV poles and feeding machines surrounded him like quiet metal soldiers standing at attention. Everywhere alarms sounded... a constant reminder that this was hell and we now lived in it. Around me in the



Nicholas Peters at birth

NICU, I saw only despair... parents with children struggling to live.

Like my newly born infant, I was abruptly and cruelly removed from the warmth of my womb-like perfect life. I was thrust head-first into a cold and terrifying imperfect world.

This was my new home. I felt sick.

Every movement I made felt unnatural and awkward. My mind was frozen. My body moved like a robot. I did not want to look around me, for everywhere I looked, I saw pain. I felt like a soldier on the battlefield, frozen by the ghastly sight of the slain, bloody carcasses at his feet. And yet, like this soldier in a war he did not create, I too could not escape my fate.

Life continued on page 13

Prader-Willi Syndrome Association (USA)

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Deadlines to submit items to

The Gathered View are:

December 1; February 1; April 1; June 1;
August 1; October 1

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

Members Only: Check our website www.pwsausa.org for downloadable publications, current news, current research and much, much more limited to members only!

User Name: pwsamember Password this issue: texas07

Note: If you have difficulty logging in to the site, you may be using a browser that prevents you from entering authenticated websites. Try minimizing your program (e.g. AOL) and clicking on Internet Explorer or Netscape. Then type in the URL: <http://www.pwsausa.org/memberonly.htm>

E-mail Support Groups: We sponsor nine e-mail support groups to share information. You'll find them listed on the web at <http://www.pwsausa.org/support>

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Ken Smith, The Children's Institute, Pittsburgh, PA

Calling All Trailblazers...

Set Your Sites on Adventure and the 2007 Conference!

We have a great line-up of presentations for the 29th Annual PWSA (USA) National Conference, held this year in Dallas, Texas at **The InterContinental Hotel**. The Conference includes **Scientific, Professional Provider** and **Chapter President/Affiliate** Days on August 1 followed by the **General Conference** and **YIP** and **YAP** Programs on August 2 and 3.

General Conference includes several sessions of interest to all attendees, plus breakout sessions specifically geared to issues and achievements of Adult, Youth (school age), and Children from age 0 – 5. Topics include:

✓ **Understanding Childhood Apraxia and Speech (Don Robin, Ph.D.)**

Discussion of signs and symptoms, impact on social and academic development, parent involvement and treatment

✓ **PWS From the Orthopedist's Viewpoint (Harold van Bosse, M.D.)**

Discussion of the orthopedist's role in children with PWS, including scoliosis, hip dysplasia, osteoporosis, other deformities and developmental delays

✓ **Nutrition 101 (Gina Salvatori, Pediatric Dietician)**

Good diet and nutrition information geared toward those with PWS presented by a pediatric dietician from the Pittsburgh Institute

✓ **Update on Psychotropic Medications and P450 Status in PWS (Elizabeth Roof, M.D.)**

Learn the latest in research on psychotropic medications and PWS conducted by a team from Vanderbilt University

✓ **Options for Crisis**

Panel of experts to include the Pittsburgh Institute and the PWSA (USA) Crisis Intervention team

✓ **Laughter after Tears: Building a Strong Family (Janalee Heinemann, M.S.W. and Lisa Graziano, M.A., M.F.T.)**

Looking at coping mechanisms to create a strong, supportive and healthy marriage and family

✓ **Baseline Establishment of Nutrition Concepts (Glenn Berall, M.D.)**

Discussion of the benefits of the diet and nutrition in PWS; alternative treatments, including Growth Hormone and Coenzyme Q10 — evidence and pros/cons; as well as vitamins, minerals, blood-work and other monitoring

✓ **School Strategies for Success**

A team of school support specialists will discuss strategies for parents dealing with common school issues. See a sneak preview of the PWSA (USA) and PWCF DVD "Understanding the Student with Prader-Willi Syndrome: Strategies for Success"

✓ **Creating a Positive Relationship with your Child's Group Home Staff**

Building trusting relationships with your child's agency staff is a two-way street — join us to learn and share how to drive both ways



The conference also includes "A Night at the Prom" Gala Banquet dinner for the YAP participants, a silent auction, music, dancing and a whole lot more. Don't be left out! Log on to (www.pwsausa.org) and download your forms or register online. **Registration deadline is July 15, 2007. A \$25 per person late fee applies AFTER July 15, 2007. No YIP/YAP Registrations will be accepted after July 15.**

Silent Auction Items Needed for Conference

We need donations for the 3rd annual Silent Auction at the Gala Banquet. Last year we raised more than \$4,000 from the silent auction and have bigger goals in mind for 2007! We're looking for the following kinds of items:

- Baskets with a Theme
- Entertainment Packages
- Sporting Equipment
- Jewelry
- Signed Memorabilia
- Children's Items
- One-of-a-kind Gifts
- Home Furnishings and Décor

Go to <http://www.pwsausa.org/conf/GeneralConference.htm> and click on **Silent Auction Donation** link at the bottom of the page. Fill out the online form and a committee member will contact you to discuss the best way to get your donated items to conference.

We're Looking for Your Stories

We're looking for inspirational stories about people with PWS to share during a special presentation at the closing ceremony at the 2007 Conference in Dallas. We receive so many wonderful stories of success, accomplishment and inspiration for *The Gathered View* that we want to give you another chance to have your stories published. Please share your story with us! Go to www.pwsausa.org/conference/conf_29/stories_needed.htm and submit your story today.

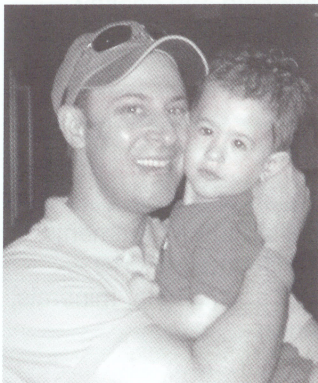
To learn the latest about conference, go to www.pwsausa.org/conf

2007 Nominees to the PWSA (USA) Board of Directors

The Leadership Development Committee has selected four outstanding candidates for the four vacancies on the PWSA (USA) Board of Directors for the 2007-2010 term, each of whom will bring skill, talent and enthusiasm to the Board. Carolyn Loker is running for the board because she will be stepping down from the presidency. (The president is appointed by the board, not by vote of the membership.) Please mark your ballot and return it to the PWSA office no later than July 15, 2007.

Members made no additional recommendations for candidates from the posting in *The Gathered View*. Other potential candidates approached by the committee declined for this year. We strive to bring choice to the voting process and encourage members to first get involved in a committee or project where your talents and abilities can be highlighted. Members' active participation is the lifeblood of PWSA (USA), and the recruitment of highly qualified people to serve on the Board of Directors ensures continued progress and increased quality of life for all those impacted by Prader-Willi syndrome. Contact the PWSA office at 800-926-4797 and get active today! — *Lisa Graziano, Chair, Leadership Development Committee*

Jamie H. Bassel, D.C., P.C. — New York, New York



Jamie Bassel with Zakary,
who Has PWS

Dr. Jamie Bassel became involved with PWS nine days after his son Zakary (28 months) was diagnosed. He is a chiropractor practicing in Manhattan. He specializes in treating spinal injuries, musculo-skeletal conditions, scoliosis and assisting in active rehabilitation. He is a member of the PWSA (USA) Research Committee and provides monthly reviews of current PWS research for the PWSA (USA) web site. He has recently joined the board of directors of the Prader-Willi Alliance of New York. He remains involved in community activities such as Avon Breast Cancer 3day Walk and volunteered after 9/11 with the American Red Cross, providing chiropractic care to law enforcement agents, firefighters and relief workers.

He and his wife Jacqueline have created Zak's Promise: Progress With Support, a foundation devoted to fundraising for research and awareness for PWS. They are co-hosting with Josilyn's Faith Foundation the 4th Annual Prader-Willi Classic on November 10, 2007 at PGA National Golf Resort in Palm Beach Gardens, FL.

John Heybach, Ph.D. — Chicago, Illinois



John Heybach

A business owner, John has been married for 36 years to Sue, an educational counselor. They have two children: Conor, with PWS age 26, a college senior who lives at home; and Michelene, 29, an attorney married to Mike Bajakian, offensive coordinator of the Central Michigan University football team. John has been on the PWSA (USA) Board of Directors for 3 years, and serves on the Strategic Planning, Executive Director Search, Finance, and Research committees. He is also president of the PWSA Illinois Chapter. John has a Ph.D. in Neuroscience from Northern Illinois University and an MBA from Kellogg Graduate School of Management at Northwestern University. Conor is a member of the PWSA USA Adults with PWS Advisory Board. "My family and I consider it a privilege to have Conor with us and I consider it a great privilege to serve on the board of PWSA USA, an organization that provides the leadership and help that continues to dramatically improve the lives of individuals with PWS and their families."

Stephen D. Leightman — Cherry Hill, New Jersey



Steve Leightman with Josilyn,
who has PWS, and Rachel

Steve is the proud grandfather of four beautiful children. After the birth of Josilyn, who has PWS, 5 years ago, he became involved in PWSA(USA). He is a first vice president with RBC Dain Rauscher in Mt. Laurel, New Jersey, concentrating on financial planning and strategic asset allocation for individuals and small businesses. He received a B.A. from the University of Pittsburgh and his M.A. from George Washington University. He also is an Accredited Wealth Manager, a certification awarded by Michigan State University. He has served on the PWSA(USA) Board of Directors since 2004 and currently chairs the Finance, Development, Office Best Practices and Office Location committees. In addition, he is a member of the Philadelphia Estate Planning Council, the Marlton Lions Club and Adath Emanu-El. Along with his wife Michele, who chairs the Grandparent Mentoring Program, Steve is a passionate advocate for PWSA(USA) and is hoping to give back a small measure of the gifts the association has given to his family.

Candidates continued next page

Prader-Willi Syndrome Association (USA) 2007 Official Proxy

Must be received at PWSA (USA) office by July 15, 2007

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

vote as my proxy at the PWSA (USA) Annual Membership Meeting in Dallas, Texas in August 2007.

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:

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

Name _____
(please print)

Signature _____

Date _____

(VOTE FOR 4)

☐ Jamie Bassel

☐ John Heybach

☐ Stephen Leightman

☐ Carolyn Loker

☐

(write-in candidate)

ALL VOTERS Must Check One of the following:

☐ I have an Individual Membership

☐ We have a Family Membership, which has two votes,
and are both voting for the same candidates.

☐ We have a Family Membership, which has two votes, and are each voting for separate candidates.
(If you are voting separately, please use separate copies of this proxy.)

PWSA (USA) Board of Directors Candidates - continued from page 4

Carolyn Loker — Kalamazoo, Michigan



Carolyn Loker with Anna,
who has PWS

Carolyn is completing her 3-year term as president of PWSA (USA) and wishes to be considered for a board of director's position. Prior to being elected president she was vice president for 3 years, served two terms on the Board and was co-president of PWSA of Michigan for 6 years.

Recognizing the unique needs of parents with newly diagnosed infants, she began and coordinates the Young Parent Mentoring Program, and also helped begin PWSA (USA) e-mail support groups. She was a parent consultant for the Growth Home Booklet, Nutrition Booklet for Infants and Toddlers, and the Handbook for Parents.

Her husband Jim, a pediatric cardiologist and medical director of Bronson Children's Hospital, serves on the Clinical Advisory Board for PWSA (USA). Jim and Carolyn cover for PWSA (USA) medical crises when needed. They are the parents of four daughters and two granddaughters. Their youngest daughter, Anna, 12, has PWS.

Carolyn spent 14 years as a pediatric cardiac echosonographer and head of the pediatric cardiac testing lab at Riley Children's Hospital at Indiana University Medical Center. After Anna's diagnosis at 17 months, Carolyn turned to volunteering for PWSA (USA).

Working For A Cure Tomorrow – Helping Our Families Today
Does your employer support your donations with
a matching funds program?
If so, please call us at 1-800-926-4797



Executive Director's View

So That Others May Live

Janalee Heinemann

When our 18-year-old grandson was killed in an accident in 2004, our daughter, his mother, came upon the accident site as she was on her way to mail his graduation cards. In spite of her anguish, she had to suddenly make a decision none of us ever wants to have to make about our children: was she willing to donate his organs so that others may live?

Her answer was yes – take what you can. But no one should have to make such an important decision at a time when you cannot breathe let alone think. So I am asking you to think about some important decisions now when the farthest thing from your mind is your child's death. I hope you will never have to implement your decisions, but who would have ever guessed that at 8 o'clock in the morning on a sunny Wednesday, our handsome, healthy, athletic Adam would be gone in seconds?

We all worry and wonder about our children with PWS. Can they be healthy and happy? Yes. How long can they live? Some have lived into their 60s.

Last year when I was diagnosed with cancer and I was answering my grandchildren's questions, 11-year-old Taina asked a good one: How does cancer kill you? I find that parents of young children also often ask how and why they die. In those with PWS, often it is due to weight-related complications, which is why we preach the importance of early diet control. But there have been sudden deaths as there are with any population. We also must acknowledge the extra risk factors of respiratory and GI complications that may go undetected due to the lack of fever and high pain threshold plus the lack of vomiting.

Certainly we all need to consider being an organ donor and to have that printed on our driver's license, but for our children with PWS, to give the gift of life there are other things to consider. The most important gift to furthering research on PWS is to insist on an autopsy and to consider brain and tissue donation.

I say "insist" because I find that often when a death is sudden, parents who are understandably traumatized are talked out of an autopsy. Many people mistakenly think that if death is unexpected or at home, there will automatically be an autopsy. That is far from the reality. An autopsy costs someone time and money. Back when I worked in a children's hospital, one medical examiner told me, "I am so over-worked and over budget that unless there is a bullet hole in the head, I am not doing an autopsy!"

God forbid that you ever have to make this decision, but it is important that you make it now when you are of sound mind. Then you are not caught in the situation of many parents who later deeply regret not having an autopsy, and

who never feel they have a good enough understanding of why their child died. If anyone tries to deny you an autopsy without a good reason, please call PWSA (USA) and we will deal with them. When we get permission, we have a team of medical experts in our PWSA (USA) Study of Death group who are reviewing the autopsies to get a better understanding of PWS anatomy, complications and risk factors.

When Kathy Hollrah of Missouri died recently, her mother Regina donated Kathy's brain tissue for research. During the visitation, all of Kathy's friends who have PWS told Regina they thought it was a wonderful idea and that this is what they wanted done when they die.

As I have written before, our children and adults with PWS have a sense of compassion far beyond what we attribute to them. They want to help others with the syndrome and to know that their lives were meaningful and of worth.

In brain tissue donation, hours can make a big difference in the quality of the brain tissue and what can be learned from it. This is not only a decision to make at the time of death, but ideally one to make and document (as in organ donation) when your child is healthy.

We hope your child will outlive you, and this next generation of children with PWS may live to be 80. Unlike organs though, PWS brain tissue is needed at any age. The brain holds the key to the symptoms of PWS, so the brain holds the key to finding the solutions. We should all be thinking about registering our "children" with PWS in one of the brain and tissue banks recommended on our web site in the Medical Alert section. If you cannot access the site, call the PWSA (USA) office at 800-926-4797, and we will send you a copy.

I have regular contact with Dick Swaab, the international expert from the Netherlands on PWS brain research. His key points are:

- * PWS is primarily a hypothalamic disorder, so we should study this structure to come up with rational therapeutic strategies.
- * It is extremely difficult to collect material to study PWS, since it is a rare disease.
- * Comparison with control material is an extra complication.
- * We are facing a new unknown problem in PWS: the way the brain is aging.

Remember, we now have an after-hours service for medical crisis and deaths, so if you need us after hours, call 941-993-7638 or the number above.

We hope your children have a healthy life and you never need this number, but as always, our mission is to further research and to educate and support you throughout the lifespan. May that lifespan be a long one!

PWSA (USA) Scientific & Clinical Advisory Board Publications

As most of you know, we have many very accomplished members on our PWSA (USA) Scientific Advisory Board (SAB) and Clinical Advisory Board (CAB) — so accomplished that it's sometimes hard to keep up with their achievements! I am proud to announce some of their recent publications:

From our Scientific Advisory Board Chair, Dr. Merlin Butler: "*The March 1 American Journal of Medical Genetics* issue which is dedicated to PWS includes 11 articles, the 2005 scientific PWSA abstracts and a review of the management textbook. All but one article is written by members of the SAB or CAB." (Much of this is thanks to Dr. Butler's efforts.) They are the following:

Volume 143A, Issue 5, Pages 413-520 (1 March 2007)

Invited Comments — *Introductory comments - Special section: Prader-Willi syndrome* (p 413-414) John C. Carey

Plasma obestatin and ghrelin levels in subjects with Prader-Willi syndrome (p 415-421) Merlin G. Butler, Douglas C. Bittel

Whole genome microarray analysis of gene expression in an imprinting center deletion mouse model of Prader-Willi syndrome (p 422-429) Douglas C. Bittel, Nataliya Kibiryeva, Steven G. McNulty, Daniel J. Driscoll, Merlin G. Butler, Robert A. White

Whole genome microarray analysis of gene expression in Prader-Willi syndrome (p 430-442) Douglas C. Bittel, Nataliya Kibiryeva, Susan M. Sell, Theresa V. Strong, Merlin G. Butler

Two years of growth hormone therapy in young children with Prader-Willi syndrome: Physical and neurodevelopmental benefits (p 443-448) Susan E. Myers, Barbara Y. Whitman, Aaron L. Carrel, Victoria Moerchen, M. Tracy Bekx, David B. Allen

Energy expenditure and physical activity in Prader-Willi syndrome: Comparison with obese subjects (p 449-459) Merlin G. Butler, Mariana F. Theodoro, Douglas C. Bittel, Joseph E. Donnelly

Clinical-etiological correlation in children with Prader-Willi syndrome (PWS): An interdisciplinary study (p 460-468) Maria Torrado, Veronica Araoz, Edgardo Baialardo, Karina Abralles, Carmen Mazza, Gabriela Krochik, Blanca Ozuna, Vivian Leske, Silvia Caino, Virginia Fano, Lilien Chertkoff [Note: This is the only article or study not involving a PWSA (USA) SAB or CAB member.]

X-chromosome inactivation patterns in females with Prader-Willi syndrome (p 469-475) Merlin G. Butler, Mariana F. Theodoro, Douglas C. Bittel, Paul J. Kuipers, Daniel J. Driscoll, Zohreh Talebizadeh

Intracranial abnormalities detected by three-dimensional magnetic resonance imaging in Prader-Willi syndrome (p 476-483) Jennifer L. Miller, Jessica A. Couch, Ilona Schmalfuss, Guojun He, Yijun Liu, Daniel J. Driscoll

Deaths due to choking in Prader-Willi syndrome (p 484-487) David A. Stevenson, Janalee Heinemann, Moris Angulo, Merlin G. Butler, Jim Loker, Norma Rupe, Patrick Kendell, Carol L. Clericuzio, Ann O. Scheimann

Research Letters

Thyroid function studies in Prader-Willi syndrome (p 488-492) Merlin G. Butler, Mariana Theodoro, Jennifer D. Skouse

Abstracts

Scientific abstract submissions presented at the 27th Annual PWSA (USA) National Conference in Orlando, Florida (p 493-502)

Guest Editor: Merlin G. Butler

Other upcoming publications from our SAB and CAB board members:

In an e-mail from Dr. Ann Scheimann: The bariatric surgery paper will be published in **JPGN (Journal of Pediatric Gastroenterology and Nutrition)** RE: JPGN-NA-07-54; "*Critical Analysis of Bariatric Procedures in Prader-Willi Syndrome*" Scheimann AO, Butler MG, Gourash L, Klish W

Also, JPGN-NA-07-54 will be publishing some of the results of PWSA (USA)-sponsored Study of PWS Deaths project entitled "*Gastric Rupture and Necrosis in Prader-Willi Syndrome*" submitted by Dr. Stevenson and including, Janalee Heinemann, Moris Angulo, Merlin G. Butler, Jim Loker, Norma Rupe, Patrick Kendell, Carol L. Clericuzio, Ann O. Scheimann

Dr. Phillip Lee had his article on *Growth Hormone and Mortality in Prader-Willi Syndrome* published in the **Growth, Genetics & Hormones** journal in March 2007, Volume 23, No.1.

In a future edition, the **American Journal of Medical Genetics** will publish Dr Moris Angulo's article on *Final Adult Height in PWS*.

Barb Whitman reports: "Just last week I got a copy of our *Dictionary of Developmental Disabilities Terminology* that was published in 2002, translated into Korean in 2005, and now has been translated into Arabic — it reads from back to front — when I look at it, the cover page is in the back. It's quite an honor to have had it translated into Arabic. Dr. John Pasquale is co-editor and genetics contributions are by Dr. Ellen Magenis."

We thank our dedicated and hardworking advisory board members for their outstanding work on behalf of our children!

— *Janalee Heinemann, Executive Director, PWSA (USA)*

PWSA (USA) Research Advocacy Is On the Move

By Jim Kane, Research Advocacy Chair

The PWSA (USA) Research Advocacy Team has been busy over the winter presenting our ideas to various groups and laying the groundwork for the future. A few examples of our progress are:

- **Developed a new presentation that PWSA (USA) will use in its work.** Obesity is the central theme of the package. It is organized around three tailored focuses: **Understanding PWS**, the **Critical Need** for PWS Research and the **Unique Research Aspects** of PWS. Each of these pieces was designed to present a quick look at PWS for the un-initiated and to present more detailed information for those interested in pursuing more knowledge. The package concludes with a **Call to Action** asking for help in the specific areas noted below:

- o Garnering advocacy for better general awareness and understanding of PWS. The increased publicity PWS has received in recent years has helped our advocacy efforts; however, the public and key potential influencers need to know more.

- o Increasing fundraising for exploring research opportunities. Funding sources for PWS are inadequate. It is necessary to secure vital financial support and from individuals, foundations, corporations and the government.

- o Inciting collaborative research through exposure within the scientific community. We hope to encourage scientists who are working on appetite control and metabolism to consider PWS issues when designing their projects. In addition, we strive to shorten the cycle time of

bringing PWS solutions from concept to practical application.

- **Special Interest Section organized within The Obesity Society, The North American Association for the Study of Obesity.** PWSA (USA) recruited 25 top scientists who are interested in the study of the various issues surrounding obesity and who were members of The Obesity Society to join with us in promoting the recognition of PWS as tool for the study of appetite and metabolism. We hope that this relationship raises the profile of PWS in obesity research.

- **Alliance created with Faster Cures-The Center for Accelerating Medical Solutions.** Faster Cures is an organization whose goal is to save lives by saving time in the discovery, development and deployment of treatments and cures for deadly disease. Faster Cures is a well-funded dynamic group that has recognized a select number of organizations which fit into their strategic plan. PWSA (USA) recently was accepted as a partner with Faster Cures in that effort. We hope this relationship garners PWSA (USA) access to people who share our desire to accelerate the progress toward solutions for PWS.

Finally, the Research Advocacy Team is always looking for help for its work. If any members are interested in helping or have contacts that may be beneficial, please contact Jim Kane at 410-321-9788 or jgkane@msn.com.

Jim and Kit Kane live in Towson, Maryland with their daughter Kate, 25, who has PWS.

How To Calculate Body Mass Index

Calculating your child's body mass index (BMI) is a simple and inexpensive way to get a sense of whether he/she might be overweight. There are better ways (i.e., tests) to determine if your child has too much body fat (e.g., DEXA and MRI), but calculating the BMI gives you a rough idea and should be used as a starting point.

The BMI is calculated the SAME way whether you are a child or an adult. What IS different is what the final number means. For example, a BMI of 20 would be lean for an adult, but obese for a young child.

To calculate the BMI, divide the child's weight in kilograms by the height in meters squared (kg/m^2). You can also go to either of the following web sites and enter the weight and height and the BMI will be calculated for you: <http://www.cdc.gov/nccdphp/dnpa/bmi/index.htm> or <http://www.nhlbissupport.com/bmi/>

To determine the correct percentile for children, you need to plot the BMI on the special curves designed by the Centers for Disease Control. For adults, no curve is necessary. A BMI of 21-25 is normal weight. Over 25 is considered overweight. Over 30 is obese. Over 40 is morbidly obese. — **PWSA (USA) Clinical Advisory Board**

Food Security is a State of Mind

Food Security is the essential ingredient for managing the food-related behaviors associated with PWS. Food Security has been defined as *the ready availability of nutritionally adequate and safe foods with an assured ability to acquire these foods in socially acceptable ways.*

In PWS, **Food Security** provides **no doubt** when meals will occur and what will be served; **no hope** of getting anything different from what has been planned, and **no disappointment** related to false expectations.

Food Security is achieved by securing food access across all environments, supervising food access across all environments, posting mealtimes and menus, and training all team members. When the individual with PWS is experiencing **Food Security**, that is, **no doubt**, **no hope** and **no disappointment** related to food, a generalized behavioral improvement typically occurs. For this reason, *Food Security is the mainstay of PWS management before considering the implementation of behavioral interventions and pharmacotherapy.*

— **From "Pittsburgh Partnership Psychiatrists' Primer for Prader-Willi Syndrome" by Janice Forster, M.D. and Linda Gourash, M.D.**

Show & Tell

View From the Home Front



Joshua carries the Olympic Torch

Joshua LaBarge, 10, who has PWS, was chosen to carry the Olympic torch for the Florida Special Olympics Area Games in March. He also won a third place for boccee ball. Way to go, Joshua!



Take Me Out To the Ball Game

PWS Awareness Month Spokesman Clint Hurdle, manager of the Colorado Rockies major league baseball team, with Trevor Ryan of Newhall California, who has PWS. "Words can't express our appreciation for the tickets and baseball cap. Trevor and I had such a great time at Dodger stadium rooting for the Rockies," writes Trevor's dad, Mark Ryan, who serves on our PWSA (USA) Board of Directors. "This picture that says it all!"



The Gathered View News Consumer

In the early years of our family, we moved to a new community and spent a month in a motel while house-hunting. After a particularly busy day, I returned to the motel room to hear the phone ringing. My arms were full of mail, kids and bags, but I dropped everything in hopes that the realtor had good news. I knew Claire (PWS), age 3, (shown right) would be happily entertained with her shoe laces, and her 5-month-old brother was not yet crawling, so I became engrossed in a pretty long conversation. When I hung up, I found the teething baby covered with a pasty goo and drool. Then I figured out why — he was EATING the Prader-Willi newsletter.

After 15 years, I still smile every time I remember that moment. There are only a special few of us who can share such a joke.— *Carol Lindsey, Clarksville, Tennessee*

Looking Back

By Randon Regnier

Editor's Note: Cindy Regnier, Randon's mother, tells us: Randon's essay for his high school English class about his PWS and a resulting back operation was first published in his school newspaper. Then, after his English teacher submitted it, an edited version was published in the February edition of Teen Ink, a nationally distributed magazine that contains stories, poems and artwork by teenagers. You can see it online at <http://TeenInk.com/Past/2007/February/Current>



Randon Regnier, 19,
who has PWS

My name is Randon and I am a senior at Bennington High School [in Kansas]. I am not the same as my friends. I have Prader Willi syndrome. Even though I don't like dealing with Prader Willi I know I can't change my condition so I manage the best I can.

One of the hardest parts is that I have trouble walking. When I was a freshman the doctor took back and leg x-rays. When my

mom saw them, she said my spine looked like a snake crawling every which way – I had scoliosis.

My orthopedic surgeon said my bones weren't fitting together right, which was making me crooked. The bones in my legs were also crooked, and though he could operate, he didn't think he should because I would have to use crutches for such a long time.

So my mom and I traveled to Kansas City where the specialist said he could do the surgery but warned there might be some pretty nasty side effects, including not recovering completely. We decided I should have this operation, so we traveled to Kansas City for appointments that tested my breathing capacity, the condition of my bones, and my blood. I also had to see a nutritionist and lots of other specialists who gave us tasks to do before the surgery.

On the morning of the surgery, Mom, Dad and Pastor Colaw gathered around my bed to pray. The surgery took all day and when it was done they wheeled me into the recovery room. I woke up with an oxygen tube down my throat. My parents were there but I couldn't talk. I felt like I was choking. Finally I got the tube out and could talk a bit but I couldn't move. I had to stay in intensive care and was hooked up to lots of machines.

Each day I progressed and one by one shed the machines. I could have a little ice at first, then some water and soda. I wanted to eat soup and real food but they wouldn't let me until my digestive system was working better. My therapist came every day to help me walk a little, going farther each day. When I could walk to the activities room and manage stairs, I could go home.

A week later I was ready to go home, but then I got an infection. People sent me lots of balloons and presents. I got cards every day and friends came to visit. I couldn't go back to school so a paraprofessional came and helped me do my work. I used a wheelchair and learned to use a walker. Finally, I could manage with just a cane and was ready for school.

The surgery really helped me, even though it and the recovery wasn't a lot of fun. But I knew what I had to do so I could be straighter. I am thankful to have rods in my back to help support me. I was fortunate to find a doctor who could operate and for all my friends who helped me get through this difficult time.

I have come to know that through faith I can deal with all the things that make me different from my friends. I know God made me the way I am and he will help me get through the obstacles of Prader Willi syndrome. I try not to let problems get me down. I just need to face them and get through as best I can.

All these experiences make me a better and stronger person. I know my future is uncertain but I will get through it. I have learned that I will not succeed if I don't try. My goal is to walk across the stage at my graduation, and with the help of my parents, my friends, and God, I will do it.

'DeLITEful Recipes From Diane' Now Posted On Our Web Site

Here is the dilemma: should we keep food uninteresting and boring in the hope that it will be less important to the person with PWS? Or, do we try to make it more like typical menus and lighten up the calorie content.

I think my philosophy goes along with the second choice. Also, factor in the rest of the family: they deserve to enjoy an interesting variety of foods. Not all of you enjoy cooking, so I will try to keep these recipes simple but most importantly, low calorie and healthy.

You may have some favorites to contribute as well, so send your recipes to national@pwsausa.org. If you have special requests for a "lite" version of a recipe, we will try to accommodate you.

Look for us in "Members Only" DeLITEful Recipes from Diane online at www.pwsausa.org

— Diane Spencer, Support Coordinator

Announcing the PWS Diagnosis and Contribution Appreciation

So often, families do not know how to appropriately tell their loved ones about a PWS diagnosis. Recently I was very touched to read two letters created by Gretchen and Larry Golub of Williamsburg, Virginia, announcing the birth of their son Maxx. We have posted them on our web site, www.pwsausa.org, as samples of 1) a letter for family and friends after the birth, and 2) a fundraising appreciation letter. The Golubs' fundraising appreciation letter is a wonderful way to remind staff, board and volunteers how they are appreciated and that what they do is so very important.

— Janalee Heinemann

Letter 1: Diagnosis Announcement

To All Our Friends and Family,

So often during difficult times many people have comforted each other with hope. An optimist, I have offered friends and family, those I love, hope for the smallest of struggles to heart-wrenching pain. From encouraging someone to find their cell phone because it would make their day easier, to hope for another's passing to be peaceful. Hope for so many things. It feels right to be hopeful when someone is in need. But I have never been certain if this encouragement was futile or helpful. Sometimes in the moment of angst, unsure of what to say, I wondered if it seemed trite to suggest a silver lining. Until now.

We have had six weeks of uncertainty waiting for Maxx's test results to come back. Those six weeks have been filled with the love, caring and hopeful words of so many of you. As the tension of not knowing grew more intense, it was your words, prayers, and positive energy that kept us strong. It was not futile or trite, it was comforting. It helped suspend thoughts of the worst that could happen. It gave us moments of respite. So now I have learned offering hope works.

Maxx's tests came back positive. He has a condition called UPD (Uniparental Disomy) Prader Willi syndrome. Now we know... there is no longer hope that he does not have it... But here's the beauty... We still have hope.

Hope for the best possible life for Maxx. Hope that he will be as happy as he is now, smiling and sweet. Hope that we will meet the challenges of a child with special needs, and that we will become better, more soulful humans because of it. Hope that science and research will find an answer to some of the challenging characteristics of PWS.

The joy of having a child is so powerful. Learning your child has special needs does not change that joy. There is no sadness. Maxx, a miraculous child we were given, is still the greatest gift that could be. We love you all.

Letter 2: Gratitude and Praise

To The Act II Steering Committee and all the Volunteers

When Larry and I were told our son Maxx had a genetic disorder called Prader Willi syndrome, we had no clue what the doctors were talking about. For quick information we

went online and found the Prader Willi Syndrome Association USA.

With all the bravado I could muster, I called PWSA (USA) and explained my son was just diagnosed and we needed help to understand how this syndrome would affect his life.

In that heartbreaking moment they offered more than information. The person on the phone, a mother of a child with PWS, guided us through the shock, pain, and all that we needed to know.

PWS is rare. Maxx's doctors have little or no experience with the peculiarities of the syndrome. Since that first day on the phone, PWSA (USA) has provided literature for Maxx's doctors and caretakers. They have arranged consults with Maxx's doctors and their board of doctors. They have coordinated a mentor family for our family and a message board to share the experiences of other parents who have trail blazed ahead of us. PWSA (USA) funds and continually disseminates information on the latest research.

Our son is beautiful. He lights up a room with his smile. We remain hopeful his young soul will continue to grow bright. We are hopeful research and science will find an answer to some of the challenging characteristics of PWS.

Because PWS is rare it is not supported by a wealth of population. ACT II's contribution to PWSA (USA) is significant. It will touch each child with PWS.

Thank you. Thank you for the time you give to ACT II [and] making it a success so my son and all children with PWS can remain hopeful for the future.

Sincerely,
Gretchen and Larry Golub

Let The Buyer Beware

There is a tried and true warning that says "If it sounds too good to be true, it probably is." This is especially true in regard to all the web sites, catalogues and advertisements promising wondrous cures or remedies for all sorts of maladies, including Prader-Willi syndrome.

Before buying, people should proceed with a great deal of caution and thoroughly review any medication (homeo-pathic or otherwise, including nutritional supplements).

Any medication should be discussed with the individual's physician prior to giving it, and the manufacturer should be investigated. Be careful of claims to treat or cure PWS and find out exactly what the manufacturer says the preparation is intended to do. Many of these "remedies" can make matters worse if they interact with other medications the person may be taking.

At the very least, it is a question of whether you want to waste your money or not.

Fundraising From the Home Front

Raising Funds and Awareness for PWS

By Jodi O'Sullivan, Director of Community Development and Jane Phelan, Editor

Some people say a game of golf is no laughing matter, but the **3rd Annual Prader-Willi Classic LPGA Pro-Am Event and Night of Comedy** brought lots of smiles. Last November's event, held at the PGA National Golf Resort in West Palm Beach, Florida, netted \$20,600 for PWS Research.

It was hosted by **Ronnie and Ira, Michael and Wendy Levine and Jamie and Jacqueline and Natalie and Stan Bassel in honor of Josilyn Faith Levine, 4, and Zakary Maxwell Bassel, 28 months, who both have PWS.** "We want to help advance research, so that Josilyn, Zakary and many others can reach their fullest potential," writes Ronnie Levine. She says the most emotional part of the evening was listening to Jamie [Bassel] and Michael [Levine] explain the support that they have given each other on this journey that they are on with their children.

About 100 people attended the golf tournament and 150 were at the comedy event. "Reach out to all who love you. You would be amazed at the response you get. When you are at any merchant that you frequent, have an invite with you and ask for something. People are very willing to help," Ronnie advises.

The 2007 event is planned for November 10, and will include both a golf and tennis tournament.

Here's how to find a bargain and save money for a worthy cause. **Karen Hamlin-Fochs of New York**, a buyer for Ross Dress for Less, organized the **2nd Annual Sample Sale for Prader-Willi** last fall and netted \$1,500 for PWSA (USA). **Karen is parent to Ryan Fochs, 5, who has PWS.**

It was a big night for **3-year-old Jacob Perrault, who has PWS**, when the **2nd Annual Jacob Bingo Fundraiser** netted \$1,802 for PWS research. It's the second year that Jacob's **Aunt Kate and Uncle Pete Buchbinder**, along with **parents Anita and Kyle**, organized the evening for family and friends to support research efforts for PWSA (USA),



writes Anita. Sixty guests attended, and Kyle's employer, Johnson & Johnson, will match funds 2 to 1, a very nice surprise.

All bets were ON when **Chea and Preston McElheney** held a **Poker Night in honor of their son, Ethan, 3, who has PWS.** They netted \$2,080 for PWSA (USA). "We had a wonderful time 'betting' big

and seeing who could keep the most chips by midnight. We had all the trimmings of a fun party, and a great group of friends to bring in the New Year," writes Preston, who adds, "The bar has been set high for New Year, 2008. We will see how big the 'bets' get for

Josilyn "Josi" Levine's family gathers for a classic photo at the 2006 Prader-Willi Classic. From L-R cousin Morgan Laufgraben, aunt Jodi Laufgraben, cousin Hayden Laufgraben, Josi (center), Ronnie Levine (Bubbe) above her, Josi's big sis Rachel, mom Wendy Levine, and Josi's little sis Sophia



Ethan and Prader-Willi." Naturally, he hopes everyone has a very prosperous year in preparation for the party!

Jim and Kit Kane of Towson, Maryland "bet" that their **March Madness PWS Pool** for their Private Foundation of Maryland had all the winnings of a great fundraiser. It was in **honor of their daughter Kate, 25, who has PWS.** During the spring basketball season, friends from all over participated, and the effort netted \$1,620.

There were BIG first birthday wishes when **Megan and Joshua Self** had a celebration in **honor of their son Hudson, who has PWS.** They netted \$13,460, including \$10,000 from an anonymous donor. "We have decided that we will leave it up to [PWSA (USA)] to decide how best to use this money to make the standard of living better for Hudson and every other person with PWS. We are passionate about the research that is continual around the world, so we're excited that some of this will go towards grants and such," write the Selfs.

Students at St. Thomas The Apostle School in Delmar, New York netted \$844 for PWS Research at a February 16th fundraiser, **"Give Your Heart for Philip."** They wore red in **honor of Philip Fusco, 15½, who has PWS.** He is the nephew of Emily Sprague, a very active volunteer for PWSA (USA), whose children attend the school. She writes, "Please let others know the wonderful outpouring of love for my nephew and others like him by our great students of St. Thomas The Apostle School."

No one has ever become poor by giving.
— Anne Frank

The rose colored glasses I once blindly wore were smashed into smitherines. My eyes, unaccustomed to this new light, could not stop crying.

In his sad and traumatic entrance into this world, my imperfect son had given me a beautiful and precious gift, the gift of sight. The ability to see the world not as I wanted it, but as it truly was.

I saw the pain and sadness... the frailty of life.

When he finally came home from the hospital, I had to hold him carefully or his head would flop quickly forward. And when it did, he couldn't breathe. I felt helpless.

I questioned God, what had I done to my son? I felt guilty.

When I took him to restaurants or the mall, people would ask questions. Why does your son have a tube in his nose? I felt embarrassed.

When I handed my fragile son to the doctor at Children's Hospital for eye surgery, I felt scared.

So many endless days brought so many endless hurtful, hard emotions. I felt so very tired.

And when my tired body seemed like it could bear no more, my floppy little child began to get stronger. And as he did, I began to feel a lost emotion... happiness.

After almost a year, Nicholas finally held up his head. That tiny little infant who struggled to breathe was now able to see the world. I felt joy.

When his g-tube was removed and the words "failure to thrive" were erased from his chart, there were tears. No more questions to answer. I felt relieved. When he pushed away his metal walker and took steps for the first time, I wept.

Slowly, I began to realize that these tortuous feelings, these hardships were somehow very important for me to experience. For it was these extremes that gave my life new meaning. I understood myself a little better. I believed I understood others better. And although these emotions left me feeling fragile and vulnerable, I couldn't help but wonder if this is God's intention.

As I became accustomed to my new vision, I saw we were surrounded here on earth by many hidden angels. Intelligent, kind human beings who were devoting their lives to curing and healing the sick. Why hadn't I seen them before? Why hadn't I appreciated them? And once again this imperfect child had enabled me to see. I could see the special souls who traveled among us here on earth. These guardians would now be a part of our lives forever. This new life of ours now seemed a little less scary.

There were other angels here on earth now visible to me for the first time... special parents of children with Prader Willi syndrome whose paths were as treacherous as ours. And with these special few we shared our advice, our tears, our love... and a unique bond was forged... for we could truly understand each other! I listened to these parents I had never met. I listened to these strangers with quiet hearts and somehow my hardened spirit was now a little lighter. Why? I do not know, for I was still sad. But releasing tears and listening to others, I began to accept and understand this challenging life.

I began to accept that my son is not like others in this world. I began to accept that this was not a curse but a blessing. To me he is unusually happy, loving and kind. I am amazed by his keen perception of human beings and his unique ability to make even the grumpiest of grouches smile brightly. He lives to dance and laugh and love. He has a warm heart and a gentle spirit. And although he is my child, he has also been my teacher.

Each of us is blessed with special gifts, and although his gifts are hidden, buried beneath a weakened body, his gifts are no less special. My son cannot run very fast, but he has the precious gifts of empathy and human compassion.

I now realize that my life with Nicholas will not be like the

lives of so many others: ordinary. It is an extraordinary life. A life filled with high highs and low lows. I would not trade one day of feeling that terrible pain because I know now the happiness that is on the other side waiting for me. What I have learned is to appreciate both. For it is these feelings, this blending of the good and the bad, that somehow seem to bring me closer to understanding my purpose here on earth.

This awareness, this blending of heart and spirit, has helped me to embrace my son and enjoy this journey we are sharing together.

It is a sad-sweet beautiful trip. It is a life less perfect. It is a life more meaningful.

Lisa Peters is Mom to Weston, 7, and Nicholas 5, who has PWS. She and husband Jeffrey live in Georgetown, Massachusetts



Nicholas at age 5

Fast Facts About Sleep Disorders

According to the National Sleep Foundation, about 69% of children age 10 and under experience some kind of sleep problem. Nineteen percent of preschoolers and 10% of school-age children snore regularly. Children who drink caffeinated beverages lose an average of 3.5 hours of sleep per week. There are more than 84 different sleep disorders, but the most common in children are sleep apnea or narcolepsy.

The American Academy of Pediatrics guidelines recommend screening for sleep disorders at each visit. This is especially important as many signs of sleep disorders are very subtle. Parents should consult their child's physician for more information.

Source: Women & Children's Hospital of Buffalo "Fast Fax for the Medical Staff," February 23, 2007

The Long Road to Victory Is Paved With Persistence

By John Heybach

When our son Conor (PWS now aged 26) was in grade school at Sacred Heart & Hardey Preparatory Academy in Chicago, he wanted to join the basketball team. We had our reservations because, of course, we did not want him humiliated and his heart broken competing against “normal” kids.

However, the team had a wonderful coach who accepted Conor and any other boy who wanted to be on the team, so we agreed. As long as team members showed up for practice and worked hard, the coach's policy was that every boy got a chance to play in every game. As you can imagine, coaches of the other private school teams against which we played took full advantage of this policy.

Conor was quite heavy at the time and given the other features of PWS was one of, if not the least, talented players on the team. However, Conor never missed a practice, was well liked, worked very hard, never lost any enthusiasm the whole 3 years he played and never complained. True to the coach's word, he and the other third stringers got to play, one at a time to minimize the damage, for 2-3 minutes each game, no matter the cost to the team.

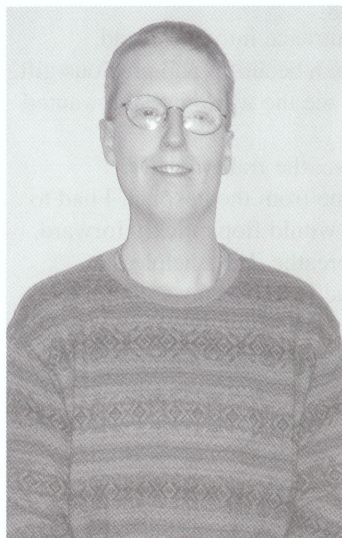
Each time he went out on the court, my heart, and my wife Sue's and his sister Micheline's hearts were stabbed by every muttered complaint of “oh no, not him” by other parents of our own team and by the chuckles of opponents. Every dropped pass, double dribble, missed shot or confusion on Conor's part was agony to us. But we controlled our tears or rage, supported him all the way and always encouraged him to pay no attention to criticism and do his best.

Our team had some very talented players. Despite the coach's policy of playing everyone, they racked up win after win and became the team to beat in the league, which by Chicago grade school standards is pretty prestigious. Conor had never scored a point in his years on the team. As the season came to an end, the team was undefeated and heading into the playoffs as the clear favorite.

Prior to the playoffs, the coach held a team meeting and asked the players to vote whether they should continue with the policy of playing everyone or if they should go with the best players only and give themselves the best chance to win the championship. The players enthusiastically and unanimously voted to play only the best players and go for the championship.

In the first game, to everyone's shock, the team got beat despite the best players playing their hearts out. The playoffs were double elimination so everyone figured this loss was a fluke and we would cruise to the championship. In a standing-room-only gym, the do-or-die second game was worse. With two minutes left in the game, our team was down by 15 points. With players and families completely dejected, our coach called a time out, cleared the floor of the first string and put in the five worst players on the team, including, of course, Conor.

The last couple of minutes were an eternity of errors and flubs as the other team effortlessly racked up 8 or so more points and our five worst guys lived up to their reputation.



Kudos to Conor Heybach, who recently lost 150 pounds

Our pain was unbearable as the laughs came from the opposition. However, down by 25 points with a few seconds left, we inbounded the ball. One of our boys somehow managed to get the ball down court and with only a few seconds left passed the ball to a very surprised Conor at the top of the key.

Conor turned to the basket, fired a jump shot and with a perfect swish, scored 2 points at the buzzer. The packed gym exploded with cheers. We lost by 23 points, but you would have thought we won. The players mobbed Conor and lifted him onto their shoulders and carried him around the court as the crowd went wild. There was not a dry eye in the place. Even the opposing team's coach and players shook Conor's hand, and their fans gave him a standing ovation. Conor went into the record books with his only two career points.

At the end of the year, at the annual sports banquet held at a very nice restaurant with everyone in jackets and ties and nice dresses, the athletic director, coaches and staff give a number of awards for outstanding athletic contributions. Awards such as MVP, high scorer, fastest time, most tackles, and so on, are awarded across the various sports throughout the year. Conor was not a candidate for any of these awards.

At the very end they then award the most prestigious, much anticipated and highly coveted trophy given every year, the Hardey Prep Athletic Courage Award. This award is typically, and deservedly, won by the tallest, strongest, best looking and most talented young man in the school. However, as the athletic director described, the award is given to the athlete who displayed the most courage throughout the year and who embodied the best values the school wishes to impart to its students.

When the athletic director announced Conor's name, we were speechless with emotion and pride. He walked to the podium and accepted the award to thunderous applause. It hangs on our wall today, and we are still as proud of him as that night at the banquet.

Although we continue to be realistic about and struggle along with Conor and his capabilities and worries about his future, he lives at home with us, is now a senior in college at Northeastern Illinois University, and made the Dean's List last year with a 3.8 out of 4.0 GPA. We try our best not to underestimate him. And — he has recently lost 150 pounds!

Conor is also a member of our Adults With PWS Advisory Board.

Our PWSA (USA) Web Site Goes World Wide

Our PWSA (USA) web site, www.pwsausa.org, now has 4,921 pages! Visitors totaled 882,662 in 2006, averaging 73,555 page views per month. Visitors were not only our neighbors in Canada and Mexico, but also people from Europe, Australia, Asia, Africa and South America.

We currently have nine e-mail support groups (listed below). Due to the nature of Prader-Willi syndrome, symptoms tend to change over the course of the individual's lifetime, so our eSupport Groups have been organized according to children's ages: Birth to 5 Years, 6-12 Years, and Teen Years. There are other groups as well. Support and input on each eSupport Group is welcome from care providers and parents of children of all ages

Log on to These PWSA (USA) eSupport Groups

Go to www.pwsausa.org/support and click on the group that interests you.

- Autism – Parents/providers of dual-diagnosed PWS and autism
- 0-5 – Parents/providers of Infant and preschool children
- 6-12 – Parents/providers of school-age children
- Teens – Parents/providers of teens and young adults
- Extreme – Discussion group for extreme conditions in PWS
- Military – Parents and providers in the military
- PWS – For people with PWS
- Spanish – For Spanish-speaking parents/providers
- Siblings – For siblings of those with the syndrome

Adults With PWS Advisory Board Opening

The Adults with PWS Advisory Board has an opening for an additional member. This group meets to discuss issues and share experiences specific to adults with PWS and also makes recommendations to PWSA (USA) on ways to help provide support for both adults and children who have PWS. The group is also planning a new venture: Ask the Advisory Board. It is a special column where readers can ask advice from PWS Advisory Board members.

Current PWS Advisory Board members are: Shawn Cooper (Georgia), Brooke Fuller (Michigan), Conor Heybach (Illinois), Kate Kane (Maryland), Andy Maurer (South Carolina), Margaret Miller (Pennsylvania) and Abbott Philson (Maine). They will be meeting at the PWSA (USA) National Conference in Dallas, Texas this summer.

If you are interested in being considered for the board, send us information on who you are and why you think you would be a good representative for children and adults with Prader-Willi syndrome. Also let us know your address and phone number. Send the information to:

Prader-Willi Syndrome Advisory Board
c/o PWSA (USA)
5700 Midnight Pass Road
Sarasota, FL 34242

Contributions in Memory Of

Paul Alterman

John & Marilyn Bintz
Suzanne Cassidy, M.D.
Bill & Judy Castle

Odell Cooper

Ashley Adams
Elsie & Don Castello
Tim & Carol Hearn

Elodia DeBlasio

Penny Ensley
Francis Mayerhofer
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Due to space limits, listed are Major Benefactors, In Memory Of, and In Honor Of. More donations are listed in the Annual Report.

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Thank you for Contributions through March 2007

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

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acknowledges the
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Angel Fund



Goal: \$150,000

Donations
as of 3/31/07:
\$124,864

Help Us Reach the Top!



National Organization for Rare Disorders
2006 NATIONAL ORGANIZATION MEMBER

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.

