



The *Gathered View*

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



Aidan Dunn, New York

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Tough As Nails

Jenni Earns Her Varsity Letter in Swimming

By Doug Noll

Nearly 50 high school swimmers received their varsity letters March 8, 2005 at the Rockville High School Swim and Dive Team awards banquet in Rockville, Maryland. This culmination of a successful season of competition is a great accomplishment for any student, but it was particularly special for my daughter Jennifer, who has PWS, who also received her varsity letter for participation on the team.

As Jenni stepped up to the podium to receive her letter from the coach, I reflected upon all she had accomplished over the past seven years.

Since Jenni's PWS diagnosis just before her 3rd birthday, my wife Linda and I have tried to keep her active to help manage her weight. As a pediatric physical therapist, Linda recognized the benefits of swimming for increasing Jenni's strength and endurance. Jenni learned to swim at age 6 through formal lessons at our local pool.

As a former competitive swimmer, I took on the challenge of helping her with stroke mechanics. Jenni loved going to the pool, and enjoyed our one-on-one swim clinics. By age 8, she was able to swim the length of a 25-meter pool. It wasn't pretty, and it wasn't fast, but she could make it across... largely aided by the fact that she floated like a cork!

It was a Saturday morning in June of 1998 that Jenni first joined the swim team at our summer pool, Manor Woods Swim Club in

Rockville. Jenni was then 9 years old, and the team was holding time trials. We thought that team participation would be good for Jenni, and she really wanted to try out for the team. While she was definitely able to swim the



Jennifer Noll, who has PWS, with her varsity letter. With Jenni are her high school coach Kevin Beabout and his wife Sarah Spindel Beabout, who was Jenni's first swim coach.

length of a 25 meter pool, the 9- and 10-year-old freestyle event was 50 meters. Confident that she could finish, Jenni dove in (sort of).

She finished the first 25 meters well after everyone else had finished the 50 meters. With all eyes on Jenni, halfway through her second length, I was beginning to scan the pool deck for the lifeguard.

But Jenni was determined, and almost 2 minutes and 30 seconds later, she finished the

Jenni continued on page 14

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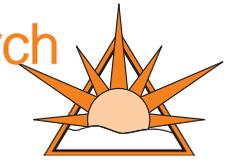
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Deadline to submit items for upcoming issues of *The Gathered View*
Jan/Feb: Dec 1; Mar/Apr: Feb 1; May/Jun: Apr 1;
Jul/Aug: Jun 1; Sep/Oct: Aug 1; Nov/Dec: Oct 1

Members Only: Check our PWSA (USA) web site for Special Opportunities Limited to Members: www.pwsausa.org
User Name: members; Password this issue is COWBOY
If asked for Domain Name it is CIMCO

PWSA(USA): Making Exciting Strides in Research



By *Janalee Heinemann, Executive Director*

Thanks to a tremendous amount of volunteer time from our energized Research Committee, the expertise of our scientists in PWS on our Scientific and Clinical Advisory Boards, our database guru Barb McManus, the funding efforts of our Development Committee, and you, our members, we've been able to put more funding and emphasis on research. Our large membership base and years of practical experience help complement the direction and implementation of research. Highlighted below are three phases of our current quest to unravel the complex puzzle of PWS.

Where We Are – And Where We Are Going

PWSA(USA) offers a total of up to \$300,000 of grant assistance for scientific researchers with an interest in improving the lives of those with PWS. Projects of up to \$50,000 per year for two years aimed at discovering and developing treatments, cures, and technologies benefiting those with PWS will be competitively awarded.

While PWSA(USA) is open to insightful grants regarding PWS, we have identified health issues we believe are especially meritorious for research focus. Grant requests in any research field (e.g. genetics, neurology, endocrinology, pulmonology) that provide insights into therapies will receive the highest priority:

Obesity: This is the number one threat to the life expectancy and life quality for those with PWS. The effort to control obesity and the resulting medical consequences of obesity, combined with the stress these issues bring to families, make hyperphagia a life-long threat. Projects leading to therapies/actions to reduce hyperphagia and/or obesity are a funding priority.

Respiratory: Due to life-long hypotonia and the complications of obesity, people with PWS are at risk for pulmonary issues, including sleep apnea, health risks from upper respiratory infections, and aspiration. Projects that could lead to therapies or action to reduce the threat of respiratory issues in PWS will be the priority for funding.

Gastrointestinal: Recent sudden deaths due to gastrointestinal events highlight the significance of gaining greater understanding of gastrointestinal processes and risks for those with PWS. Studies to develop therapies or action to reduce risks of gastrointestinal issues are a funding priority.

Funding Valuable Research Projects

Current research being funded

- Dec. 2003 — Dr. Jean-Pierre Chanoine, Effect of Somatostatin on Ghrelin Concentrations, Food Seeking Behavior and Weight in Patients with PWS
- Sept. 2004 — Elisabeth M. Dykens, Ph.D., The Use of Psychotropic Medications in PWS
- Dec. 2004 — Dr. David A. Stevenson, Causes of Death in PWS
- Mar. 2005 — Dr. Daniel J. Driscoll, Ph.D., Dr. Anthony Goldstone, Ph.D. et al., Functional Magnetic Resonance Imaging of Reduced Satiety in PWS and Obesity

Our Years of Progress

- Genetics – diagnosis & genes identified
 - 1981 — Deletion in long arm of chromosome 15 identified as cause of many PWS cases.
 - 1983 — Deletion origin determined as from the father's contribution to the chromosome pair.
 - 1989 — Maternal uniparental disomy (UPS) identified, meaning both of the 15th chromosome pair are from the mother.
- Imprinting/epigenetics — PWS as model for this important area
- Mouse models
- Brain – hypothalamus
- Treatments – growth hormone – FDA approval in 2000
- Psychiatric meds such as SSRIs
- Earlier diagnosis and treatments = increased quality of life – over 600 families are part of the PWSA (USA) New Parent Mentoring Program.
 - Parent support groups (1975 USA; 1980s UK)
 - Collaborative Research Groups — Rare Disease Clinical Research Network and European Union groups
 - IPWSO (1990) = World-wide support — 60 countries are now members
 - Education, awareness (of families & physicians)
 - Communication (e-mail, Internet, etc.)
 - PWS as important genetic model to understand obesity and appetite regulation

Influencing Government Funding

Support researchers by actively advocating in DC for NIH funding and other government funding to go to PWS research.

Bringing Scientists Together for Research

Sponsoring a two-day fall meeting for experts in research on hyperphagia (uncontrollable appetite) to share current knowledge and identify and plan for future research.

Sponsor an Annual Scientific Conference — the only PWS specific conference in the U.S. — which brings together top researchers and physicians in the field of PWS to share knowledge and brainstorm needed research.

Daily work with our two medical/research boards to collaborate on medical and research issues.

Supporting Researchers

Sharing research and medical information on PWS at medical conferences, on the web, and in the newsletter .

Announcing research projects and encouraging participation.

Writing letters of support for appropriate PWS research.

Make Sure You Are Counted: Help Us Complete Our PWS Database!

PWSA(USA) currently has the largest database collection of information on children with Prader-Willi syndrome, but some of it needs updating and all data on families lacks essential information that could be crucial to improve the medical care of our children.

Board Member Barbara McManus is helping to improve our database by increasing the size and accuracy of the information. You can find the form on our web site at www.pwsausa.org/population/ or e-mail us at national@pwsausa.org, or call the national office, 1-800-926-4797 and ask to have a form sent to you.

Everyone who completes a form will receive a copy of our new Medical Alert booklet, which is essential for doctor and emergency room visits.

In a perfect world, PWSA(USA) would have the names and pertinent information needed for everyone with the syndrome. There is power in numbers!

If we can acquire a more comprehensive database, National Institutes of Health (NIH) and other funding sources will be more willing to help our children through funding continued research in PWS and obesity. You don't need to be a member of PWSA(USA) to be included in this data collection.



Board member and PWSA(USA) Webmaster Barbara McManus wants to hear from YOU

You can help us help you, your family and all those who have been touched by Prader-Willi syndrome just by completing a form and becoming part of our national database. Please act now!

PWSA (USA) Database: Information Update to April 2005

Total respondents to date: 1,141

Please note that when viewing percentages, 30% of respondents had children under age 5. In a future edition of *The Gathered View*, we will break down the statistics into different age categories, which will change the percentages. We will also add information to the *Members Only* section of the web site and share more information in future *Gathered View* editions.

At Birth	Type of PWS
<1% Twins – identical	41% Paternal Deletion
2% Twins - fraternal	21% Maternal Uniparental Disomy (UPD)
3% Assisted reproductive techniques	2% Imprinting defect
25% Breech	2% PWS Like
22% Premature	2% Translocation
27% Emergency c-section	31% Unknown
52% Tube feeding	

No.	Ages	Demographics
339	0 to 5	51% Female
216	6 to 12	49% Male
160	13 to 19	3 sets of identical twins (both have PWS)
383	20 to 59	19 sets of fraternal twins (one has PWS)

IMPORTANT NOTE: Because of the potential of future journal publications, we request that this information NOT be reprinted without express written permission from PWSA(USA). We are sharing this information as a courtesy to our members, and to those who participated in the PWSA(USA) survey.

Major Medical Concerns – Current or Past

64% Weight related	1% Mitochondrial disorder
39% Sleep apnea	10% Seizure
9% Aspiration	13% Autistic behavior
19% Other respiratory complications	9% Diabetes
8% Heart problems	9% Hypothyroidism
10% Osteoporosis	15% Pubic or axillary hair before age 8
34% Curvature of the spine (scoliosis, kyphosis)	16% Hormone replacement therapy (e.g., estrogen/ testosterone)
14% Fractures	4% Gall bladder disease
7% Hip dysplasia	0 Pancreatitis
7% Other bone problems	11% Gastric/intestinal disorders
45% High pain tolerance	
33% Severe skin picking	54% At some time have received or are receiving Growth Hormone



Let's Love Our Children By Taking Control

Carolyn Loker

Dear Families,

Yes, I certainly understand why you as parents had a range of emotions while watching the 20/20 segment about PWS. I just watched this again, and cried for our children, and even had goose bumps when Dr. Dan Driscoll was talking about our children and stated, "We think we're going to get major clues by understanding Prader-Willi syndrome, which is one reason for obesity that gives us a window of opportunity to go in and help to understand other causes of obesity, and, eventually, to figure out what's broken and then how to fix it."

And also the commentator stating, "Today, kids born with Prader-Willi can get off to a better start. They can be diagnosed virtually at birth and start hormone therapy to assist in their development. Driscoll is studying the brains of kids with Prader-Willi. He thinks research into how Prader-Willi syndrome triggers this condition, what body chemicals are involved and how they interact could yield benefits for everyone who struggles with their weight."

Yes, it is sad that our children have PWS, and we do not know what the future holds for them. But if you can see in your heart to celebrate, let's do. Let's celebrate getting an early diagnosis; let's celebrate early intervention; let's celebrate this list of wonderful parents willing to help each other; let's celebrate that we have the PWSA (USA) organization willing to help spread awareness, educate, counsel and research for a cure. Let's celebrate that PWSA (USA) has wonderful researchers on our boards who dearly love our children and want to find that cure for them.

So what must we do as parents? Do we let our children take control, or is it our place as parents to take control, to guide them, to keep them healthy even if it means saying "No."

Saying no is loving them! Keeping their weight in an appropriate range, even if we have to lock, is loving them. Keeping their tantrums at bay is loving them. If we don't do this now, at their young age, then behaviors will be formed, and it will be much more difficult to change.

Recently I have heard of so many of our children age 3 to 9 years old who are morbidly obese. What is really distressing is that these are parents who *have* received an early diagnosis. It's time to set appropriate external controls for our children in every aspect: at home, school or wherever they are. Do trust that our children want that; they will love you for it because it shows that you care. This takes our children's anxieties away, if we as parents have those systems set in place.

I'll share our story about Anna. I guess you can say I'm one of those "older" parents now. Our sweet Anna is 10 years old and was diagnosed at 17 months of age. Many of you are probably saying, "Wow, that was late!" **CELEBRATE YOUR EARLY DIAGNOSIS!**

Dr. Jim and Carolyn Loker with their daughter Anna, age 10, who has PWS



For us, 10 years ago, that was early! But it didn't change anything; she was already getting early intervention, and back then, growth hormone was not recognized by the FDA, but that didn't stop us. She started GH as soon as she had a stimulation test to prove that she was indeed GH-deficient and after we won our appeal with our insurance company. **CELEBRATE BEING ABLE TO START GH EARLY AND NOT HAVING TO GO THROUGH THE APPEAL PROCESS AND A DAUNTING STIMULATION TEST!** Soon after starting GH, Anna sprouted like a weed and now measures a fraction under 5 feet!

As soon as the diagnosis was made, we knew we had to be vigilant with counting calories (although her weight was okay at the time), and I can proudly say that Anna is tall and looks slim, weighing in at 78 lbs. So at almost 5 feet tall and 78 lbs. puts her at the 85th percentile for height and the 50th percentile for weight. And to top that off, she is a very sweet and happy girl. **WE ARE CELEBRATING THAT!**

Love continued on page 15

27th PWSA(USA) National Conference

July 27 – July 29, 2005

Sheraton World Resort, Orlando, FL

www.pwsausa.org click on Conferences/Events



Round 'Em Up And Get Ready To Head On Over To Conference!

With our annual PWSA (USA) National Conference fast approaching, we're expecting a great turnout! It includes a Scientific, Provider and Chapter President/Affiliate Day on July 27th followed by the General Conference and Youth Programs on July 28th and 29th.

General Conference includes several sessions of interest to all attendees

- Respiratory & Apnea Issues
- GI Issues: Perforation & Stomach Necrosis
- Life Enrichment Trusts
- The Latest in Research and an Overview of the Scientific Session presentations
- Age-appropriate Sharing Groups and Grandparent Program

Special breakout sessions feature topics specifically geared toward the issues and achievements of Adult, Youth (school-age), and Children age 0–5. Topics include:

Adult Sessions

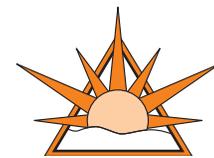
- Uncomplicated PWS: Cognitive & Behavioral Characteristics, Essential Environmental Components
- Complicated PWS: Medical Complications, Psychiatric, Complications & Crisis Intervention
- PLAN: Planned Lifetime Assistance Program
- Successful Vocational Programming
- Components of a Quality Residential Program

Youth Sessions

- Ins and Out of IDEA and IEPs; IEP Questions & Answers
- Behavioral Issues
- Psychiatric & Medication Issues
- The Pragmatics of Speech & Language

Children Age 0–5 Sessions

- Overview — What every parent should know
- Sensory Integration
- Speech and Language Guides
- IDEA and IEPs



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Conference concludes Friday night with the annual **Gala Banquet**, which this year has a country-and-western theme, and includes a live performance of the song "**Brand New Me**" by the recording group **Hometown News**.

Don't miss these important deadlines: Registration deadline is June 30, 2005. A \$25 per-person late fee applies AFTER June 30. No YAP/YIP Registrations will be accepted after June 30. No registrations can be accepted after July 18th.

Log on to the PWSA (USA) website and download your forms or register online TODAY!

Chapter View

Chapter activities are popping up like spring daffodils. Annual Walk-a-Thons are planned for **Southern California** May 1 and for **Northern California** May 21. In April **Wisconsin** sponsored its annual Hobby, Social & Training Day, offering opportunities for siblings, children and adults with PWS to try out a new hobby or expand on an old one. **Pennsylvania** plans its sixth Annual Golf Outing in May. **Florida** prepared for its annual overnight Spring Conference in April.

PWS Families of Ohio held its Annual dinner, dance and auction in March. Total funds raised came to \$18,000! These funds will be used for a donation to National, National conference grants for Ohio families, PW Families functions and other organizational needs, as well as a donation of \$1,500 to the International PWS Organization IPWSO.

In **New York** in March the Winthrop Pediatric Department and the Metropolitan Support Group with Dr. Moris Angulo and his staff combined to present a Symposium for parents, siblings and caregivers on practical strategies for everyday challenges and new advances in

PWS. Presenters included well recognized physicians, Janalee Heinemann, executive director of PWSA(USA), and the Hon. Daniel D. Angiolillo, president of the New York chapter.

The **New York** State Developmental Disabilities Planning Council (DDPC) awarded the Research Foundation of the Office of Mental Retardation and Developmental Disabilities (OMRDD) up to \$140,000 for the first year of a two-year project to develop a comprehensive approach to the identification, assessment of needs, intervention methodologies and training for individuals with PWS, their families, professionals and other caregivers. Funding for year two, approximately \$160,000, will be contingent upon successful completion of year one activities. The New York chapter has been and will continue to be integrally involved with the implementation of this grant, with parents, siblings, medical and other professionals being asked to serve on the task forces and Advisory Board.

Congratulations, New York! Wouldn't it be wonderful if something like this could be done in all states?!

— *Lota Mitchell, Associate Editor*

PWS in the News

Television Programs Deliver Two Strong Messages

By *Lota Mitchell, Associate Editor*

With not one but two television programs aired on major networks about the syndrome, PWS got a great big awareness boost in April!

"It's Not My Fault I'm Fat," filmed by the BBC (British Broadcasting Company), aired four times on the Discovery Channel. The show followed two British males, Craig, 13, and Chris, 22, and an American girl who went to the Children's Institute in Pittsburgh, Leona, 13. All were dangerously overweight. With considerable sensitivity, the concluding message pointed out how very difficult it is to walk in their shoes.

Although he weighed more than 400 pounds, Chris wanted so badly to be independent. Some of the British viewing audience reacted with anger that he was not forced to accept intervention, literally to save his life; thus social services stepped in and did a mandatory placement. Then, following the negative press that led to his being forced into placement, there was reverse public pressure, and Chris was let out on his own again. The issue of respect for autonomy versus need for care is a thorny one and not limited to Great Britain.

Certainly tears were shed by some who watched the program. Others wished it could have been more informative, including showing some of the strengths of people with PWS and their successes, rather than having the entire focus on appetite, obesity and behavior. But, as one person commented, "I personally felt the story was good. It was not so much about PWS but about the struggle with their hunger."

Kate Kane of Towson, Md., who has PWS, was interviewed for the TV program "20/20"



The 20/20 segment, "Rare Disorder Causes Endless Hunger," featured Maribel Rivera, 24, from California, and Kate Kane, 23, from Maryland, along with an interview with Dr. Dan Driscoll, who is on the PWSA(USA) Board of Directors and also chairs our Clinical Advisory Board. He stated, "We think we're going to get major clues by understanding Prader-Willi syndrome, which is one reason for obesity, that gives us a window of opportunity to go in and help to understand other causes of obesity and, eventually, to figure out what's broken and then how to fix it."

PWSA(USA) President Carolyn Loker said, "Millions of people now know or have heard, maybe for the first time in their lives, the term Prader-Willi syndrome. Just the fact they mentioned that PWS could hold the key to the obesity

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Suggestions for Creating A Medical Information Notebook

By Vicki Knopf

As the parent of a child with PWS, most of you have probably encountered medical professionals who have never heard of Prader-Willi syndrome and you have had to explain the syndrome and how it impacts your child.

Several years ago after having to give a dissertation on PWS at midnight to an ER doctor who had never heard of PWS before, I decided to put together a medical notebook for each of my three kids who have PWS. It has proved to be an indispensable tool many times.

Often during an emergency it can be difficult to remember important information such as medical conditions and medications. For us, the medical notebook has accompanied ambulance personnel twice during emergencies, and each time we have gotten tons of praise from the EMTs for providing the information they needed to provide the proper care to our child.

Things you will need to get started:

- A vinyl covered loose leaf notebook. I bought mine at an office supply store for \$1.99
- Some computer paper
- Clear page covers
- All your contact information
- Prescription information

On the outside **FRONT COVER** of the notebook, write: **MEDICAL INFORMATION FOR:** (your child's name). Medical Alert Brochure: A Diagnostic and Reference Guide for Physicians and Other Health Professionals.

Inside the notebook cover, write: If found, contact (add your name and contact information).

PAGE 1 should contain the following:

- Your child's full name
- Birth date
- Address
- Phone number
- Both parents' full names
- Emergency numbers, cell phone, pagers, etc
- Primary care provider information
- Insurance information (make sure to include the name of the person who carries the insurance and their employer)

PAGE 2 should start with the sentence "(insert your child's name) has PRADER-WILLI SYNDROME."

Then explain any other medical conditions and allergies your child has, and ALL medications, the doses and time of day given. Don't forget to list any supplements and Growth Hormone, too.

- List any and all surgeries; year and reason for the surgery
- List any past broken bones or other significant injuries
- Explain any history of seizures, even febrile seizures
- List any hospitalizations, including date and reason.

PAGE 3 AND PAGE 4 should contain the Medical Alert Brochure: A Diagnostic and Reference Guide for Physicians and Other Health Professionals, which is available through PWSA(USA). I use two brochures, displaying one side on page 3 and the other side on page 4. PWSA(USA) recommends also including the new Medical Alert booklet, essential for doctor and ER visits.

PAGE 5 should list all specialists your child sees, along with their phone numbers.

The notebooks I use also have a pocket on the inside and back covers. I keep several copies of the Medical Alert Brochure available to hand out to any professionals we see. I also keep several sheets of notebook paper in the back for me to write down notes.

It is extremely important that you keep the notebook current!

Remember to check it often and change any medications as dosages and medications change and add any medical information as needed. I have my sheets typed out as MS Word Documents so that I can update them in my computer when information changes.

It is also essential to keep the notebook in an easily accessible location so that you can grab it at a moment's notice should it be needed.

Remember, this book is about your child, so customize it with any other personal information you feel is important to know in the event of an emergency.

I hope you won't ever need this book, but if you do, you will be prepared to answer questions that could save precious time and make a huge difference in the medical care your child receives.

Vicki and her husband David Knopf have seven children, including three children with PWS, two of them adopted. They live in Salem, Connecticut. Vicki heads the Parent Mentoring II program and serves on the Publications Committee.

The Chuckle Corner

In the Beginning...

I was talking to Alex, my 12-year-old with PWS, about the changes he will be encountering as he is going thru puberty. We talked about his voice changing and his "Adam's apple" becoming more prominent.

He turned to me and touched my neck and said, "Mom, this is your Eve's apple!"

**Mary Lynn Larson
Appleton, Wisconsin**



Do you have a joke or funny story to share? Please send it to the PWSA(USA) office. Be sure to include your name, telephone and address in case we have questions.

View From the Home Front

FYI: Some Conference Expenses May Be Tax-Deductible

Internal Revenue Service, Publication 502, Medical and Dental Expenses, which explains the medical and dental expenses that may be claimed on Schedule A, states “You can include in medical expenses amounts paid for admission and transportation to a medical conference if the medical conference concerns the chronic illness of yourself, your spouse, or your dependent. The costs of the medical conference must be primarily for and necessary to the medical care of you, your spouse, or your dependent. The majority of the time spent at the conference must be spent attending sessions on medical information.

Caution The cost of meals and lodging while attending the conference is not deductible as a medical expense.”

- Admission would be the part of the registration fee for the sessions only. That information will be available at the Conference.
- It is your responsibility to keep all receipts, including the written information on the Conference topics and description of the content of the sessions.
- If you have other questions, please contact your personal tax advisor.

— *Kay Goldberger, PWSA(USA) Treasurer*



You Never Know What You Can Do Till You Try

Last year Christine and Jeff Bevacqua of Tinton Falls, N.J. hosted a dinner and dance for friends and family in honor of their nephew Jack Martin Bevacqua, age 3, who has PWS, shown above with his parents Christie and Kevin. Christine and Jeff collected gifts and raffle items, and were hoping for 100 guests and maybe \$3,000. **They raised \$12,000!** This year, they’re trying again. They plan to hire a band instead of a DJ, find even more great raffle prizes and get all of the food donated to offset expenses. Who knows how much they’ll raise this time!

L-R: Shaina, brother Kyle, Rhiannon,
Guy, Kendall, Ryan, and Kaylie.

Christian, who has PWS, is the cutie pie in the middle.

Christian’s Family Christmas

Hello, my name is Christian Coats and I have Prader-Willi syndrome. I’m only 17 months old so I don’t know much about PWS, but what I do know is how much my family loves and cares for me.

Just before Christmas my 12-year-old cousin Kaylie found a donation card for PWS. Nana explained to her that funds were needed to help people with PWS.

Kaylie decided that she wanted to help, so she typed up a description of me and PWS and passed out flyers in her neighborhood, asking people to please leave out any bottle returnables that they had. She spent the next week collecting all the bottles. Her mom and dad matched what she collected and then my other cousins — Kendall, 8, Guy, 12 and Shaina, 19 — also gave their own Christmas money. Then they spent the night before Christmas calling family members to donate also. They had raised \$600 to donate to PWSA(USA) in my honor and presented this donation to me, my mom, dad and brother Kyle on Christmas! My cousins were all so excited that they could of cared less about their own Christmas gifts.

It was the best Christmas our family has had, and as you could imagine, a lot of tears were shed. We are all so proud of our family. With love, faith and support like that, I can



conquer Prader-Willi. Special thanks to all my donators: cousins Kaylie, Guy, Kendall, Shaina, Ryan and Rhiannon; Nana, Mimi and Papa; aunts and uncles, Mike, Karrie, Lori, Guy, Lori and Jimmy; great-grandparents and Bonnie, Don, Ed and Sandy.

Love, Christian

Kelly and Steve Coats live with their son Christian in South Lyon, Michigan.

Stomach and Intestinal Problems in People with PWS: Some

By Barb Dorn, R.N., B.S.N.

My son Tony, now 20, who has PWS, has been experiencing problems with abdominal pain, constipation and hemorrhoids. Recently I have communicated with several other parents who have shared their stories about stomach and intestinal problems in their children. I was amazed to hear how common these problems are. It is important for us to get more definitive answers and solutions for these gastrointestinal concerns.

We continue to learn more about health issues and Prader-Willi syndrome (PWS). Over the past few years, we have gained a greater understanding of various stomach and intestinal problems that appear to be somewhat more common in persons with PWS. We now know that symptoms of stomach distention or

amount of food that the stomach can accommodate. When a person over eats, the stomach stretches. It may become “over stretched” or distended. We know that people with PWS do not have the normal mechanism of registering fullness as they eat. They are at a very high risk of over distending their stomachs.

It has been found that people with PWS who have suffered from acute idiopathic gastric dilatation with gastric necrosis have had this occur shortly after a binge episode. It is not surprising to learn that persons with PWS who already have generalized low muscle tone may have poor muscle tone in internal muscles of their bodies.

**Acute = Sudden onset/severe Idiopathic = Exact cause unknown Gastric = Stomach
Dilatation = expand, stretch, open Necrosis = Death of tissue (stomach)**

The usual symptoms seen in gastroparesis include abdominal distention or bloating, abdominal pain, heartburn,

bloating can possibly be related to a condition called gastric dilatation, a life-threatening condition. We may be beginning to have answers to other stomach and intestinal concerns; however, at the same time, this knowledge is opening the door to more questions. It is our hope that we will gain a better understanding of these problems today so we can prevent them from ever occurring in children and adults with PWS tomorrow.

It is believed that if a person with PWS greatly distends his/her stomach, it can stretch to the point that it cuts off its blood supply, thus causing necrosis (the stomach tissue dies). This can be a life-threatening condition if it is not quickly diagnosed and treated. Over the past few years, it has been discovered that many people with PWS have developed ACUTE IDIOPATHIC GASTRIC DILATATION WITH GASTRIC NECROSIS. Unfortunately, most of these cases have been diagnosed in a postmortem examination.

vomiting and regurgitation of stomach fluid into the mouth. These symptoms can be very difficult to detect in people with PWS. It is urgent that any signs of acute abdominal illness be evaluated by a health care professional.

Gastroparesis, Gastric Dilatation/ Necrosis and PWS — What Do We Know?

PWSA (USA) receives calls from around the country about people with PWS who are experiencing acute gastrointestinal problems. More and more children are being diagnosed with a problem called GASTROPARESIS (weakness of the stomach). This condition occurs when there is a delay or slowing in the contraction of the stomach. Because of this delay, stomach contents build up and abdominal distention can occur.

The stomach is a muscle that contracts very much like our heart muscle. Unlike the heart, instead of pushing blood, the stomach pushes food out of its cavity into our intestine for further digestion. Feeling full is our body's mechanism for regulating the

If a person with PWS is experiencing gastrointestinal symptoms and problems, he/she may be referred to a specialist called a gastroenterologist (a doctor who specializes in disorders of the stomach and intestine), who will conduct tests to determine the cause of these problems. Optimally, gastroparesis is diagnosed through a gastric or stomach-emptying test. Food that has been “marked” is given to the patient. A scanner then

Those with PWS may be at higher risk for having gastroparesis. Some risk factors seen in both conditions summarized below.

Risk factors for Gastroparesis

- Diabetes – most common cause
- Adrenal and thyroid gland problems
- Certain drugs weaken the stomach – many antidepressants and heart medications
- Neurologic or brain disorders such as Parkinson's, stroke and brain injury

Risk Factors Seen in PWS

- Diabetes
- Many with PWS have been found to have low functioning of the thyroid gland.
- Many with PWS take antidepressant medications as part of behavior management and some may be taking heart medications.
- We continue to learn the effects of PWS on brain functioning.

tracks the time it takes for food to leave the stomach.

Another test that may be performed is an electrogastrogram (EGG). This is a test similar to the EKG test done on the heart. The EGG measures the electrical waves that normally sweep over the stomach with each contraction. In gastroparesis, these electrical waves are slower than normal.

If caught early, gastroparesis can be treated. If there is an underlying medical condition, it needs to be treated. Diet and nutrition must also be adjusted. Since fats delay stomach emptying, foods high in fats should be avoided. High-fiber food also stays in the stomach for a long time. Such foods may need to be restricted if gastroparesis is severe. Liquids leave the stomach faster, so they are encouraged. It is also been found that eating frequent small feedings 4-6 times a day may be helpful. In many cases, medications may be used to help stimulate the stomach to contract and empty more normally.

It is important to follow the advice and recommendations of the health care professional and/or dietician who is most knowledgeable of that person's condition and needs.

QUESTIONS: Is gastroparesis a common finding in children and adults with PWS? What should be done to diagnose and treat this condition? Are there any persons with PWS who seem to be at higher risk?

Constipation – Could this Be a Problem for People with PWS?

Over the past year, PWSA(USA) has received an increased number of reports of constipation in children and adults with PWS. In many cases, this problem has been discovered by accident. Oftentimes, a large amount of stool has been noted in their intestines while having an x-ray or test done that is not specifically looking for this problem.

Many parents and caregivers also report that children or adults with PWS experience rumination (the regurgitation of undigested food from the stomach back up to the mouth). For so long, it was believed to be a behavioral issue. Could this problem be related to gastroparesis? Do we need to change our approach in its management? Is this problem a sign of gastroparesis?

So far, no research studies have been done to suggest or confirm if those with PWS might be at higher risk. Intestines, like the stomach, are muscular organs which push contents forward so that nutrients are broken down, absorbed and/or eliminated as part of the digestive process.

Constipation can be defined as infrequent passage of hard, dry stools or difficulty in evacuating stools. Ideally, a person should have a bowel movement every day or so, and it should be soft and bulky. There can be several causes for constipation. Some of the more common causes are summarized in the box below.

Common Causes for Constipation

- Lazy colon that does not contract properly and move the stool through the intestine (a "hypotonic" colon)
- Thyroid deficiency
- Low potassium level
- Certain medications such as medications used to manage mood/behavior, pain, diuretics (water pills)
- Spastic colon
- Tumors or advanced diverticulosis
- Abuse of laxatives
- Disruption in normal routine – often seen when a person travels

The longer stool remains in the colon, the greater the chance of it becoming hard and dry. As stool travels through the intestine, more and more water is absorbed, resulting in firmer, harder stool. When a person does not have adequate water intake, the problem can get worse. Water and other fluids help to keep the stool moist and prevent this.

If a person has a "lazy colon," it may be contracting, however it may not be contracting strong enough to provide

the person with adequate elimination of stool. In these situations, a person may be having a BM every day and still have a large quantity of stool remaining in the colon. This build-up can also cause over-distension of the colon. It can cause pressure — both forward (toward the rectum) as well as backward (toward the stomach). There has been a question as to whether this build up of pressure in the colon may be adding to the problems in acute idiopathic gastric dilation and necrosis. Many people who have suffered with this condition have also reported a problem with constipation.

The primary way constipation is diagnosed is by listening to a person's history and complaints. For many people with PWS, that reporting is often sketchy and incomplete. In the early years, parents may be assisting with toileting hygiene issues and see their child's stool. As they grow older and more independent, this is not the case.

If a problem is suspected, the health care professional may perform a physical exam along with additional diagnostic testing. Blood testing may be done to rule out a thyroid or potassium deficiency. A barium x-ray may be performed. This is an x-ray using a contrast solution (barium) that is instilled with an enema into the lower intestine. Other tests such as a sigmoidoscopy or colonoscopy may be indicated. In both cases, a flexible lighted instrument is inserted into the rectum in order to view the intestine. The sigmoidoscopy allows the health care provider to view the rectum and lower descending colon. The colonoscopy is a more extensive test in which all of the large intestine can be viewed. If polyps (blood-filled growths

Stomach continued on page 12

that can often develop into cancer) are found, they can be removed and biopsied. Growths may be one of the more serious causative factors that need to be ruled out.

Treatment of constipation is dependent upon its cause. Once serious problems are eliminated, simple measures can be used.

Guidelines for Treating Constipation

- Eat regularly (not usually a problem for persons with PWS).
- Drink plenty of water and fluids daily (often difficult for persons with PWS).
- Encourage regular walking and/or exercise.
- Use a bathroom when the urge to have a BM occurs. If needed, set aside 15 minutes after a meal to sit on the toilet.
- Eat a diet of high fiber, fruits and vegetables (fresh is often better).
- Use laxatives and/or enemas as recommended by your health care provider. There are different kinds of laxatives that work on the intestine in different ways. Your provider can assist you in choosing the correct one. Overuse of laxatives can cause the colon to become dependent upon them.

QUESTIONS: Are people with PWS at higher risk for constipation? Do they have a tendency to have a “lazy colon”? Are they effectively and adequately emptying the colon? Can people with PWS prevent issues with constipation? If yes, what appears to be the most effective form a treatment? Does constipation predispose the development of acute idiopathic gastric dilatation with necrosis?

Hemorrhoids and Anal Fissures – An Explanation for Rectal Irritation and Picking?

Hemorrhoids are a common nagging disorder. They are dilated (enlarged) veins that occur in and around the anus and rectum. They may be internal (inside the rectal canal) or external (outside). They can cause some uncomfortable sensations and problems, including itching, irritation, bleeding and pain. If the hemorrhoids are external, they can often be seen as

small protrusions from the anus. If they are internal, they may not be seen, and a person may not be aware they have them. Conditions that can contribute to the development of hemorrhoids are poor bowel habits, constipation, diarrhea, obesity, pregnancy and straining during a bowel movement.

Anal fissures are small tears in the lining of the anus. They can result from a dry hard bowel movement that causes this tissue to break. They are also seen when a person experiences bouts of diarrhea or irritation. A fissure can be quite painful during and following a bowel movement.

Bleeding and itching may also be associated with these. They can become infected so that an abscess or ulceration may develop. In these cases, fever, drainage and swelling may also be present.

Diagnosis of any rectal problems is primarily done by examination by a health care provider. Because of the presence of bleeding, further studies may be done to make sure other more serious conditions (colitis, Crohn’s disease, polyps, and tumors) are ruled out.

Many of these problems resolve with no treatment. However, symptomatic treatment is often helpful in minimizing the discomfort associated with these problems. Stool softeners help to reduce the pain in passing the stool. Medicated creams and/or pads may decrease pain and itching. A sitz bath (soaking the buttocks in warm water) helps to relieve discomfort and promote healing. Medications such as antibiotics and/or suppositories may be prescribed. The health care professional may need to surgically open up an abscess to promote drainage and relieve

pain. The itching, pain and irritation of hemorrhoids and other rectal problems can be very bothersome. In addition to this discomfort, the problem can be compounded if a person is also experiencing rectal pressure often associated with severe constipation.

QUESTIONS: Do people with PWS have a tendency to have problems with hemorrhoids, anal fissures or other rectal problems? Is the start of rectal picking a result of persons with PWS experiencing these sensations and/or problems? Could this problem be prevented or decreased by paying closer attention to bowel habits, hemorrhoids, anal fissures and/or other rectal conditions?

Questions and Answers — Where Do We Go from Here?

We are just beginning to learn and question how the gastrointestinal system works in persons with PWS. We are also starting to gain knowledge about some of the health concerns that are also being diagnosed. We don’t have all the answers. What we do know is that we need to take a closer look at stomach and intestinal problems in people with PWS. We must learn what can be done to prevent serious health problems from occurring. We must proceed by encouraging and supporting more research. We must do everything to nurture the search for more answers.

Barb Dorn is an RN at the University of Wisconsin Hospital and Clinics, past president PWSA(USA), past president and program director PWSA of WI, Inc. She lives in Verona, Wisconsin with husband Don and sons Tyler and Tony, who has PWS.



Managing Conflicts of Interest in Research

By *Janalee Heinemann, Executive Director*

Since two recent research grants involve members of our medical boards, AND since following all ethics of non-profit standards is important to us at PWSA (USA), these are the methods we use to avoid and/or manage conflict of interest.

1) When a board member or close affiliate is involved with a grant or funding request, that person is excluded from all conversation, advocacy, and vote on the topic.

2) Those reviewing the grant are asked to evaluate and assure not only that the grant request is appropriate, but that the funding request is equal to or less than what would be appropriate or found elsewhere to assure a fair transaction.

3) Our three boards (governing, scientific, and clinical advisory – 38 members in total) are large enough and diverse enough to help avoid the type of favoritism observed on some very small boards.

4) We have a clear conflict-of-interest policy.

5) We have an attorney on our governing board and are members of a program (MAP) that allows us open access to consulting with an attorney who is a non-profit specialist.

6) We follow the guidelines of the National Center for Nonprofit Boards and other respected monitoring agencies.

7) We maintain open disclosure on our actions and transactions.

8) We have records to show that the action makes organizational sense.

To exclude some of the best PWS researchers and talent from our boards would limit the quality of the work and the research we support. To exclude any possibility of a grant to these committed and talented people would penalize them for the volunteer work they commit to PWSA (USA). None of the non-profit ethics regulations or recommendations state that no grants or funding should ever be awarded to those on a non-profit organization's board. Instead they recommend managing the potential for conflict of interest by setting and following appropriate guidelines.

We have worked very hard at doing so over the years. In fact, some board members have been declined grants following peer review, because some of the most zealous scrutiny has come from fellow board members.

PWSA(USA) has a 167-page Policy and Procedure Manual which took us years to establish, and which we are continually building upon. We review and refer to it constantly to assure our members, our donors, the government, and ourselves that we are following all requirements established by agencies that monitor non-profit organizations.

Also note that we have membership in the Better Business Bureau and the Combined Federal Campaign, and are registered to raise funds in every state. We spend hundreds of hours to assure that every dollar given is used appropriately to enhance the lives of our children. — *Janalee Heinemann*

Tressa Enjoys Exercise Therapy With New Tryke

By *Mary Pringle*

Tressa now looks forward to working out, thanks to the delight of riding her new AmTryke®. It has allowed her to experience the pleasure of riding freely among peers without disabilities, and I have seen improved motor skills and strength development.

So what is an AmTryke? It's the trademarked name for a therapeutic tricycle for children with disabilities. Rotating handle bars are attached to same chain drive as the foot pedals, allowing rider's arms and legs to propel the tryke, and results in a total body workout. Straps secure the feet to the pedals, while torso and lap safety belts maintain the rider in the seat. A wide wheel base and narrow turning radius provide stability. It's fun for Tressa to use, which helps her body to gain strength, balance and tone.



Tressa Pringle, who has PWS, riding her tryke

Tressa received the Toddler model AmTryke, a therapeutic tricycle suitable for children about 1 to 4 years old. There are other sizes to meet the needs of all our kids. Such trykes are fitted through a licensed physical therapist. You can apply for a tryke through your local chapter of AMBUCS™, an organization dedicated to creating mobility and independence for people with disabilities. A bicycle company now manufactures them, and to date almost 5,000 trykes have been distributed.

Tressa was one of the first to receive the toddler style when it was released in late 2004. Contact your local chapter to get fitted for your tryke. Sometimes the AmTryke can be provided to children with disabilities at little or no charge. Go to <http://www.ambucs.com/AamtrykeDemoSites.shtml> and click on your state to find your representative. Or call

AmTryke Coordinator Pam Burleson, National AMBUCS, Inc., 3315 North Main St., High Point, North Carolina 27265; phone: 336-869-2166, Fax: 336-887-8451.

Mary and Clarence Pringle are the parents of Tressa, 3, who has PWS. They live in Cape Coral, Florida. The Pringles have adopted six children with disabilities.

Looking for The Next Super Teen

Super Teen April Boughton (L), who has PWS,
with her sister Emily



An article about April Boughton recently appeared in the *The Next Step* magazine. This magazine is targeted to teens and their life after high school... college, careers and life in general. Many of the teens in the Super Teens section have been nominated by the parents, teachers, counselors and friends. They are all involved in an amazing number of activities and do their best at everything they do. April is one of these winning super teens, and she appeared on the COVER of the March/April 2005 issue.

April is a 15-year-old freshman at Clay High School in South Bend, Indiana. She is the youngest of six children, and she has also had 13 foster siblings during the last five years. This experience has inspired her to become a future foster parent.

April has volunteered at St Joseph Regional Medical Center for a year, where she works on a floor that serves people with long-term needs. "In my volunteer work, I make a list of what other volunteers should do when they work," April says. "This is based on my experience with the patients and nursing staff."

She is involved in sign language club, Reins of Life horseback riding, has participated in the basketball and ice skating competitions at Special Olympics and is an altar server and Eucharistic minister at her church.

Nowhere in the magazine article was it mentioned that April also has Prader-Willi syndrome.

Do you know someone you would like to nominate for the March cover next year? You can apply to nextSTEPmag.com/SuperTeens. Maybe we will see you next year as our New Super Teen!

— Diane Spencer, Support Coordinator

Jenni - continued from page 1

race, crying, to a standing ovation from the entire team and all the parents present. We knew right then and there that we had found a supportive, caring group of families and coaches.

Jenni continued her involvement with Manor Woods Swim Team for the next six summers. The team practiced five days a week for 1 hour over each eight-week summer season.

The exercise she received was tremendous, helping her to manage the weight that inevitably increased over the winters. She also benefited from the social involvement on the team, and from the sense of accomplishment she received as she improved her times. It never bothered her that she finished last in almost every "B" level race that she swam in.

We rewarded her with a dollar for every race in which she improved her time (and still do), which she promptly spent at the pool snack bar. But these were well-deserved treats. The team has a "buddy system" where older team members are paired with younger swimmers to help develop comradeship and a sense of team inclusion. Jenni benefited from this, both as a "little buddy" when she joined the team, and later as a "big buddy" to younger team members. At the end of each summer season, she received a participation trophy and participation ribbons that were added incentives.

At age 12, Jenni started on growth hormone therapy. As she grew, her muscle-mass and strength increased. This helped her to continue to improve in her swimming and to gain the endurance required to swim longer races. She

learned to swim all four strokes, and continued to gain confidence. At the end of last summer, we couldn't imagine that Jenni would be able to swim the 100-yard events required of high school swimmers. But she has been able to do so, and will continue with these events in the 15- to 18-year-old age group this summer.

Since that Saturday in 1998, Jenni has continued working on her swimming, out of the spotlight, steadily improving at her own pace and working very hard in practice. Her participation on the high school team this winter has been much the same as in the summer, with the community of coaches, parents and swimmers equally supportive and inclusive. Even though she is the slowest swimmer on the team, Jenni fulfilled all of the participation requirements to receive her varsity letter.

In addition to her letter, she also received the "Team Spirit" award for her encouragement and support of her teammates at the swim meets.

And while all of this made us very proud of her, perhaps the most special award she received was last summer when she was given the "Tough As Nails" Coaches Award for her work ethic in practice and her team spirit.

But isn't that a fitting description for each of our kids with PWS? They each are "Tough As Nails." We just need to have the love, patience and vision to help them achieve their best.

Doug and Linda Noll live with their daughter Jenni in Rockville, Md.

Sibling View

Calling All Siblings: Help Others By Sharing Your Experiences

By Lota Mitchell, Associate Editor

Calling all who have or have had a brother or sister with PWS! Everyone from 8 to 80 — you are needed! Even though you may not recognize the importance of your experiences and views, you have lots to share. You know more than anyone else what it is like to grow up with a sibling who has Prader-Willi syndrome. As we learn more from you, maybe suggestions and ideas will emerge about how to help others having the same experiences and feelings. There are two ways for you to share your knowledge and experience.

The first is a survey with some questions for you to answer. You can get the survey by going online to www.pwsausa.org/sibling.asp, filling it out and with a click submitting it right there. For all who are computer and Internet savvy, this is the way to go. Or if that won't work for you, call the national office, 1-800-926-4797, and a copy will be mailed to you. Finally, with a little procrastination and a trip to the national conference this summer in Orlando, you can pick up a copy there to fill in and return.

We welcome writings 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 attention of Lota Mitchell at the PWSA (USA) national office, or e-mail to her at ljecholsm@juno.com.

Love - continued from page 5

How do we make this all work? Structure and routine with her eating schedule, three nutritious meals and two snacks a day given at the same time every day with absolutely *nothing* in between those times except Crystal Light and Trident gum.

Anna has accepted this. Of course, she tells me she is hungry in between those times, and of course it breaks my heart to tell her it's not time to eat yet, but I love her and I know it has to be this way!

What about behavior? I see when we are not calm, not patient or something is out of routine that her anxiety will increase, although not to the point of tantrums. So it's up to our family to pre-plan and explain to Anna what and when something is going to happen. It is our job as parents *not* to allow irrational behavior to take over control.

If you have read down to this point, bless your heart. Please know that there are very successful stories amongst "the older generation," but it takes diligence. And we in the "older" generation are here to help you. To share with you, during my writing this story, my sweet Anna handed me a carefully hand-crafted note that reads "I LUV YOU MOM"!

Hugs to all.

This will not take a lot of your time, doesn't have a grade, and definitely isn't very hard. In fact, you might even enjoy doing it. What more could you ask than that?

The second is to write a piece about your brother or sister with PWS. It could be about your relationship with that person, perhaps something special about them, maybe your frustrations and even anger about the situation. The national office will collect all these writings and put them together into a booklet that others can read. You can mail it to the national office or email it to ssurvey@pwsausa.org.

The deadline for both the survey and a contribution to the sibling booklet is September 30, 2005. So you don't even have to hurry to get it done — but a warning: it's so easy to procrastinate! Please, please, do the survey and also consider also writing something for the sibling booklet.

[Important note: This survey is strictly for siblings and not to be confused with the survey to update the database. The two are entirely different.]

News - continued from page 7

problem in the general population was a big WOW! The government has millions of dollars that can be allocated for the obesity issues in the US. This will give us more dollars for research, WOW! More diagnoses will be made because of this program and with our numbers increasing, this will bring about more people, more voices willing to help in our cause."

Indeed, Support Coordinator Diane Spencer reports, "...the [national] office has received countless calls and emails... from people who have a child they now suspect may have the syndrome, or they know of someone who may have the syndrome.... We at the national PWSA office are grateful for the exposure and the opportunity to reach out to help these people. Also, we are deeply grateful to the families that participated in the presentation."

An e-group member commented, "This story coming out on national television has to be one of the best things that has happened to PWS. People need to be aware of the effects of the syndrome. PWS parents struggle every day not only to keep our kids healthy when they are at home but also when they are away from home and even in school. I hear all the time how the school systems are not listening to the parents and are not doing what is right for our kids. We need more shows like this to educate people, including the educators themselves!"

Yes, many thanks to the families, to Dr. Driscoll, to Executive Director Janalee Heinemann, who worked with both producers, to ABC, and to the BBC. For those who are interested, we will show both the BBC show in its entirety (no commercials!) and the 20/20 broadcast at this summer's national conference in Orlando.

We Remember...

Every person has 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.

We Remember Jeremy – And We Thank the Girards

Jeremy Girard was a high school junior when he passed away on Dec 26, 2004 due to gastric necrosis and a stomach rupture. His biggest goal in life was to be just like everyone else and be able to do what everyone else did. Although with PWS he could not always do this, he tried to the best of his ability. It was never important to Jeremy how well he did something, only that he accomplished his goal.

He loved music, so he joined the chorus and sang his best. He wanted to have all regular classes in school. He worked hard to accomplish this goal and had a B average. He loved cards, board games and puzzles. He was continually working on one or the other of them. He was also a great YU-GI-OH card player.

Jeremy was well known for his huge smile and good disposition. We have learned that Jeremy touched more lives for the better than we could ever have imagined. Jeremy always accepted everyone as they were and was kind to everyone.

Jeremy is greatly missed by all.

After the tragic death of their 17-yr-old son, Pete and Gayle Girard looked for ways to honor Jeremy by helping others dealing with Prader-Willi syndrome. They gave PWSA(USA) a huge lift to support our critical office automation capabilities with a new file server. Not only did the Girards purchase this for us, but Pete made a special trip to our Sarasota office to install it.

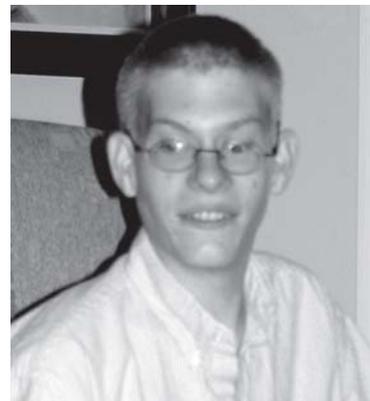
This new computer resource will provide us the necessary disk storage and processing power to support the

ever-increasing PWS population for the next few years. They have also donated Medical Alert booklets to the Florida State Chapter to distribute to all of the Florida families. The Girards feel strongly that EVERY family should have one of our Medical Alert booklets. If anyone cannot afford a booklet, call the PWSA(USA) office and the Girards will cover the cost.

Jeremy's twin sister Amanda and her friend plan to volunteer at our youth program at conference this summer.

We sincerely thank the Girards for their compassionate hearts. Through their gifts of kindness, I am reminded of a poem by Edmund Burke: "The true way to mourn the dead is to take care of the living... keep on with your work and bring joy to others."

— *Janalee Heinemann*



Jeremy Girard

Thanks CIBC World Markets Miracle Day You Made A World Of Difference!

From funding through a grant by CIBC World Markets Miracle Day, we have been able to ship hundreds of videos to 16 the following that have them. Thanks more children world will get and treatme... lives will be saved.



free medical states and to 17 countries requested to funding, around the a diagnosis generosity,

Denmark * Japan * Philippines * France
Holland * Spain * Sweden * UK * Morocco
Germany * Australia * Greece * Portugal
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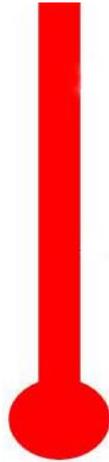
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