



The

Gathered View

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

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Determined Racer Earns Admiration and Success

By Kathy Johnson, Selah, Washington

The race is not always won by the swift, but by the determined.

"Riders up!"

With a smile on his face, trying to stand on his bicycle pedals while balancing in the gate, he waits. It's another race and another day. He knows he can do it. He will cross the finish line! The place doesn't matter, it's just the finishing. Spectators and racers cheer for him. The victory is not his alone, but for everyone who has witnessed his progress.

Phillip Johnson was born March 18, 1992. Our first-born son was beautiful and perfect looking, but the doctors thought something was wrong with him. He had poor muscle tone and problems sucking. Ten days after his birth, we got his diagnosis.

They gave us two sheets of paper, copied from an old medical journal. The pages told us that our son was missing a tiny piece off the 15th chromosome — Prader-Willi syndrome. The article said that tiny missing piece would cause him to eat anything and everything, whether it was edible or not. His mental age (IQ) would be about five years old. His maximum height would be four feet. His muscle tone would be so poor he would never be able to balance and pedal a bicycle.

Maybe it was denial or just plain determination, but we started the long journey to give Phillip the most normal life possible. The specialists recommended that we wait until he was delayed a year or more to do anything.

And of course we didn't listen to them.

When Phillip was two, he became a big brother: we had Alex. Phillip enjoyed helping take care of the baby. He tried so hard to be a big brother and has always been very proud of his little brother. On Phillip's second Christmas, we got him a bicycle with training wheels, on which he proudly scooted around the house. Three months later, he was pedaling around the house. He started growth hormone on his fourth Christmas. His muscle tone improved and he tired less easily.



Phillip Johnson with his trophy

In April 2001 Alex took up the sport of Bicycle Moto Cross (BMX). Alex and Phillip were determined that Phillip would race too. With his younger brother coaching and with help, the training wheels came off. And so started Phillip's BMX racing career.

On June 9 at Yakima Valley BMX during the Race for Life (a race to raise money for kids with leukemia), Phillip took to the track on his K2 BMX and crossed the finish line on his own power. Everyone was cheering, and I was crying. It was a Miracle. A racer came up to him and gave him his first place trophy, saying "Phillip had earned it."

Phillip has quite a collection of trophies and ribbons and medals, not only from the tracks where he has

raced, but also from racers. He has made friends everywhere we have raced. We spent the rest of the year racing almost every weekend and traveling around our state.

At every track, Phillip has been treated like all the other racers. When he has needed help to find the right gate (sometimes the gates are not numbered and you have to count), the track officials or even his fellow racers have helped him.

In September we raced the Washington State Championship. There were racers from Washington, Oregon and Canada. It was a huge race, and as Phillip pedaled his way

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The Prader-Willi Syndrome Association (USA)

5700 Midnight Pass Road, Suite 6
Sarasota, Florida 34242

1-800-926-4797

9 a.m. to 7 p.m. Eastern Time

Local: 941-312-0400

Fax 941-312-0142

e-mail: national@pwsausa.org

www.pwsausa.org

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NEWSLETTER

Jane Phelan, Editor

Lota Mitchell, Associate Editor

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**We're looking forward to seeing you at
Conference 2002**

July 11-13

Salt Lake City, Utah

For last minute details, call PWSA (USA)

or go to www.pwsausa.org

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

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

Two Educational Videos Now Available

We are pleased to announce our two new educational videos:

- *Prader-Willi Syndrome: The Early Years*

— This video serves younger families whose child has Prader-Willi syndrome. It offers hope, help and practical suggestions for those young families with a child newly or recently diagnosed with Prader-Willi syndrome, while at the same time sensitively recognizing the myriad and confusing emotions a family may experience when first coping with a diagnosis. Medical, genetics, speech and physical therapy, early intervention, and family interviews are highlighted.

- *Prader-Willi Syndrome: An Overview*

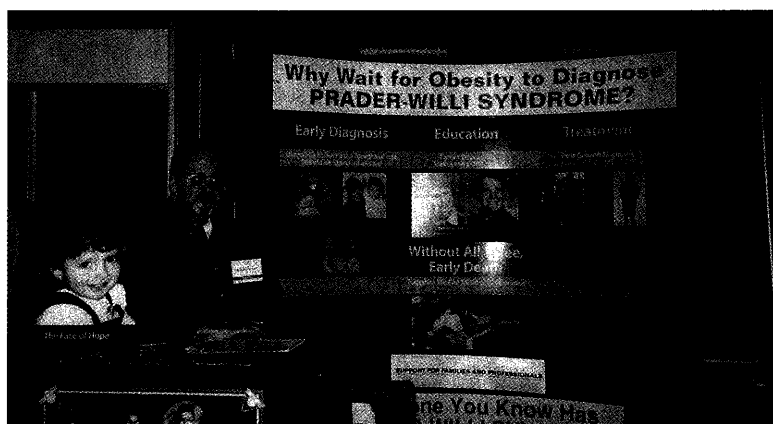
for Health Care Professionals — This video provides an overview of Prader-Willi syndrome and the accompanying management issues for general medical and other health care practitioners, including pediatricians, endocrinologists, speech and language therapists, educators, psychologists, social workers and case managers.

It gives a clear understanding of the genetics of PWS, the impact on families, and crucial issues of medical, diet and behavior management. In our opinion, it is a must viewing for all professionals dealing with the syndrome.

Cost of video is \$15 members & \$20 non-members plus shipping and handling.



PWSA (USA) volunteers and staff pitch in to pack boxes and mail more than 5,000 free educational videos about PWS to physicians around the nation. From L-R: Norma Rupe, Christine O'Donnell, Annie Durell, Gilda F. Hilton, Paul DiPlacido and Bill Rupe. Christine, visiting from Scotland, dropped in the first day of the mailing project and came every day until it was finished. She is now a regular volunteer.



New PWS awareness booth

Volunteer Manny Emmanuel at the new PWSA (USA) awareness booth. Manny and Executive Director Janalee Heinemann worked the booth at a major pediatric conference held recently in Baltimore and gave out more than 400 free CDs of our Medical Overview to physicians attending. They were assisted by volunteers Ann Vucci and Jim Kane.

Angel Fund Contributions

Year 2000/2001 Year to date 2001/2002

\$70,906

\$73,734



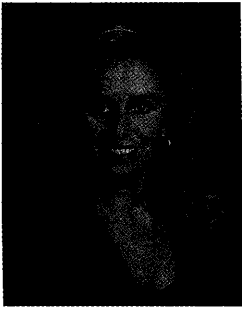
PWSA(USA) Now Included on 2002 Federal Campaign List

PWSA(USA) is now eligible to receive donations contributed by Federal employees. PWSA(USA) will be included in the 2002 Combined Federal Campaign (CFC) National List.

Our CFC identification number donors will use to designate their contributions to PWSA(USA) is 9858.

If you are a Federal employee, or know someone who is, remember that you can now make contributions to PWSA(USA) using our donor number.

If you have questions, please call the PWSA(USA) office.



Hands Around The World

By Janalee Heinemann

Pam Eisen (our IPWSO Delegate) and I were invited to go early to Italy for the IPWSO meeting where there were 90 parent and professional delegates from 40 countries represented. We joined IPWSO President Giorgio Fornasier and his wife Maurizia for their 30th wedding anniversary celebration and also had the opportunity to spend time with Helena Portugal, president of the newly formed PWS Brazil organization — our “twinning” nation. With her was Solange Kobage, the volunteer attorney who is assisting the group with the legalities of forming their non-profit.

The most charming member of our initial group was 26-year-old Daniele, Giorgio and Maurizia's son who has PWS. Daniele showered us frequently with kisses on both cheeks. When his father told him to quit, Daniele told him, “You are just jealous because you are married and I am not!”

Most of us know Giorgio as the president of IPWSO and father of a son with PWS; in Italy we discovered there are many other layers to Giorgio. He is a professional opera singer, composer and musician. He is also owner of a business, has a weekly television program, is an artist, climbs mountains, gardens, makes his own wine and is very involved with the village church. (As well known as he obviously is in the community, even more popular is Daniele, who charms all with his gregarious personality.)

In spite of Giorgio's incredibly busy life, he manages to make time for PWS: He spends two full days volunteering at the new IPWSO office at BIRD (a two-hour drive from his home), and hours daily on PWS projects.

For this first ever meeting, Giorgio organized it, made all travel and hotel arrangements, and shuttled attendees to and from the distant airports. It was touching and humbling to see Giorgio, his family and the founders of B.I.R.D. (see below) work such long hours cooking for us, cleaning and refurbishing the dozens of rooms at BIRD, and preparing all of the details of the program. Also, volunteers of BIRD and friends of the Fornasier's donated needed items and time.

In our “me first” society, it was a treasure to watch our beautiful Italian friends give so much. It was the same Herculean effort that you see at our annual conferences in the states — with a large group giving all they have just for the sheer satisfaction of knowing that you made a difference. Why would you put yourself through such effort? It can only be because you have such a compassion for the cause and the people involved that you are willing to give everything you can possibly give.

This meeting was special for many reasons; one was that so many of the attendees who were from poorer countries were able to attend thanks to a major donation of \$18,000 from an anonymous parent member and another large donation from Pharmacia.

It never ceases to amaze me that due to our common bond, language is no barrier to sharing the feelings of the heart. There were families from Spain, Egypt, Israel, Greece, Poland, South Africa, France, Finland, the UK, Belgium, Switzerland,



Giorgio Fornasier with Janalee, Helena Portugal, Pam Eisen, Solange Kobage and Maurizia Fornasier.

Denmark, Argentina, El Salvador, Slovenia, Malaysia and more. Our parent representative from Cuba was not allowed to leave the country. At her request, an empty chair was left to symbolically represent Cuba.

There were times when you could barely understand a word spoken, yet you learn to communicate with your hands, your eyes, your tears and your smile. For this brief moment in time, we were not countries fighting each other, but parents and professionals working together for a cause.

Although we could not even say a complete sentence to each other, the story of Anna and Giuseppe Baschirotto was told through their sad, kind eyes and warm smile. Their son Mauro died at age of 16 from a rare disorder. They have since committed their money and their lives to creating the Mauro Baschirotto Institute for Rare Diseases (B.I.R.D.) to help all children with rare disorders.

BIRD was originally a boarding school that once belonged to priests, which includes a beautiful, 16th century villa in the

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The Magic of IPWSO: Twinning with PWSA-Brazil

By Pam Eisen, PWSA (USA) IPWSO Delegate

Joining hands with our friends from 40 countries as we sang "Fly High," IPWSO's theme song, Janalee Heinemann and I glanced at each other with tears in our eyes. During our week at B.I.R.D. our emotions ran the gamut. We witnessed the power of parents and professionals sharing information and working toward solutions, with determination and love for our children. We experienced the magic of IPWSO!

This passion for making a better life for people with PWS was demonstrated so beautifully by our twin country, Brazil. Helena Portugal, the courageous woman you have met in my previous articles, and Solange Kobage, lawyer for PWSA-Brazil, traveled the distance to this gathering against many odds.

Solange, a woman with a big loving heart, had never heard of PWS until she met Helena about a year ago. Donating her time and efforts, she is resolved to help Helena develop a substantial national association for her country. At her own expense, she accompanied Helena to gather information needed in this endeavor. Physically, this was a difficult trip, as Solange has severe asthma complicated by the fact that a bout with cancer left her with one lung. Despite the difficulty in catching her breath and the language barrier, she was always smiling and eager to fully participate.

Helena's desire to meet us and join in this exceptional international meeting is a dramatic story. While on vacation in Rio de Janeiro (just seven weeks prior to our meeting), Helena's 15-year-old daughter Fefê (who has PWS) became seriously ill with intestinal problems and was rushed to the hospital.

Obese, with poor muscle tone, behavioral outbursts, breathing problems, hypertension and diabetes, Fefê was a challenging patient. Initially, doctors diagnosed her with appendicitis and recommended immediate surgery. Based on her experience as a nurse and a mother who has devoted herself to learning about PWS, Helena refused permission for surgery.

Searching for answers, Helena admitted her daughter to a well-known hospital in Sao Paulo, where Fefê was diagnosed with an acute intestinal infection. She was released after 15 days of intensive antibiotic therapy, but within days the situation worsened and Fefê was again admitted to the hospital. Because the doctors were unfamiliar with PWS, they were reluctant to treat her. Even when Helena, with her professional background, shared information on the syndrome some doctors were skeptical about the authenticity of her sources.

Emotionally and physically exhausted, Helena desperately reached out to PWSA (USA) with pleas to help her save her child. She urgently needed guidelines on anesthesia for a PWS patient, as doctors stressed the necessity of an endoscopy.

E-mails flew across the ocean from Giorgio Fornasier, who translated urgent messages in Portuguese, to our office in Sarasota. David Wyatt (our compassionate, competent crisis counselor), Janalee, Dr. Ann Scheiman and I all became involved in getting the medical information to Helena.

Because of the difference in time zones and languages, this was no easy feat! Helena had difficulty getting to a computer while in the hospital. Without a translator, Dr. Scheiman could

not just pick up the telephone and call to authenticate Helena's information and discuss the case. Despite all the obstacles, with tenacity, the necessary information was conveyed.

By sharing our organization's knowledge and experience with professionals in Brazil, Helena says that we "saved Fefê's life and paved the way for other children with PWS." Fefê was released shortly before Helena left for Italy. Heart wrenching though it was for her to leave Fefê at this time, she was determined to attend the meeting, gather information and make a difference for children throughout her country.

In Helena's words our twinning and the beginning of PWSA-Brazil is *"for us, today, a dream... for them (families of Brazil), tomorrow the pleasure of and direction of an... organization. For us it represents Accomplished Mission... a humanitarian project... That is the reason why we are all together... moving mountains... OUR LOVE... The love of SPECIAL PERSONS!"*

A Quick Look At Brazil

Editor's Note: Since Brazil is our "twinning" country, a bit of information about it might be of interest. The following is excerpted from a full-page feature article on Brazil published in the Pittsburgh Post-Gazette on March 24, 2002.

Brazil has First World industries—steel, electronics, automobiles, aerospace—along with First World financial institutions, universities and cultural attractions. Brazil also has Third World poverty, corruption, crime and disease.

Brazil is the fifth largest country in the world, bigger than the U.S., excluding Alaska. It is the fifth most populous country, with 174,468,575 people. Life expectancy is 63.24 years. Its languages are Portuguese (official), Spanish, English and French. Whites make up 55% of the population, with mixed white and black 38%, and black 6%; 83.3% of adults are literate, and 80% are Roman Catholic (at least nominally).

It produces more goods and services per person than each of the top five except the U.S.... It is a huge exporter of agricultural products and raw materials.... Brazil's single biggest exporter is a high-tech industrial company—Embraer, the fourth-largest aircraft maker in the world... behind Boeing, Airbus and Canada's Bombardier.

Brazil also has many shantytowns, known as "favelas." They are like feudal societies financed by drug sales, protected by violence, and operated by patronage. The drug lord reigns; the police, most of them paid off or uncaring, keep their distance. Throughout Brazil, murder, kidnapping, robbery, drugs and AIDS are epidemic.

On the political front, as president for the past seven years, Fernando Henrique Cardoso with a center-right coalition has restrained government spending—except for education and health—and resuscitated the economy. He cannot run again in the October election. Brazil has 18 political parties. At the moment, Brazil's maturing political and economic system certainly seems a model of stability compared with those of its neighbors.... and it is also beginning to wield global influence, despite its myriad problems.

— Lota Mitchell



Understanding the Lessons of Loss

By Lota Mitchell

A phone ringing at midnight is never a good sign. Wakened from a sound sleep Thursday night just before Easter, I grabbed the receiver with that sinking feeling in the pit of my stomach. On the other end was my beloved first cousin, Charlie, with the tragic news that his daughter's husband had been killed in a helicopter crash in California a few hours earlier.

Perhaps some of you saw on the news about the crash of a Navy helicopter in the Sierra Nevada mountains, killing two and injuring four others.

One of the two killed was Lt. Commander Jason Bayer, naval fighter pilot aged 34, husband of Ann (better known to our extended family as Missy), father of daughter Gabriella age 1 and yet-to-be-born son Jason Christian due in June. Jason Bayer was one of the finest men I've ever known, in every way — intelligence, personality, character, deeply committed to his career, his country, those he loved, and his God.

Shock. Denial. Disbelief. Those first grief reactions to sudden loss set in immediately. "This can't be true, it just can't be!" "Maybe a mistake." "I can't believe it." Not the fun loving Jason whose voice on their answering machine had responded, "Hello! This is Darth Vader!" Not the Jason of deep faith who sent his email response to a prayer request: "Prayers on tap... and flowing." This wonderful man could not be gone. But he was.

As a board member with a young child commented when we were discussing Jason, many in the PWS family have choked out those same words — "No, it just can't be!" — with the loss of the expected normal baby or child when the diagnosis of Prader-Willi syndrome is made. And they realize that life will never again be quite the same. I experienced those same feelings also when I lost a beloved son to an automobile accident — and everyone experienced them when 9/11 happened and we all lost our sense of security and our belief in our country's invulnerability.

Woven through the grieving is the question, Why? Why Jason, a young man with everything to live for and so much to offer? Why my baby or my child? Why me? After much pondering, I've concluded that there are two "whys" — one pragmatic and one philosophical. The pragmatic why is easy: a 15th chromosome abnormality causes PWS, pilot error or mechanical failure downs the helicopter. The philosophical why is the tough one, and each one of us must somehow come to our own answer, or accept the lack of answer, for ourselves.

From the Book of Job in the *Old Testament* to the more current book *When Bad Things Happen to Good People*, men and women have struggled with the philosophical why of loss and tragedy on both an individual and a global basis. Maybe the



Lt. Cmdr. Jason Bayer with his wife Ann and daughter Gabriella

In the beautiful little book *The Fall of Freddie the Leaf*, by Leo Buscaglia, Ph.D., the young leaf Freddie asks the wise leaf Daniel about death. "Does the tree die, too?" Daniel answers, "Someday. But there is something stronger than the tree. It is Life. That lasts forever and we are all a part of Life."

focus on the enigma of why should give way to consideration of the practical meaning these shattering events can have in how we conduct our lives. What lessons in living can we find in loss?

For me, first of all, it means appreciate. Appreciating and being grateful for what we have now, this day, understanding there is no guarantee on tomorrow for me or for anyone I love.

Loss continued on page 7

Meet Our Chapter Presidents

By Lota Mitchell, PWSA (USA) President

Let me introduce you to a few more of our hard working Chapter presidents, people who take a lot of time out of their busy lives to help others through their chapters.

CALIFORNIA FOUNDATION — Mike Raleigh at one time taught and did research at UCLA. At present, he is teaching school mainly, math and science, in addition to some consulting. The eldest of his four children, Sean, 20, has PWS. Mike feels that the younger siblings have benefitted from having their handicapped older brother.

This chapter is one of the few lucky enough to have a real Executive Director. Fran Moss has functioned in this position for 10 years. Daughter Melissa, 29, the youngest of her three children, has PWS. Fran's husband Frank, who was National Conference Committee chairman at the time of his death and had served on the national board of directors, died this past year, and responsibilities are heavy for her now.

MINNESOTA — Both Carol Hearn and husband Tim are children of ministers, and both are lawyers. A graduate of Harvard Law School, she left her law firm after her first child and now works one 1-4 days a week in the legal department of the local newspaper. Carol's sister had a stroke at 18 that took away her voluntary muscle movement and another 13 years later, which destroyed her short-term memory. She says in comparison her child with PWS, David, age 9, so far has been "a piece of cake." He is the youngest of three. Carol is a candidate for the PWSA(USA) Board of Directors.

Loss - continued from page 6

Treasuring husbands and wives who are still beside us, friends and extended family, too. Giving them a hug today and saying I love you. One mother wrote in a chapter newsletter, "What we lost and forgot in the first year and a half [after our son's] birth was ourselves." If your total focus is on what you've lost, how can you appreciate fully all you do have?

It means appreciating our other children who do not need us any less because they have a sibling with PWS. They can get lost when all the family energy is sucked into the whirlpool of Prader-Willi syndrome.

It means appreciating every accomplishment of our child with PWS. Oops! Do as I say, not as I did. When my daughter Julie first stood up in her crib, my husband Dave rejoiced over this big developmental step. He did it right. I burst into tears because she was so late doing it. I did it wrong. Rejoice in each accomplishment, no matter how small.

Finally, it means looking at the big picture, rising above the petty squabbles that divide people and organizations, the power struggles, the trivial resentments, all the nasty disagreements that cause us to lose sight of our common goals. In the years that

MISSOURI — Married 18 years, Debbie Holt and her husband just moved to Missouri a year or so ago. They have a daughter 16, a son 14, and Billy 4 ½, who has PWS. Debbie says "Kids are my life." She likes to bowl and is very much into holistic and spiritual healing.

WISCONSIN — A transplant to Wisconsin from Michigan, Kate Beaver and her husband added to their family of two boys by adopting Hana (pronounced Honna), now 15, from Korea when she was 18 months. They had seen a book on unwanted children. Although they knew she had some sort of problem, it was not diagnosed PWS until she was 6. Kate has a master's degree in social work and works in the substance abuser field.

This is another lucky group which has an Executive Director, **Barb Dorn**, who in June 2001 finished her three-year term as PWSA(USA) president. Barb, an R.N., and her husband have two sons, the older of whom, Tony, aged 15, has PWS. Two teenagers keep her very busy. **Mary Lynn Larson** has taken over the function of providing information and referral, while Barb does a great deal of outreach, e.g., training and consultation.

Praise for the PWSA (USA) organization

I continue to be in awe at the passion and commitment that I see in all of you involved in improving the lives of people with PWS.... I learned even more by meeting the families and people who live with PWS.... I have hope that these children will have a brighter future because of your dedication to them and their syndrome.

I've been a member of PWSA(USA), it seems that there have always been issues of various sorts with people taking a stand on one side or the other. That's fine; that's how democracy works.

What is not fine is if strong opinions harden into being opinionated, if emotions ignite into anger, if necessary respect for others deteriorates into character assassination, and if a situation which could have been constructive becomes destructive. The risk is always there.

We're all in this country, we're all in this PWS family, and we're all in this life together — and (to use an old cliché) nobody is going to get out alive. Let's focus on what we want to accomplish, on helping when help is needed, on being peacemakers when there is strife, on supporting those who are grieving or just need a shoulder, and yes, on loving each other (even those we don't particularly like).

Goodbye, Jason. You loved greatly, and you were loved greatly. May we all as individuals, as parents and grandparents and professionals, and as members of PWSA (USA), remember the lessons of loss.

What's New in PWS Research

By Janalee Heinemann

As Elisabeth Dykens, Ph.D. reported in the January/February 2002 issue of *The Gathered View*, "There are now more than 750 known genetic causes of intellectual disabilities, and Prader-Willi Syndrome actually enjoys more research than many of these other syndromes."

She also noted, "Now more than ever, PWS is the focus of genetic, medical and behavioral research." What we as parents would like is to have an influence on the type of research we think will have the most impact and benefit for our children with PWS. Following are just some of the current research projects going on that I think you will find of particular interest.

USA — CoQ10 and Research Studies

We are quite aware of the flurry of interest in CoQ10 being used for PWS, with some parents reporting dramatic improvement in energy and strength and others reporting no improvement.

Until we have scientific information through well-designed, controlled studies, PWSA (USA) is currently not able to make a specific recommendation for or against the use of CoQ10 in the medical treatment of individuals with PWS. PWSA (USA) is seeking ways to help facilitate these necessary and important studies.

There will be late-breaking news on CoQ10 and related studies by the time you receive this issue of *The Gathered View*. Check our web site, www.pwsausa.org, or call our 800 telephone number to receive this new information.

(USA) — Dr. Shapira on Topiramate & Neuroimaging (fMRI)

Although the initial intent of this study sponsored by PWSA (USA) was to study the reduction of appetite and weight loss, serendipitously, topiramate (Topamax®) showed reduction in the self-abusive behaviors (picking) of adult study participants with PWS and improved healing of sores. Although it has shown mild weight loss, there is not a change in appetite as was shown in individuals with epilepsy during clinical trials with this medication.

Further research is planned regarding this drug's effect on picking and wound healing — and potential risks. I caution our readers that NO drug should be tried on our children without all of the facts.

A physician considering using this medication for self-injury is welcome to contact Dr. Shapira at the University of Florida. We do not give out the numbers of our physicians for questions from parents in cases like this — because they would then not have the time to do the valuable research and treatment needed.

Dr. Shapira and his team at the University of Florida, which includes Dr. Dan Driscoll and Dr. Yijun Liu, have also completed initial studies reviewing the brain's response to glucose with Neuroimaging through functional magnetic resonance imaging (fMRI) scans.

The preliminary results recorded changes in the prefrontal cortex/hypothalamus of patients with PWS during sugar loading. There appears to be a delay between the brain activation following glucose administration in individuals with PWS than that in healthy controls and obese individuals. This information needs follow-up, thus Dr. Shapira plans to pursue NIH funding.

Dr. Shapira plans to report information about this study at the meeting in Salt Lake City in July.

Dr. Shapira will write a more detailed report on both these intriguing studies for an upcoming article in *The Gathered View*.

England — Dr. Holland & Psychosis in PWS

On a more disturbing note, Dr. Tony Holland from the UK reported on his study of Psychosis in PWS. Of 25 patients with PWS 18 years or older, seven (28 percent) had severe affective disorder with psychotic features with a mean age of 26.

In the general population of adults with learning disabilities, 5 percent psychosis is the average. Of those in the PWS study, all five (100 percent) with Maternal Disomy (UPD) after age 28 became psychotic. Of the 14 with a deletion, only one became psychotic (1 of 14 = 8 percent). Also, one person with an imprinting center mutation

became psychotic.

Although this is only a very small population studied — and I know it will be very disturbing news to parents of a child with UPD — it is imperative to follow up with a larger sample, which is being done as I write.

If there is truly a correlation between UPD and psychosis in adults with PWS in their mid to late twenties, there may be ways to treat prophylactically (before the first occurrence) to prevent the psychosis. The process of psychosis itself is very damaging to the brain and produces more psychosis, thus prevention of even the first episode could be very helpful.

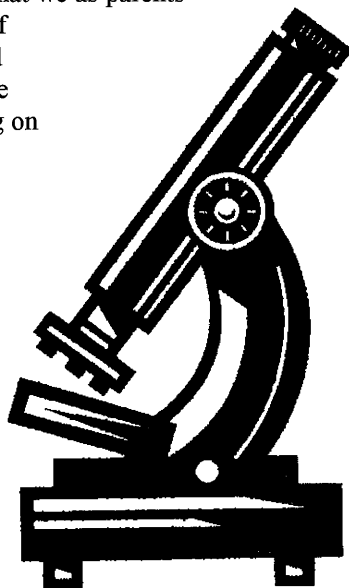
Also from Holland et al. on OCD behaviors — Dr. Holland concurs with Dr. Dykens that the compulsions in PWS are similar with those seen in early childhood in the normal population. Very few had true obsessional thoughts. More common were loss of temper, repetitive questions and insistence on routines.

And more from Dr. Holland — In a study of health risk factors, with 66 in study — 50 percent had history of respiratory infections; 29 percent, fractures; 22 percent, leg ulcerations in adults; 20 percent, sleep disorders; and 15 percent severe scoliosis.

Sweden — Dr. Ritzen & Growth Hormone

Dr. Martin Ritzen reports in his growth hormone studies that with growth hormone, there is improved body composition, lean muscle mass improvement, increased alertness, strength and agility, improved respiration and increased bone mineral density.

Research continued on page 9



"Prader-Willi Syndrome actually enjoys more research than many of these other syndromes. Now more than ever, PWS is the focus of genetic, medical and behavioral research."

Elizabeth Dykens, Ph.D.

Accentuating scoliosis and diabetes are still reasons for careful monitoring.

Dr. Ritzen states that in adults, lack of sex hormones is more of a causative factor in osteopaenia than growth hormone. Using a testosterone patch on males with PWS was mentioned as a good alternative to prevent the spiking — thus reducing the risk of escalating aggressive behavior.

USA—Dr. Whitman, Dr. Carrel, et al. & Behavioral Impact of Growth Hormone with PWS

Dr. Barb Whitman reports that no differences were found between treatment and control groups, nor within groups across measurement points for attentional symptoms, anxiety, obsessive-compulsive complex, violence or psychotic symptoms. A significant positive effect was seen on the reduction of depressive symptoms — primarily in those over 11 years old.

Growth Hormone Book Well Received

The book, *Growth Hormone and Prader-Willi Syndrome: A Reference for Families and Care Providers*, is being well received by physicians and other health care professionals.

It is a comprehensive reference for all medical providers considering or already using growth hormone with children who have Prader-Willi syndrome. It is also an excellent resource for parents.

To date, we have received nothing but positive feedback on this book. One endocrinologist wrote, "I just wanted to tell you that the *Growth Hormone and Prader-Willi Syndrome* publication is by far the best monograph on growth hormone for any condition that I have ever seen... and believe me, I've seen quite a few over the years. I hope that your unrestricted educational grant will allow widespread distribution to all caregivers, pediatric endocrinologists, pediatric endocrine nurses, nurse practitioners, and geneticists. Thank you for putting this together!"

As you are probably aware, under the Orphan Drug Act, the U.S. Food & Drug Administration (FDA) determined last year that PWS is an indication for treatment with Genotropin, which is a form of growth hormone manufactured by Pharmacia Endocrine Care. While Genotropin is currently the only treatment approved specifically for growth failure in children with PWS, we feel this book gives an unbiased perspective of "if, when, and how" to treat.

Our Growth Hormone book was edited by parent member Linda Keder, with coordination of graphics, layout, production and printing by parent member Don Goranson.

PWSA(USA) can provide this 53-page, 8 x 10 book at a cost of \$5 to members and \$10 to non-members. For more information, call the PWSA(USA) office.

The Chuckle Corner

My daughter Jeannie Dickinson was in the shower one day recently. My granddaughter Jessika was playing quietly and it was mid-day.

All of a sudden there were loud pounding noises in the house. Jeannie thought Jessika was in trouble, and quickly jumped out of the shower, grabbing a small hand towel to cover up some. She went in the living room to see a man at the window cupping his face to see in. OOPS! Jean ran back and got her bathrobe and went to the door.

Three police officers met her. One stated with a smirk, "Someone at this residence called 911."

Jean looked over at Jessika who was standing shyly in the corner.

Jean asked, "Did you call 911?"

Jessika answered, "Yes, I had a sore throat and I needed a doctor!"

The police officers laughed and told her she did the right thing. Jean said, "Don't tell her that! She'll be calling all the time."

Grandmother Barb McManus, Buffalo, New York



Do you have a joke or funny story to share with readers about Prader-Willi syndrome? Send it to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions. We'd love to hear from you!

Sleep apnea and oxygen levels

A recent sleep study proved our son, Patrick, age 4, had sleep apnea.

My husband Howard and I felt Patrick breathed funny since he came home from the hospital at three weeks of age. At first, we thought it might be due to his NG feeding tube.

Whenever Patrick would get a cold, he would have sinus and ear infections. The ENT put ear tubes in both ears when he was almost 2 years old. Patrick didn't have any ear infections after that but continued to have sinus infections occasionally that needed antibiotics.

Patrick slept fairly well and didn't wake up very often during the night. We did notice he would stop breathing for a while and then re-start after a few seconds or so. Patrick would also sleep with his head arched back in the CPR position to open his airway to breathe better. His fingertips were red, which can indicate oxygen deprivation. Patrick's breathing was very loud and labored.

At Patrick's last ENT visit to check his ear tubes, I asked the ENT to check Patrick's adenoids. This was done in the doctor's office with a scope. The ENT felt Patrick's adenoids were on the mildly large side, but didn't warrant being removed without a sleep study.

The sleep study was painless. The tech put an oxygen monitor on his big toe and monitors on his legs, back, chest, and head. When Patrick first went to sleep, his oxygen levels dropped into the 70% range. During REM sleep, his oxygen levels dropped into the 50% range. Oxygen levels should be close to 100%.

Surgery was done to remove Patrick's adenoids and tonsils. Morphine was used to help with pain and steroids were used to reduce swelling. An overnight stay in the hospital was required because Patrick's oxygen level wasn't at the proper level. By the next morning, Patrick's oxygen level

was in the 90% range and he was jumping up and down on his hospital bed.

The ENT doctor made sure to leave a nice ridge when trimming Patrick's adenoids so he wouldn't have nasal sounding speech.

Now that Patrick's adenoids and tonsil areas have healed, he sleeps very quietly. We can't hear him breathing at all. Patrick is also growing a lot. Children need good sleep to grow properly. According to Dr. Merlin G. Butler, sleep apnea is common for children with PWS. I wish I'd had Patrick's adenoids checked out sooner.

Terry Schlange, Marysville, Kansas

Sleep apnea has many causes

Sleep problems leading to sleep apnea can be due to many causes, including increased size of the tonsils and adenoids, a flacid oropharynx due to poor muscle tone or increased tissue elasticity, neurological conditions, tumors, metabolic conditions, obstruction, congenital malformations involving the oral/pharyngeal/laryngeal cavity, obesity and syndromes such as PWS.

Although there have been only a few studies in PWS and sleep assessments, this descriptive report further illustrates the problems that can occur in children with PWS. The frequency of this finding in PWS can not be stated accurately but it may be relatively common.

Merlin G. Butler, MD, PhD, FACMG

*William R. Brown/Missouri Chair of Medical Genetics and Molecular Medicine, Children's Mercy Hospital
Professor of Pediatrics, University of Missouri-Kansas City School of Medicine*



Pretty Woman

Kerry Howe, age 32, is stepping out on the town. She is a client at Pathways-Davis Road I.C.F. in Corning New York. Kerry joined her family at a party in Hammondsport. The Howe family expressed appreciation to the providers at her group home who assisted Kerry with her glamorous presentation and transported her to the event.

Coming Soon! Supportive Living Care Plan CD

We will soon have available a Supportive Living Care Plan that will be available in CD format to enable you to customize it for your adult child or provider client.

It will be in multiple formats for user compatibility. This outstanding booklet was created by a professional parent, Geraldine Dicosimo, for her daughter Christine.

Both parents and providers have reviewed it and think it is outstanding both as a Consistency Care Plan and for staff training. A hard copy of the original booklet will accompany the CD.

Our computer guru grandmother, Barb McManus, is creating the CD format that will allow others to adapt it to fit anyone with the syndrome. Expected release date is for our July conference. What would we do without our volunteer families?

My Journey Through PWS with Colleen

I would like to share with you Part Two of growing up with Colleen. I wrote to *The Gathered View* when Colleen was about 5 years old. I shared with you the joy her birth had brought into my life. Now she is 10 years old, and I am writing to you today with much pride and joy in my heart.

We recently attended a parent-teacher conference and the reports were glowing. Colleen is not at the top of her class, but she is to me. This is where my story continues.

Colleen attended a regular pre-school in which her teacher pleaded with us not to place her in a special education class. We wanted the best for Colleen, and felt special education would provide all the extra help she needed. She did well in kindergarten, with promises of mainstreaming her in one or two classes the following year.

In second grade we realized Colleen was at least 6 months behind the regular classes, and mainstreaming her was no longer a viable option.

Then I made a painstakingly difficult decision to mainstream her in the third grade. My decision was not



Colleen McMaster

supported by the special education committee, but by law Colleen had the right to be tried in a regular class. Her IEP was padded with all kinds of provisions to assure her success.

Third grade was hard. We worked together sometimes 3 hours at night. I am lucky because we both enjoy working together, so it was rarely an issue. She also had the added burden of OT, PT, speech therapy, and every service you can imagine pushed in during the school day.

She struggled academically, although she loved attending the neighborhood school where she was with her older brother. She grew socially, as she had contact with her peers. Fourth grade went better, and fifth grade is better still.

Colleen has blossomed into a young pre-teen, a lot like her peers in many ways. She is also well behaved in class. In retrospect, the timing of placing her in a regular class was perfect, as the standards in New York state now require special education children to take the same state exams as the regular education kids. Hopefully she is better prepared, as the standards appear to be held higher for her in a regular class.

The food issue is minimum and so is her stubbornness. She definitely has PWS and has to know what and when she will eat. She has rarely taken food without permission and has better will power than I will ever have. She knows a lot about Prader-Willi syndrome, and she is self-educated on the calories of all the foods she consumes. She also cuts back on the quantity of food if she feels she is gaining too much weight. Colleen is on the heavier side, but has maintained the same weight and height ratio since she was 2, when she started on the growth hormone. I believe the growth hormone has given her a lot of advantages in defying the effects of Prader-Willi. She has learned to ride a bike, no simple task as we practiced on a hill in a vacant parking lot every day for 3 months. She is still working on starting to ride her bike from a flat surface.

She also dances jazz, tap and ballet. She expects to dance on toe someday. No way. But Colleen doesn't know the meaning of limitations, nor does she think she has a disability. She'll probably dance on toe and I'll cry again, as I do every time she does something I thought never would be possible for her.

Is Colleen a special case? Am I a Super Mom? Can every child with PWS accomplish the same goals? I don't know, but what I do know is that possibilities are endless for our children.

We have only to dream, believe, love and support our children to aspire to be the best they can be.

I never dreamed Colleen would attend middle school mainstreamed, but she will next year. Her fifth grade teacher told me, "She'll do well in middle school. Colleen strives to meet the expectations that are placed on her. She gets a lot of pride from the small things and she builds on that to tackle the bigger challenges."

I have learned not to underestimate Colleen, and not to underestimate any child with PWS, because only God knows what they truly can accomplish. I love you, Colleen.

Joanne McMaster, Rochester, New York

PW

POST OFFICE

For people with PWS



Pen Pals Wanted

- My name is Lance and I am 18 and I am A Prader Willi Syndrome and I am looking for Pin pals to talk to and Please Email Me and My email Adress is SuperDude877@cs.com
- My daughter's name is Elizabeth Thorpe, and she is 23. She loves horses, reading and any type of activity. She will be getting a computer at the end of next month, so anyone can contact her at 18 Oliver St., Framingham, MA 01702. She would like a pen pal close to her age.

A Thank You From Matthew

Dear Janalee and David,

Hi thank you for writing a nice letter to the north west air line. thank you for letting my hole family go to California. thank you for letting me help others with power willi sidrummy. I herd that Janalee has a son name Matthew who has the same sidrummy as me. what school is your son in? My school is Highland pines. My teachers are Mrs. Bye and Mrs. hays. My reading teacher is Mrs. Hennry. What teachers do you son have. I am in intermuls basketball.

love,

Matthew Salehi, Vassar, Michigan

Thanks To Our Members Supporting Fund-raising

CIBC 'Miracle Day'

CIBC World Markets "Miracle Day" fund-raising campaign donated \$51,129.00 to PWSA (USA)!

A special thanks goes to Mark Greenberg who made this possible, and to his fellow employees at Denver Security Traders and Invesco.

Mark, his wife Robin Fleischmann and his family have all been wonderfully supportive. Little Zachary is a lucky fellow!



The Sway on the Bay fundraiser in Sarasota was a big success, and included free gondola rides, music, photography and a silent auction.

Sway On The Bay

In Sarasota, Florida, *Sway On The Bay* with Boris and His Saxophone — was a big success. Thanks goes to *Caroline's on the Bay* who donated the use of their restaurant and staff, and Boris who donated his time as a musician and gave free gondola rides.

Thanks also goes to the many clients of Personalized Fitness who donated Silent Auction items, Eric Hilton for donating photography, and the PWSA (USA) staff for donating their time in planning and working the event.

Maryland 'Tag Day'

The Vuccis are at it again! St Peter's School in Baltimore, Maryland, had both a "Tag Day" and a St. Peter's "Raffle" to support PWSA (USA).

This is the school where Anne Vucci teaches. Ann is a teacher and the mother of 2-year-old Maria Christine Vucci, who has PWS.

Anne's husband Bill was significant in assisting us to get on the Combined Federal Campaign list, and Anne worked the awareness booth at a recent medical conference in Baltimore (See the photo on page 3).

The Vuccis are certainly living proof of the many ways you can help raise funds to benefit PWSA— no matter where you live. They are also a wonderful example of the many people who make up the heart of our PWSA (USA) membership.

Another way to Impact on Research: Brain Tissue Banks

We received a thank you from Lori Rich, who wrote, "I want to express my appreciation to Janalee for taking over and handling Lindsay's wish of donating her brain and tissue."

Although it is difficult to think about, we should all consider having our children registered at one of the brain tissue banks — or at least keep the information accessible. As I reported in the last issue of *The Gathered View*, Lindsay was adamant that she wanted to donate her hypothalamus when she died. Due to the short window of time that Prader-Willi syndrome hypothalamic brain tissue is best preserved for research, I worry that we sometimes miss the opportunity to support research in this significant way. Remember, by making this precious gift, you could be one of the keys to unlocking lifesaving discoveries.

In the past, we worked only with the Brain and Tissue Bank for Developmental Disorders. But now we have met with the Human Brain Tissue Bank at the University of Florida, so we also have an opportunity to use this alternative. Both have pre-registration programs and both will send you written information.

We hope you never need it, but please keep the following information available. Remember — with brain tissue, hours can make a difference.

Human Brain Tissue Bank at the McKnight Brain Institute of the University of Florida

The general number for more information is (352) 294-0537. The toll free pager number of Barbara "Bobby" Colon is (877) 206-7302. (This number should only be used if there has been a death of someone with PWS.) A backup pager number is Dr. Eskin at (352) 727-4602.

Brain and Tissue Bank for Developmental Disorders

There are two numbers, which are used for both general information and for donations. The Baltimore, Maryland number is 1-800-847-1539. The number for Miami, Florida is 1-800-592-7246. Donors should register with only one bank.

If you need help with all this, just call PWSA (USA) and we will guide you.

Trophy - continued from page 1

around the track (three racers, he was third), the whole place was cheering for him. It was the most wonderful thing to hear.

At the ceremonies for Rider of the Year, Phillip got a Special Recognition. It says: "For having the courage and determination not only to try, but to find in the attempt, a success, indescribable; yet so significant that all who witness the aforementioned success are compelled to testify that Miracles Do Occur."

We have just started our 2002 BMX Racing year. February 17 was another one of those days that brought tears of joy to my eyes. Phillip actually passed another racer, not just one Moto but all three Motos. This was his first second-place medal. The spectators and racers were screaming so loud that all you could hear was "Go, Phillip, go!"

And he did.

Kathy and Jeff Johnson are the proud parents of Phillip, age 10, who has Prader-Willi Syndrome, and Alex, age 8. They live in Selah, Washington.

Phillip races at the 2001 Washington State Championship, where he placed 3rd.



Hands - continued from page 4

foothills of the Berici Mountains near Vicenza in Italy. Within 3 years, they have been able to build three state-of-the-art laboratories to test for and treat rare disorders. IPWSO has had the privilege of being the first rare disorder to have an office in B.I.R.D. There are many, many rooms still needing to be refurbished for future use, so both IPWSO and B.I.R.D are in the process of creating a volunteer program to help with reconstruction, laboratory work, and the office. We will write more on this later.

America is one of the first country members of the IPWSO twinning project, and is partnered with Brazil. Pam and I learned to appreciate more what we do have in the USA as we talked with parent representatives from other countries.

- Alex Korth from **Argentina** told of how he had to fly to another city so that he could use his German passport to fly to Italy. When I asked why (assuming it was for political reasons), he said no, it was because his government is in such disarray that they had not paid their bills and now could not get the right paper to make passports!

Alex showed slides of the beautiful first-ever PWS group home he and his wife spent their entire life savings on to create, which came complete with farm animals and a lot of property. They had eight people with PWS living there, but when the financial system collapsed in December in Argentina, they had to close down, and all of the young adults who lived there had to move back with their families.

- Helena from Brazil (our twinning contact) said that in her country, physicians often did not have enough paper to write prescriptions, so you had to bring your own paper for prescriptions. (See Pam's article for more on Brazil.)
- The representative from Israel worried the entire time about what might be happening to her family with the fear of suicide bombers.
- Dr. Osama Zaki from Egypt told me he was ashamed of his first name. Dr Zaki wanted information on how to put on a conference. His goal is to go back to his country and put

together a conference for parents and physicians since awareness of PWS is non-existent in his country.

Many of the representatives who attended are in the very initial phase of trying to form a national organization, and do not have as much as a brochure on PWS in their language. Of course, we will — and have — sent them materials we have created, along with our blessing to translate the publications in their own language.

There were several presentations from scientists and parents around the world and group meetings to discuss the direction IPWSO should take for the future. Besides office space for rare disorders and research potential, there is the possibility of considering sending families there from countries with no resources for a diagnostic workup, education and support, networking with other nations — then going back to their own nation to initiate services. How to support future IPWSO conferences was also discussed.

The highlight of the meeting was the concert Giorgio and a full ensemble put on for the attendees in the 15th century church at BIRD. This was the first event in the church, which has been closed for decades and is now in the process of being restored. The concerto played and sang Zipoli's beautiful music from "The Mission." (For more information go to web site zipoli.it, or contact the national office.) Giorgio is well known in South America for the concerts he performs of Zipoli's music.

The concert ended with the entire ensemble, led by Giorgio and Monica Fuhrmann of Germany (also a parent, professional opera singer and IPWSO board member) singing the IPWSO theme song, "Fly High." Tears of joy, a tremendous feeling of brotherhood and sisterhood and a standing ovation ended the concert.

During the concert, I reflected on how the story of the resurrection of the music from "The Mission" fits the story of our families — of rising from the ashes of despair to create a new way to sing our song to the world.

Angel Fund Contributions December 2001 - March 2002

Heavenly Angel (\$500-\$999)

James & Dolly Brien, Sr. *(in honor of Katherine Pate)*

Arch Angel (\$250-\$499)

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