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

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

"Moo-ving Forward" from Milwaukee

Over 400 people, including more than 100 volunteers, attended the 30th Annual PWSA (USA) National Conference in Milwaukee, Wisconsin, July 2-4, 2008. After Scientific and Providers conferences and Chapter Presidents Day on Wednesday, July 2, the general conference opened Thursday in an emotion-filled session with Richard Pimental, one of the leaders in forging the Americans with Disabilities Act. His personal story, portrayed in the movie *Music Within*, brought us all near to tears as he combined memories, history, and humor to illustrate the power of love.

Pimentel quoted Oliver Wendell Holmes, saying "Most people go to their graves with the music still inside them."

Concurrent sessions spanned scientific, therapeutic, educational, residential, familial, and behavioral topics. Families and friends shared a Gala that featured a silent auction and hip-hop music by The Figureheads, a nonprofit musical group that thrilled both dancers and listeners with their audience interaction and positive message.

"A terrific conference. I was telling my wife that I have so many of those "spine tingling" moments at the PWS conference, I'm just so moved by the warmth, support and drive that this group has, and the many caring people who are members. As always, I'm proud to be associated." ~Harold Van Bosse, M.D., member of the Clinical Scientific Advisory Board

Conference Co-Chairs Barb and Don Dorn, Mike and Mary Lynn Larson, and Chad and Melissa Sirovina led a large contingent of Wisconsin Chapter members planning and executing diverse conference activities including a Youth and Infant Program (YIP) serving 32 children 5 and under. The return of Wild Willy and Silly Lilly from previous conferences delighted the children. Many thanks go to all for their hard and successful work!

Our Executive Director Craig hanging out with cows and kids

"….. the conference was a great experience for myself and my daughter."

At the annual business meeting, Dr. Merlin Butler, Chair of the PWSA (USA) Scientific Advisory Board who has recently moved to the Kansas

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Janalee with Isabelle Lutz and sister Natalie

Wild Willy makes a friend

In this Issue

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

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Members Only: See our web site, www.pwsausa.org, for downloadable publications, current news, current research and more. Limited to members only.
User Name: pwsamember
Password: support08
Note: If you have difficulty logging in, please contact info@pwsausa.org.

E-mail Support Groups:
We sponsor nine groups to share information.
Go to: www.pwsausa.org/support

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Deadlines to submit items to *The Gathered View* are: Dec. 1; Feb. 1; Apr.1; Aug. 1; Oct. 1

Executive Director's View

Photo by Eric Hilton

Craig Polhemus

An Exciting Year – An Inspiring Challenge

On July 3, 2008, I spoke at PWSA (USA)'s annual membership meeting in Milwaukee, Wisconsin, saying in part:

It's been an exciting year.

- For the first time in history, families of those with PWS have access **24 hours a day, 7 days a week**, to emergency medical counseling and referral through a pilot project launched in February 2007.
- We handled **almost a thousand crisis counseling calls in 2007, up more than a third from 2006**, covering everything from behavior at school through insurance eligibility to law enforcement and residential placement issues, and on and on. So far this year, calls are running another 20% higher.
- PWSA (USA) spent **more than twice as much on research** as in any prior year, and we made five exciting new research grant awards.
- We published a **new handbook** on supporting adults with PWS in residential settings. (See page 15.)
- The PWS network **advocated successfully** for improvements in SSI eligibility processes and against further restrictions on growth hormone availability, working with the National Organization for Rare Diseases, Foundation for Prader-Willi Research, and other groups.
- Millions more Americans learned about PWS as our national spokesperson, **Clint Hurdle, led the Colorado Rockies to the World Series** through an unbelievable sweep of all 7 playoff games.

Parents, remembering how weak their children with PWS were at birth, feel pride and hope as they grow stronger. Just like our children, the family of PWSA (USA) is getting stronger each day, week and year. With our New Parent Mentoring program, our Package of Hope for new parents, our Crisis and Family Support programs, medical education and awareness initiatives, our educational resources and publications, our e-mail support groups, our Chapters, our research, our many, many volunteers and donors, PWSA (USA) is here to help.

> As always, we need to look to ourselves, to work together to raise funds to maintain and continue expanding our services to famiies struggling with PWS.

All these initiatives depend on – you: families interested in helping each other through generous donations, fundraisers, and volunteer work raising awareness and funds.

Like other nonprofit charities, PWSA (USA) faces special challenges in a weak economy. For several years, we generated income adequate to fund our many programs and services and build some reserve. But as the economy weakened in 2007, donations dropped for crisis support, for research, and for other programs. So far, despite some very successful grassroots events, 2008 looks even more challenging.

What is the answer? As always, we need to look to ourselves, to work together to raise funds to maintain and continue expanding our services to families struggling with PWS. (To help, visit www.pwsausa.org/donate or www.firstgiving.com/pwsausa.)

Although the PWS community is growing stronger, we still have a long way to go before every doctor, every law enforcement officer, every government official, and every potential donor knows about PWS. And we can watch the results of our efforts:

- as more and more medical practitioners learn about the special needs of those with Prader-Willi,
- as better behavioral techniques are discovered, tested, and disseminated,
- and as research theories are translated into effective treatments.

Our victories will add up, from season to season to season, until our children, our adults, even our soon-to-be-elderly relatives with PWS know the joys of good health, increased independence, and, some day we pray, even freedom from hunger and from impulses they can't control.

Together, we can achieve miracles for our children. ■

Craig

Medical View
Ask the Professionals

Carnitor (L-Carnitine) is a diet supplement used to prevent and treat low blood levels of carnitine. Carnitine is a substance made in the body from meat and dairy products. It helps the body use certain chemicals (long-chain fatty acids) for energy and to keep you in good health. Low blood levels of carnitine may occur in people whose bodies cannot properly use carnitine from their diets. Symptoms are low glucose, muscle weakness and low energy. It is one of the supplements being used more recently with PWS along with CoQ10 and fish oil.

Questions:

Are there any side effects of concern on Carnitor? How do they decide on dosage? Is there any particular brand that is better?

Answer:

Dan Driscoll. M.D., chair of PWSA (USA) Clinical Advisory Board (CAB), & Jennifer Miller M.D., member of the CAB

- You are not exactly sure what you are getting with an over the counter preparation and they are not all the same. That is why we prefer the prescription – Carnitor (L-carnitine)
- We like to check a level first before prescribing and then later if the child is taking the medicine.
- It should be done under the supervision of a physician.
- It seems to help some, but not all so there is no sense using it for years if you do not see an effect in the first 3-6 months unless there is a deficiency.
- 50 mg/kg per DAY for children is a reasonable dose to start, but depending upon levels it can be titrated up or down. We usually divide the dose 2-3 times per day.
- Side effects are minimal ("fishy" smell and diarrhea if the dose is too high) and can be reduced if necessary by starting at a lower dose and then gradually increasing. Some parents are seeing some irritability when it is started which they are attributing to the dose being too high as it goes away when the dose is decreased. ■

Research View
Scientific Day Presentations at the 30th Annual PWSA (USA) National Conference July 2, 2008, Milwaukee, WI

Full abstracts with further information may be found on the PWSA (USA) web site Members Only, or call the office.

Endocrine Review

Plasma Adipocytokine Measurements in Children with Prader-Willi Syndrome (PWS) Compared to Obese and Lean Control Children: Relationship to Insulin Sensitivity

Human Chorionic Gonadotropin (hCG) Stimulation Test in Male Patients with Prader-Willi Syndrome

Changes in Head Circumference with Growth Hormone Therapy in Individuals with Prader-Willi Syndrome

Cognitive and Adaptive Functioning in 4 -11 year old Children with Prader-Willi Syndrome who are Receiving versus not Receiving Growth Hormone Treatment

Genetics Review

Magel2-*null Mice Display Altered Behavior, Abnormal Neurochemistry, and Reduced Brain Volume*

Loss of the Prader-Willi Syndrome Gene Magel2 affects Reproductive Function in Both Male and Female Mice

Unique Deletions in Prader-Willi Syndrome

The snoRNA SNORD115 (HBII-52) that is not Expressed by People with Prader-Willi Syndrome Regulates Alternative Splicing

Mice Solely Expressing the Fully-Edited Isoform of the 2C-subtype of Serotonin Receptor Exhibit Characteristics of Prader-Willi Syndrome

Research View continued on page 7

Visit our newly improved web site for more pictures, regular updates and more... www.pwsausa.org

Osteoporosis Evaluation and Therapy in Prader-Willi Syndrome

Consensus Statement of the Prader-Willi Syndrome Association (USA) Clinical Advisory Board

Many individuals with PWS have osteoporosis (low bone mineral density). This condition is most often diagnosed in adolescence and adulthood. The cause(s) of the osteoporosis is not totally clear, but it is thought to be primarily due to the growth hormone and sex hormone deficiencies that occur in PWS. Hypotonia is probably a contributing factor as well.

Bone mass typically accumulates until around the age of 30, with the maximum accrual time for bone mineral density being in adolescence. Puberty is often delayed or incomplete because of a deficiency in sex hormones in individuals with PWS. This interruption of normal puberty in combination with growth hormone deficiency probably results in less bone mineral mass being accrued during adolescence in individuals with PWS compared to the normal population. However, the process may begin earlier than adolescence due to other hormonal abnormalities which affect bone mineral density.

Physical inactivity and limited weight bearing also play a role in the onset and exacerbation of osteoporosis. Exercise is an essential part of the life style for all individuals with PWS, and the health benefits of exercise must continue to be emphasized. Also, recent studies suggest that the use of psychotropic medications may play a role in the genesis or exacerbation of osteoporosis. It is well known that individuals receiving anticonvulsants for seizures or mood stabilization are at greater risk for osteoporosis. Adults receiving selective serotonin reuptake inhibitors (SSRIs) have greater bone loss and lower bone mineral densities. Children and adolescents receiving SSRIs are at risk for decreased bone mineral accrual and bone formation. Given the large number of individuals with PWS who are receiving psychotropic medications, extra care for evaluation and management of these individuals is required.

Osteoporosis is diagnosed with a dual-energy X-ray absorptiometry (DEXA) scan. A DEXA scan is a painless low dose X-ray procedure. DEXA scans of children and adolescents should be interpreted only by experts experienced in scoring these scans in pediatric patients. DEXA scans which are interpreted compared to adult standards (T-scores) often overestimate the presence of osteoporosis in children and adolescents. Although the normative pediatric databases are small, the interpretation of the DEXA scan should contain an age-, gender-, and race-matched Z-score. Frequently radiologists or other individuals who evaluate DEXA scans do not have access to this information. A Z-score (or T-score for adults) that is between 1 and 2 standard deviations below normal is considered osteopenia (weak bones), while a Z- or T-score that is more than 2 standard deviations below normal is considered osteoporosis. You should ask your physician to provide you with the Z-score (if you are under 18 years of age) or T-score (if you are an adult). DEXA scans should be monitored every one to two years in adolescents and adults with PWS.

Other assessments that are valuable for individuals with osteopenia or osteoporosis include measurements of serum calcium, phosphorus, magnesium, parathyroid hormone (PTH), alkaline phosphatase, 25-hydroxy-vitamin D levels (calcidiol), and 1,25(OH)2-Vitamin D (calcitriol). Many individuals in the United States are deficient in dietary intake of vitamin D and calcium. These nutritional deficiencies play a big role in the development of osteoporosis. Other laboratory measurements should include evaluation of thyroid function, prolactin, sex hormone levels, and growth hormone levels.

If osteopenia or osteoporosis is present on DEXA scan, the primary treatment is maximizing vitamin D and calcium intake in the diet. A nutritional consult should be obtained to assess current dietary intake of calcium and vitamin D. Current recommendations for adults (note that pediatric standards vary according to age) are that dietary calcium for individuals with low bone mineral density should be at least 1,500 mg per day and vitamin D intake should be at least 600-800 IU per day. Some studies indicate that even these amounts may be inadequate to significantly improve bone mineral density. Ideally, serum 25 vitamin D levels should be followed, with the desired concentrations being at least 30-32 ng/ml in order to improve bone mineral density.

In many cases the dietary intake is inadequate and supplementation of calcium and vitamin D is necessary. It is important to know that most calcium supplements are calcium carbonate which is only 40% bioavailable (meaning that a calcium supplement which contains 500 mg of calcium carbonate only provides 240 mg of elemental calcium which can be used by the bones). Vitamin D can be purchased over the counter without a prescription in 200 – 1,000

Medical View continued on page 6

Osteoporosis – *continued from page 5*

IU capsules or may be purchased at higher doses with a prescription. The best way to give calcium supplementation is with food, no more than 600 mg of elemental calcium at a time, and no more often than every 2 hours to allow maximal absorption.

Although medications called bisphosphonates (e.g., Fosamax, Actonel, and others) are commonly used in adults with osteoporosis, the use of these medications in adolescents and young adults remains controversial. Some experts in pediatric bone disease recommend that these medications not be started in young people with osteoporosis until they have had a fracture. The long term risks of these medications are unknown at this time. However, there have recently been reports of an increased incidence of jaw necrosis after dental procedures associated with these medications. Bisphosphonate therapy may be considered in adolescents or young adults once vitamin D and calcium supplementation are maximized. More research is needed to identify the long-term risks that may be associated with these medications in adolescents and young adults.

Other important treatment options for osteoporosis include hormone replacement therapy (such as estrogen, testosterone, thyroid hormone and growth hormone). These treatments have been shown to improve bone mineral density in individuals with PWS. Starting these therapies before adolescence, if possible, should be most beneficial. Supplementation of vitamin D, calcium, sex hormones and any other modality of treatment for osteoporosis should be monitored by a physician. ■

Expected Significance of Current Research Sponsored by PWSA (USA)

To get a report of the twelve active grants that are being sponsored by PWSA (USA) plus our Medical Database project and the expected significance, go to www.pwsausa.org. …or calling the PWSA (USA) office for a copy. We want to thank all who have donated or hosted fundraisers to make this important research possible. We are improving the quality and length of our children's lives TODAY! It is not just a dream for tomorrow.

~Janalee Heinemann, MSW
Director of Research & Medical Affairs

Guidelines for Postoperative Monitoring of Pediatric Patients with Prader-Willi Syndrome

Winthrop University Hospital, Mineola, New York, has cared for over 300 patients with Prader-Willi syndrome. The Prader-Willi Center at Winthrop is a national referral resource for these patients. Many of them have chosen to perform their emergency and elective surgeries at our institution. The hospital recommends the following, based on its experience:

Background Information:

Patients with Prader-Willi syndrome are known to have increased morbidity after surgery due to:

- Abnormal physiologic response to hypercapnia and hypoxia
- Hypotonia
- Narrow oropharyngeal space
- High incidence of central, obstructive and mixed apnea
- Thick secretions
- Obesity
- Increased incidence of scoliosis with decreased pulmonary function
- Prolonged exaggerated response to sedatives
- Increased risk for aspiration

Recommendations:

I. Infants and children with Prader-Willi syndrome who undergo deep sedation and general anesthesia should be recovered in a monitored unit, either the Pediatric Recovery Room or Pediatric Intensive Care Unit.

II. Continuous monitoring of pulse oximetry for 24 hours postoperative is strongly recommended with attention to airway and breathing.

III. A conservative approach to pain management and use of narcotic agents is recommended.

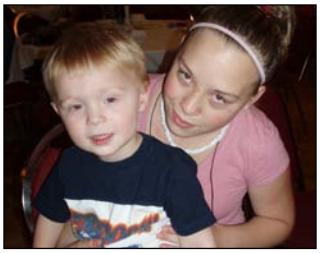
IV. Full assessment of return of GI motility prior to initiation of intake by mouth should be done because of the predisposition to ileus after surgery.

V. Direct supervision (1:1) is essential to prevent foraging postoperatively.

~Moris Angulo, MD – Director of Medical Genetics, Assistant Director of Pediatric Endocrinology
~Mary Cataletto, MD – Associate Director Pediatric Pulmonology
~Maria Lyn Quintos-Alagheband, MD – Associate Director Pediatric Critical Care Department of Anesthesia

VI. Monitor for picking of wounds.

Happy Conference faces...



Research View – *continued from page 4*

Medical/Behavioral Review

Relations between Maternal Stress and Offspring Behavior in Prader-Willi Syndrome

Factors Effecting Cognitive and Achievement Abilities in Prader-Willi Syndrome

A Preliminary Description of PWS Behaviors across the Lifespan: Stability and Change

Stress and Coping among PWS Families and Caregivers

Outcomes of Intensive Behavioral Intervention for Individuals with Prader-Willi Syndrome

A Multidimensional Information Model Supporting the Comprehensive, Individualized Plan of Care within a Problem-oriented Knowledge Repository for Prader-Willi Syndrome

Bioenterics Intragastric Balloon for Treatment of Morbid Obesity in Prader-Willi Syndrome: a Long-term Study

Scoliosis and Prader-Willi Syndrome: Results of the Latest Survey

Surgical Treatment of Spinal Deformity in Prader-Willi Syndrome

Moo-ving Forward – *continued from page 1*

University Medical Center, received a special award for distinguished service to the PWSA community. Speaking from the floor, long-time member and past president Dr. Delfin Beltran reminded attendees of PWSA (USA)'s founding and spoke of the tremendous growth of PWSA programs and membership since then.

"I thought that [Janalee] did an absolutely super job summarizing the PWSA sponsored research projects for families… tone was just right, and the content was conveyed in a straightforward, honest and upbeat way that families could readily appreciate and understand. Thank you!"

Friday's sessions included sensory integration, Individualized Education Programs, behavioral techniques, and residential service models, plus focused sharing sessions. An extended Health Update session permitted parents to ask Drs. David Agarwal, Jennifer Miller, and Ann Scheimann questions. As other medical and behavioral experts in the audience chimed in, this session vividly illustrated the value of the PWSA (USA) conference as the world's largest gathering of family, friends, and professionals concerned with PWS.

" The atmosphere was festive and the food was very good. Although RAP is not my favorite type of music, the Figureheads were 'awesome'!"

At the closing session, participants thanked Conference Coordinator Kerry Headley, who is leaving that position to join the PWSA (USA) Board. Executive Director Craig Polhemus, in a quick summary of Chapter activities, said, "I hope you find that joining together in Chapters and support groups repays your investment of energy with information, companionship, and inspiration that can help carry you through those long, challenging days when you feel all too alone. And give our e-mail support groups a try as well – I've never seen a more active, supportive group of parents. We are many, yet we are one."

Led by two friendly "cows", the YIP participants marched in to close the Conference. Linda Gourash, Janet Forster, Janice Agarwal and Carol Hearn reprised their conference-opening number, *Gotta Keep on Moo-Ving*, giving a burst of energy that lasted well past the end of the session.

"The conference turned out absolutely fantastic!" ■

Do you share PWSA (USA)'s vision of a world where:

- Everyone with PWS receives an early diagnosis, terrific medical care, insurance benefits, and a free and appropriate education;
- Each adult with PWS has both a satisfying job and an appropriate place to live an independent, secure, socially-fulfilling and productive life; and
- The most debilitating aspects of PWS (and perhaps the entire syndrome) are eliminated or alleviated through groundbreaking research?

If so, ***WE NEED YOUR HELP*** to make that vision a reality.

Over the past three years, PWSA (USA) has dramatically increased services while simultaneously increasing our reserves. But given today's economic condition, we simply cannot sustain our growth without your urgent help.

- An influx of research donations in 2005-07 enabled us to spend more than twice as much money on research in 2007 as in any prior year. We must build on our tradition of funding high-quality, high-impact research.
- Our 24-hour medical crisis hot-line pilot project was funded by a special one-time grant. We mustn't let this life-saving project vanish.
- We handled almost a thousand crisis counseling calls in 2007, up more than a third from 2006. So far this year, calls are running another 29% higher than that. Each call requires, at a minimum, that there be a person to answer the call, a phone line, and an infrastructure that supports the gathering and dissemination of accurate information to the family in crisis.

These initiatives - and many more - require continuous funding. Each year, about 1,500 people donate at least $100 to PWSA (USA). About 200 of these give $1,000 or more, and a handful give much more. To achieve our vision we must expand this list of dedicated donors.

If you are already raising funds for PWSA (USA) and are giving all you can, THANK YOU!

If you think you can do more, please consider helping in any or all of the following ways:

- Go to **www.pwsausa.org/support/donateform.asp** and make as generous a contribution as possible or mail a check to PWSA (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238.
- Set up a personal web site though **www.firstgiving.com/pwsausa** so your friends, family members and business associates can easily donate to PWSA (USA) in honor of your child or loved one with PWS.
- Consider holding a fundraiser to benefit PWSA (USA). The national office **(info@pwsausa.org)** has lots of materials available to get you started, guide you through the process and help make your event a smashing success.
- If you know someone who is connected with a foundation, government funding agency and/or corporation that may have an interest in supporting our efforts, please contact our Executive Director, Craig Polhemus, at **cpolhemus@pwsausa.org** so we may follow up on your contact.

Please help as much as you can, for if we don't sustain PWSA (USA), who will be there when we need help?

Carol Hearn
Co-Chair, PWSA Board of Directors

Steve Leightman
Chair, Finance Committee

The Great Fundraising Adventure: From Doldrums to Dollars

by Dominique Deleage

When my son Charlie, born in February 2007, was three weeks old, we received a phone call from our pediatrician with the results of the genetics testing. After 12 days in the hospital, Charlie was now home with an NG-tube, and we were just happy about having him with us. The pediatrician said, "Charlie has been diagnosed with Prader-Willi syndrome," and explained what it was. We had never heard of it. He had also booked an appointment for us with our local geneticist, and gave us the link to the PWSA (USA) web site. We looked at the site right away and took a couple of weeks to contact PWSA directly, letting the news sink in first.

It was a lot to swallow… yet, Charlie was, and still is, so sweet and cute. After the initial shock, I just wanted to find a way to turn this into something positive, anything really, to get us out of this negative tailspin. My frame of mind was: "What can we do to help channel our emotion and energy into something positive for Charlie, and for our family?" Being disappointed and depressed wasn't going to help Charlie, so we needed to find something else.

My husband and I decided that the "something positive" should be a fundraiser benefiting PWSA. It was the only way we could think of to help Charlie, and it turned into a wonderful experience. We decided on a mini-golf tournament and contacted some of our friends with a request to help us in our endeavor. All of them responded with a resounding 'Yes!' We held a kickoff meeting and started planning the event. We looked for a location, looked for sponsors, put together a web site, and spread the word.

Charlie - one happy little guy

Anytime we contacted someone to support our fundraiser, we got that and much more... We talked about it to our families, who live far away, and they made donations. We talked to Jessica and Tom Howard, parents to Riden (age 2 at the time, with PWS), to learn more about PWS, and they joined us in planning the event. We talked to our friends, and they helped us find sponsors and participants. We contacted my Mom's groups, and they came to play or donated money. I talked to my classmates and professors (I am a grad student at Georgetown University), and they came to play and gave us sponsorships. We contacted our local PWSA chapter to help promote it to local families, and they both helped us spread the word and made a donation. It was a very uplifting experience!

On September 22, 2007, the very day Charlie turned 7 months, 60 participants gathered for our 'Putt for PWS' fundraiser. Sixteen sponsors had agreed to support our effort. The weather was perfect, and everyone enjoyed a fun morning away from hectic everyday life. Even my university friends, for whom a Saturday morning 10AM start was rough, were delighted to be out and play. It was a great time! And most important, we were able to raise $5,800 for PWSA, well beyond our $2,500 goal!

I am thankful for all the overwhelming support we received, excited our fundraiser raised money for PWSA, and amazed by the wonderful adventure it turned out to be. We're doing it again September 20th this year! Feel free to e-mail me for ideas, comments or else at dom@puttforpws.com. And contact PWSA and experience your own fundraising adventure. You will be glad you did!

~Dominique Deleage
Mom to Alexandre 2 ½, and Charlie, 16 months with PWS-UPD
Arlington, VA

Production, printing and mailing of this newsletter was underwritten by a generous grant from CIBC World Markets Corp./Miracle Day USA.

Fishing and Catching

By Dan Yashinsky

We're rigged for muskie. My son, Jacob, is casting into the boat basin at the foot of Bathurst Street– waters that rarely float a sunfish, let alone the mighty muskellunge, but it's a good place to try out his new equipment. Our hopes for a fish aren't particularly high. We're just happy to be down here, sipping lukewarm coffee, watching the lake bright with late sunlight, companionably chatting about his day at high school and mine at work. We do a lot of fishing around Toronto, with meager results. We often have to remind ourselves that the sport is called "fishing", not "catching."

Mostly we fish in a lake up in the Gatineau Valley. We have countless pictures of him standing proudly on the beach holding a surprised-looking bass for a photo op. Some we keep and cook, but most are returned to the dark lake waters.

Jacob, Dad and fish

The son I'm fishing with is our youngest child, now 17. It's amazing that he's here at all. When he was born he had an Apgar score of two. This is a measurement of vital signs, and six or seven is considered normal. He spent his first three weeks in the neo-natal intensive care unit. At four, he was diagnosed with Prader-Willi syndrome.

He's a good fisherman. He has patience, tenacity, a formidable capacity to concentrate, and an uncanny ability to imagine where the fish may be lurking under the surface. Sometimes these qualities help him - and us - cope with PWS; sometimes we're swept away by it, discouraged and panic-stricken by crises none of us has the wisdom to resolve. But even on the bad days, days when we get the dreaded call from the vice-principal to say something's happened and could we come to the school immediately, even then we try to remember that he - like all teenagers with a disability - faces each day with more courage and heroism than many people muster in their whole lives.

He knows that his beginnings were precarious. Once, as he was trying to get me to pick up the socks he was too lazy to reach for, I asked why I should do him that favor. "Because," he said, playing his heroic ace, "I chose to live." It didn't work, of course, but we both laughed. He also knows that his disability is an enormous, complex, daily challenge. It is difficult for a teenager with PWS to be in high school, to walk through a cafeteria filled with tempting food, to focus on academics when your body tells you to go secretly foraging for left-overs.

As all parents do, whether or not a child has a disability, we've learned to store up the good moments as ballast against the hard ones. We rejoice in the memory of him giving the opening speech at the Ontario Prader-Willi Syndrome Association 2007 conference, or performing a poem at an open mic, or using his exceptional sense of pattern to create a piece of beautiful gemstone jewelry or to win at Scrabble. We hold on to a sense of his immense generosity and sweetness as an antidote to the daily, demoralizing struggle with the syndrome's insidious effects on behaviour, rationality, and health. In other words, we keep fishing, even if we don't always catch what we're hoping for.

My favourite fishing story is about the first fish he ever caught. We were out on a rowboat near the shore of an island. His rod bent double and I said, "You're caught on a log." He shook his head and whispered, "It's a fish." "It's a log," I affirmed with grown-up certitude. Then the line began to run out, and, after a memorable battle, my seven-year-old fisherman reeled in a two-pound smallmouth bass. I was wrong, as he's never tired of reminding me. I was wrong, and delighted to be so. I was wrong, but may I say in my own defense that it's sometimes hard for parents to tell the difference between a log and a fish.

~Dan Yashinsky, Jacob's father, who says he is a "storyteller and author of Suddenly They Heard Footsteps – Storytelling for the Twenty-first Century", lives in Toronto, Canada.

Looking ahead to the Holidays

By Janalee Heinemann, MSW, Director of Research & Medical Affairs

The holidays are typically a food fest in our country – and often a stress fest for our PWS families. With good planning, a happy holiday for all is possible.

Thanksgiving, Christmas or Hanukkah

- Communicate to all involved in a holiday gathering the importance of food control. Make sure everyone knows the "rules of engagement" and agrees to cooperate.
- See that someone at all times is clearly in charge of your child with PWS. Clearly define when you are "changing guards". Dr. Linda Gourash says, "*When everyone is in charge – no one is in charge.*"
- If your child is old enough, rehearse the "rules" before the special day and come to a mutual agreement on what your child will be allowed to eat. You can barter, e.g., "*Do you want a little extra turkey and dressing, or do you want a piece of pie as your special treat?*"
- It is okay to request that Grandma and other relatives tuck away tempting items during your visit and to discreetly check with you prior to offering your child a treat.
- Make sure you know what everyone is bringing, so there are no surprises on what the choices will be.
- Grandpa, Grandma, aunt or uncle, may want to bring a special gift toy to compensate for the food they have to deny your child.
- Go over with the hostess or your family on how to contain the accessibility of food. See to it that where your child is sitting there will not be a lot of bowls of food, rolls, or condiments nearby (our children can consume many calories with the extras – sugar, butter, catsup, etc.).
- After eating, when people are just visiting, either have all the food put away or have someone responsible for guarding it.
- Your child must have the security of knowing you will be strong in your commitment to protect them from food – in spite of themselves. Giving in, even once, means several battles ahead. I know you get tired of hearing it, but consistency is the key.

Trick or Treat! – For Halloween tips, go to the PWSA (USA) web site and read the article from Vickie Fetsko which is a reprint from PWSA of Ohio newsletter.

Of course, each family must judge their own situation based on their child's food drive and their own rules on treats. Some families are raising their children to never have any sweets – no exceptions. Others (like ours) just go by calories and the weight of the child, trying to keep the diet less in quantity, yet similar to others in variety. Often, the most important thing is to prevent food sneaking or food demands. There is a large variance in the food drive of children with PWS. Some will ask or beg for more food, but make no significant attempts to sneak food. Others will go to great extremes to get food and are incredibly clever at doing so. ■

HOLIDAY ALERT

The holidays have an extra risk factor for our older children and adults with PWS. Four individuals with PWS were reported to have died of gastric rupture and necrosis. Furthermore, 4 additional individuals were suspected to have gastric dilatation and perforation, but without autopsy evidence. Some of these were over the holidays or special events and due to a food binging episode that led to necrosis (deadening of the tissue) of the stomach wall and a perforation (tear) in the stomach. In most of the deaths, the person with PWS was relatively slim, so there was no great concern about weight gain. Keep in mind that a person with PWS, who is slim still does not have total food control. When one also has many opportunities for food ingestion, the lack of feeling full, the high pain threshold, and a weak vomiting reflex – then one has the potential of filling the stomach dangerously full. Because there are many food binging episodes of our children and adults with PWS, most not having such disastrous results, we think there are probably other factors that play into this life-threatening situation that we are currently researching. One hypothesis is that due to prior food binges, and stomach muscle weakness, certain areas of the stomach wall become thinner putting this area at risk.

Please see that the safety and security that your child deserves is provided. ■

International View

Report on the First International PWS Caretaker's Conference

In June, I had the opportunity to represent PWSA (USA) as part of the American delegation attending the First International Caretaker's Conference in Herne, Germany, sponsored by the International Prader-Willi Syndrome Association. This conference was inspired by the leadership of IPWSO President Pam Eisen, and its purpose was to begin to develop a "best practices" model of care based upon caregiver/provider experience around the world.

During the conference, work groups spent a total of 8 hours developing statements of consensus and areas for additional discussion around a variety of topics including: Environmental Structure of Living, Communication with People with PWS, Training for Teachers, Nutrition Management, Aspects of Psychological Work with people with PWS, and Crisis Management. I participated in the leadership team for the Crisis Management workshop. The conference was attended by 170 people representing 16 different countries. Despite significant differences in language and societal context, the discussions were intense and very productive. I came away from this fantastic experience with several reflections:

- It was a rare opportunity to interact with global PWS experts.
- I was impressed by the universal sense of care, compassion, and commitment of fellow participants.
- There was a strong passion (cutting across cultures) for the importance of recognizing and protecting the individual rights of people with PWS.
- We discovered common challenges for people with PWS regardless of country, including placement (especially as adults), accessing effective educational opportunities, respite care, medical care, employment, and the need for crisis assistance.
- We also discovered some significant differences including: What does independent living mean for a person with PWS? Can behavior be changed in a person with PWS or only managed with proper environmental supports? Should physical restraint ever be an option (many participants said no)?

Finally, because of the conference, I now have a number of global colleagues I can ask for advice and share experiences and insights with. It is heartening to know we are not alone in the struggle to support people living with PWS. Every day, in every part of the world, others are doing the same. This gives me a new source of strength, wisdom, and hope for the future.

~Evan Farrar,
Crisis Intervention Counselor

Update on Pam Eisen

Most of you read about Pam's diagnosis of pancreatic cancer. We are happy to report that she is doing much better than expected and not only attended the Germany conference, but was involved throughout and presented twice. Pam is a woman with great vision, compassion, and tenacity. You may be able to keep a good woman down, but not this woman on a worldwide PWS mission!

Chapter View

Our chapters, which just had the once-a-year meeting of their leaders at conference, are amazing, creative, and wonderful! —and so vitally important to the mission of PWSA (USA)! Some are large, like affiliate **California Foundation,** which has 477 active General Members, 218 professional members, and a myriad of projects under the guidance of Executive Director Lisa Graziano. Some are small, like **Indiana,** just getting started again with nine families.

Here's just a few highlights of their recent activities, projects and advocacies:

New Jersey had guest speaker Jennifer Zarcone, Ph.D., from the U. of Rochester Medical School, presenting on "Understanding How the PWS Brain Works" at their June meeting…PWSA of **Ohio** is planning both a Fall Mini-Conference and their October weekend camp, themed around Halloween, for those with PWS age 8; parents can get a respite weekend or volunteer to help out…In the Spring of 2008, the Family Retreat for PWSA of **Georgia** was held at Forrest Hills Resort in Dahlonega, GA. They were able to rent a Lodge with enough bedrooms to house the entire group of almost 70 people.

Arizona identified 13 new families in the state with ages of the kids with PWS ranging from infant to 13. The chapter has a new board, a bowling event in January, a family fun day in April and a walk in May with 80 people attending…**New York's** 2008 conference in Albany had over 200 attendees, and at its first Providers conference over 80 providers attended. …The Prader-Willi **Florida** Association holds two conferences

Chapter View continued on page 14

From the Home Front
The Long Road to Kindergarten

We live in a town that actually puts lots of resources into its special needs children and the preschool program. Our daughter Molly had a wonderful experience in the preschool program and was blessed with the most nurturing, loving teacher one could imagine.

Molly had been attending school only a few months before she started to play school at home–even before she could speak. One day I found Molly standing on the living room couch with a small flag in her hand, pointing to the letters in a framed inspirational print on the wall. She had lined up all of her friends–Big Bird, Elmo, and her favorite baby doll–and had begun to teach her first class. She was three.

Molly on her last day of preschool

Molly is now five and "being a teacher" is still her favorite thing to do. She now recites the pledge of allegiance as she begins her class each day. Her imaginative play is amazing.

In September, Molly will begin kindergarten. When we were sent to observe the class chosen for her, I watched yet another amazing teacher work with a classroom of severely disabled children. Beautiful children they were, but I couldn't imagine how Molly, who never stops speaking, and I do mean never, would be challenged in this class. There were no true peers for her, no one for her to laugh with or be silly and sing with. How will she ever build her social skills if she has no peers around her? When the teacher proudly spoke about how they are able to work with each child individually, I was thinking how would she ever transition to a larger class if she never has to learn to focus her attention in a larger group.

So I raised lots of questions. What other options are there for her? How are children assessed to be in the learning disabled versus the multiply handicapped versus regular kindergarten? What would it take for her to be successful in the next level class? What I learned was that her preschool teacher and team needed to know that she would be nurtured and loved after she left them. The class they had recommended offered unlimited TLC, but lacked challenges and role models. Would Molly have liked it, you bet. What's not to like about having the attention of loving adults all day long. I was more concerned about the challenges that would not be presented.

We have finally confirmed Molly will be going to the learning disabled classroom. It will follow the standard kindergarten curriculum and has the capacity to work in smaller groups according to strengths. This has probably been the hardest decision we have had to make so far.

This process was long, with many sleepless nights. I am certain I will have more sleepless nights come September, but know that we have the support of her team if this new environment is too stressful for Molly.

Many of us look to find meaning and understanding when we consider that our children were born with a disability, trying to identify some "reason" in all of it. Well, if Molly was sent to teach us something, to challenge us in some way, it was to learn to speak up–not to just accept what we are told. As Molly met milestone after milestone sooner than we were told to expect, her grandfather would say "Maybe Molly doesn't agree with her doctors; maybe she has her own ideas about what her life will look like." We believe she does.

~Mary Speiser
Sayresville, NJ

Sam Forestier is passing the Torch at a June Special Olympics police sponsored event in Springfield, Illinois. Then he competed in the state finals for gymnastics and won a silver medal for male floor exercises. Sam is 13 and lives in Athens, Illinois, with his parents, Robert and Sheila Hall. ■

CHUCKLE CORNER

Forget Willi! Sophie told her parents: "Mom & Dad – I think I have it figured out. Since I am so high functioning, I think I only have Prader." ☺

~Susan Henoch,
Princeton, NJ

Chapter View – *continued from p. 12*

a year, one in the fall at Gainesville and one in the spring closer to the southern end of the state. On the average, about 75-125 people attend.

After much hard work, **Utah** was able to get their state legislature to award $60,000 for a care manager to "manage" the care of all people with PWS living in Utah. These funds include a stipend for their state conference this September with Dr. Linda Gourash and Dr. Janice Forster, who will train Utah's families, clinic physicians, and new care manager. A nutritionist will also be hired by the state to create proper diet plans for home and school for all children with PWS. Also in September, a new clinic for children with PWS will open.

The annual General Education Meeting of the **Prader-Willi California Foundation** will be held on Nov. 8, 2008 in Sacramento. Topics will include special needs trusts and wills, core therapies of OT, PT, and speech, getting needed services, and improving the workplace for adults with PWS. ■

If you are a Federal Employee, you can help!

PWSA (USA) qualified for membership and has been a part of the Combined Federal Campaign (CFC) since 2002. If you work for the federal government and its agencies, you can make a donation via the CFC to PWSA (USA)! Funds derived from the CFC offer essential support for programs and research supported by PWSA (USA). The CFC holds activities during their campaign in different local areas around the nation. You can participate by selecting PWSA (USA) to receive donations, and spreading awareness of PWSA (USA) so others can learn about PWS and make donations, too! The PWSA (USA) CFC identification number is 10088. This year so far PWSA (USA) has seen more donations through the CFC than in any year prior. Thank you to all those who support PWSA (USA) this way! Your contributions are greatly appreciated and help ensure our loved ones with PWS have the best futures possible! Questions?, please call PWSA (USA) at (800) 926-4797 and ask for Ann Coyne, our contact for CFC. ■

A View of our Board of Directors

At a meeting of the PWSA (USA) Board of Directors in April 2008, the board voted to expand the size of the board from twelve members to between twelve and fifteen members, the exact number for any given year to be determined by the board. The board accomplishes its work by means of 12 committees and a variety of special-topic teams. By adding a few new board member positions, the board hopes to spread the workload a bit.

Carol Hearn, Co-Chair, PWSA (USA) Board of Directors

Congratulations to Michael Alterman, Kerry Headley, Janice Agarwal, Ken Smith, Carol Hearn and Dan Driscoll, M.D., who were elected in July to three-year terms on the Board. And heartfelt thanks go to Bill Capraro, who has completed his term and is stepping down. ■

Sibling View

PWSA (USA) received a donation from Network for Good, and it came from the web site Your Cause. Ross Park has a brother with PWS, and the following is from his web page (Cause: Prader-Willi Syndrome–Advancing Research/Awareness):

"This cause is very personal to me because my younger brother Whit (24) was born with Prader-Willi Syndrome. Growing up, this was a difficult syndrome to understand as a young kid and sometimes made the relationship between my brother and I hard. But through support from my family and great friends I continued to learn about my brother and his syndrome. I credit a lot of who I have become to what I have learned from my brother and the hardships he has overcome in his life. He is an amazing guy and inspires me everyday with all that he is able to do and the person that he has become. I am blessed that we have been able to get closer as the years have gone on. My brother Whit currently lives in Langhorne, PA at the Wood Services where he graduated from school in the summer of 2006 and currently works at their on-site warehouse facility running their retail store and welcome desk."

~Ross Park, New York City

Ross asked that the web site be included, which is www.yourcause.com/scotiger81. Be sure to check it out!

We Remember

Christopher Huff

Christopher died at the age of 5 in November 2007. He had brought a tremendous gift of life, courage and love to his family. The day before he passed away, he attended a drum-making workshop. The drum, called an Ashido drum, was 12", handmade of wood, painted with a real goatskin top stretched on it. He had a grand time and slept with his drum that evening.

Stan, the Drum Man, and Christopher really hit it off that day. He is offering workshops for kids for special needs and asked Christopher's mother if he could call them "Christopher's Workshops." They will be free, offered in each area where he has other workshops scheduled, and will accommodate about ten children.

If anyone is interested in having a workshop in their area, contact Christopher's mother, Patti Kelley-Huff, at pattikelleyhuff@yahoo.com. ■

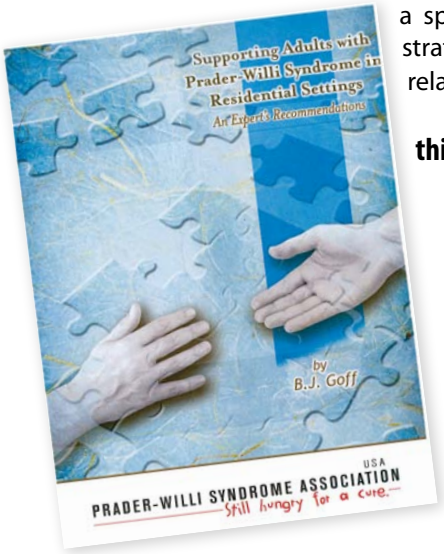
Beth Marie Carlyon

Beth Marie Carlyon, 55, died May 3, 2008, in Auburn, California. In spite of her lifelong struggle with PWS, she was described as an example of loving kindness and childlike enthusiasm to all those she knew. Actively involved with several organizations for special needs individuals, she enjoyed arts and crafts, competed in bowling in many recreational events, and loved camping and swimming. ■

"It's only when we truly know and understand that we have a limited time on earth - and that we have no way of knowing when our time is up - that we will begin to live each day to its fullest, as if it was the only one we had."

Elisabeth Kubler-Ross

An Important New Publication for Providers, Caregivers and Parents



Supporting Adults with Prader-Willi Syndrome in Residential Settings - An Expert's Recommendatrions fills a major gap by providing providers, caregivers, and parents of those with Prader-Willi syndrome (PWS) an extensive manual covering residential care issues. It may be used as part of a specialized training program for PWS. The manual includes management strategies, suggestions for all phases of life in the residence, provider/parent relationships and many more helpful ideas offered by B. J. Goff, Ed.D.

Every caregiver supporting a person with PWS should own a copy of this excellent resource.

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info@pwsausa.org — www.pwsausa.org

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Thank you for Contributions in June and July 2008

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

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Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers.

PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to **www.pwsausa.org/donate**

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