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

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

Christopher, the Drum, and Van's Warped Tour

by Pattie Kelley-Huff



Van's Warped Tour with drums in Buffalo.

The threads that weave through the tapestry of our lives can leave us feeling bewildered, sometimes leaving a smile on our faces, or at other times, a tear and a broken heart. One can only hope that when we pull back, hold our heads up and take in the whole of our woven journal, we will be gifted with a vision that is pleasing and satisfying to our eyes and soul.

My dear son, Christopher Huff, was born with PWS on November 17, 2001. We didn't know this diagnosis until years later. He had a multitude of other medical issues and special needs. To say we were overwhelmed, under-prepared and exhausted is probably understated. As any parent knows, love is a powerful force in our lives, and it alone can make us rise to even the most difficult circumstances. And so it was with Christopher...

We were totally in love with this child, and we would care for him and his needs just as we cared for five older siblings! Many times in his short life we thought we might lose him. With great trust in God, we limited ourselves to taking one day at a time--or one hour or one minute at a time when it became necessary—and gave thanks for every single day we had with him.

Despite our best efforts, we simply couldn't predict all the twists and turns, the warfs and woofs, of his life. Tragically and still without real explanation, Christopher died in his sleep on November 16, 2007, suddenly and unexpectedly.

The day before Christopher passed away he attended a drum-building workshop with homeschoolers in our area, led by Stan Secrest from New York. Stan has become a treasured friend to our whole family. Christopher, quiet, patient and humble, was drawn to this man with the same nature, a dear and tender friendship made that day. I was touched to learn that the huge bouquet of red and yellow flowers (Chris' favorite colors) at the funeral were from Stan. At the funeral, "Amazing Grace" was played on the bagpipes, in our Irish tradition, and on Christopher's newly made African Ashiko drum.

Later in the spring, Stan offered a special drum workshop for Christopher's five siblings and the rest of the family. During the weekend spent with us, Stan expressed an interest in offering drum workshops for other individuals with special needs. His heart for folks with special needs was transformed into his willingness to work with me to develop drum workshops for others with PWS.

In June 2009, I got an urgent e-mail from Stan about a fabulous opportunity he had to raise money for

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Megan

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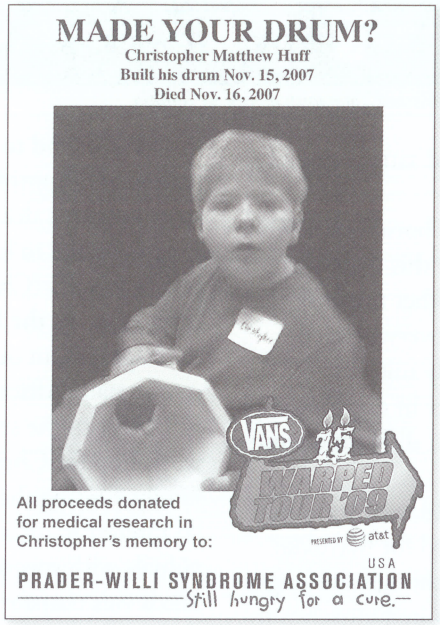
Drum, *continued from page 1*

my favorite cause...medical research toward a cure for PWS! He had been approached at a music festival in Tennessee by Kevin Lyman and Sarah Baer, founder and organizer, respectively, with Van's Warped Tour. Fifty bands travel together during the summer, playing in about 60 cities. Celebrating its 15th year, this traveling music festival has been very successful. In the last several years in an effort to find ways to support worthwhile causes, they created a non-profit arm of Warped Tour called Unite the United which focuses its energies and resources to that end. Kevin had asked to buy 50 drums so each band on the tour could build and personalize one. The idea was to have a day on the tour when all bands would make the drums as memorabilia and then auction each one off on EBay. One more very important detail--did Stan have an organization he would like to designate to receive the proceeds of the auction?

The next few days were exciting as we communicated with PWSA (USA) and Warped Tour to work out the details. The drum workshop for the bands would be offered at the Buffalo venue on July 16th. We distributed plenty of PWSA bracelets to Warped Tour staff and musicians, many of whom put the bracelets on immediately and wore them the rest of that day. Our family designed special t-shirts with Christopher's photo and the question, "MADE YOUR DRUM?" on them. With the generous assistance of Kmart, Office Max and Kaman's Art Shoppes (Six Flags Chicago), we provided shirts to the Warped Tour staff, our family, Stan and all who helped with the drum building.

Our family traveled to Buffalo to assist Stan and to represent PWSA (USA), as well as to personally thank the musicians for their efforts in memory of Christopher. The Warped Tour family treated us like kings and queens that day....VIPs! While all were mindful of the tragedy that brought us together and the hunger for the cure for PWS, the atmosphere was pleasant, the weather perfect, and all were on board to bring us closer to our heart's desire... to completely understand and one day conquer all the challenges of PWS. Even the folks from KIA, one of the tour's sponsors, were interested.

Christopher's brothers and sisters were thrilled to meet hundreds of band members and folks associated with the tour. We stood on stage for several performances. Kevin and



T-shirt design

Sarah took a special liking to Mike, Christopher's brother closest to his age and playmate.

We were invited to attend any of the Warped Tour venues and did go to Milwaukee and Chicago as VIPs where we promoted the cause and hope to continue in the future.

Forty-seven drums were built that day. All were flown to Los Angeles and photographed for the auction by Unite the United. A few were auctioned off on EBay, and more will be offered during the spring. 100% of the proceeds will go to PWSA (USA) for medical research in Christopher's memory. Just before Christmas I received a wonderful e-mail from Sarah Baer informing me that Unite the United was going to donate $5,000 to PWSA for medical research in Christopher's name and memory. I was delighted to learn that Billboard Magazine announced that Kevin Lyman was selected to receive their Humanitarian Award for 2009.

Learning to live without Christopher has been an incredible challenge for us. Some days it is difficult to put one foot in front of the other. On those days, when I look at Christopher's photograph, I am reminded to lift my head and hold it high. I close my eyes and take in the view, take a deep breath and remember the light. I can feel myself ascend this difficult terrain to the top of the hill, with Christopher's love and spirit in my heart. Here I can see, in my mind's eye, a glorious and breathtaking tapestry, entwined and woven into a cloth that radiates hope with lots of help from those who have gifted his life and memory with beautiful and valuable strands and threads.

His tapestry remains a sign and symbol, encouraging all who see it to know that his life was well-lived. In his loss, it points to a future where others with PWS will not die suddenly, unexpectedly, and without a clear understanding of the cause. This will be a world where mothers and families will not need to grieve their loss, a world where hunger ceases for our loved ones because we have found a cure, a world in which we can mark a day in time when the effects of PWS no longer ravishes the lives of those who face this challenge. ■

The Agarwals (and PWS) Go to Africa

"Our trip was fantastic!" says Janice Agarwal, a highly trained pediatric physical therapist who speaks frequently at PWS conferences and meetings and is a member of the PWSA(USA) Board of Directors. She and husband David, radiologist and a member of our Clinical Advisory Board, and their two sons, Sam (9) and Alex (10, PWS), spent five weeks in Kenya in March. Here is their story, as she tells it.

Our primary mission was to work and teach at the Moi University Teaching and Referral Hospital (MTRH) in Eldoret, Kenya's fifth largest city. The smaller of Kenya's two medical schools is based at MTRH, a public hospital with over 300 beds taking care of more than 500 inpatients, often two patients to one bed. Indiana University School of Medicine, where David works, partnered with MTRH in 1989 in an effort to combat AIDS in Africa. The partnership has grown to include surgery, medicine, radiology, and pediatrics.

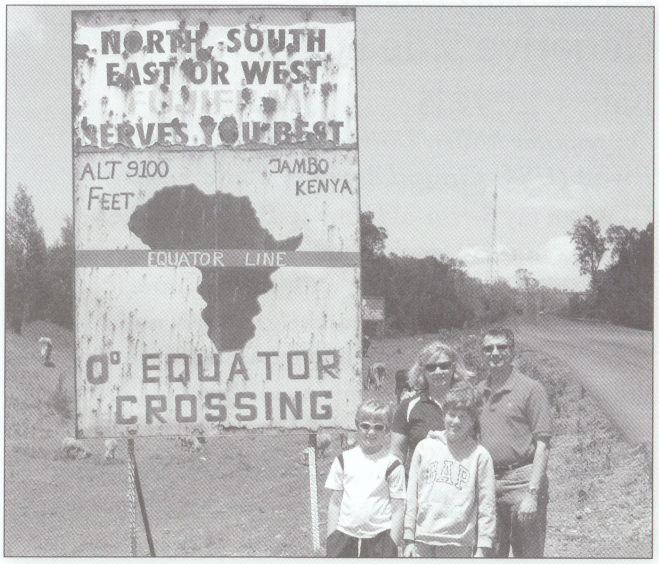
David had great opportunities to lecture, teach, and take care of patients using techniques never before seen in western Kenya. I worked with Kenyan physical therapists on the wards and in the neonatal intensive care unit, teaching manual therapy and emphasizing parental involvement in the care of their own children. Together, we were given the opportunity to present a full lecture about Prader-Willi syndrome to Pediatric Grand Rounds at MTRH.

We do not know of any cases of PWS in western Kenya, most likely because (1) nobody knows about it, (2) high infant mortality rates (especially for children with failure to thrive), and (3) families fearing judgment of others for having a child with a disability. We were well received and hope that our PowerPoint will be used over and over as one small step to diagnosis and support.



Alex holding baby during a hike up to see the Crying Rock in outside the Kakamega Forest.

Alex and Sam home-schooled from 8 a.m. to 1 p.m. Twice a week they visited the rehab center, which is part of the pediatrics wing, and played with the kids in the hospital who are invited to come to sing, play games, and have fun. Sam loved playing with the children. Alex took a very special liking to holding babies that had been abandoned and were awaiting placement into orphanages. He would



Family at the equator

sit with the babies, feed them, rock them, or just talk with them.

On weekends and during the last week of the trip, we explored national parks, forests, animal reserves, and lakes around Kenya. The boys loved going on safaris, feeding eagles, riding camels, petting orphaned elephants, and kissing giraffes. They made friends and penpals everywhere they went and are still making sounds like wildebeests (gnus) at home.

One weekend we visited the Kakamega Forest, a forest that once stretched the entire width of Africa. There are currently only three spots left with original forest – Uganda, Kenya and Congo. After a long day hiking, we decided to see a local folklore called the Crying Rock. Halfway up the hill, we were met by the local villagers who continued up the hill with us. Every time we got to a spot where we could rest, Alex insisted on holding a little baby that one of the older children was carrying. I understand from our guide that the people were all talking about "this boy who loves little Kenyan babies."

Everyone (but Sam the monkey and the entire village who grew up on the hill), had difficulty climbing down. Two older girls insisted on helping Alex. At a very difficult point one girl, Irene, put Alex on her back and carried him. Initially, I was nervous, but our guide insisted that these girls were very strong. They have great balance and

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ASK THE PROFESSIONALS

Negative Side Effects of High IGF-1 Levels

Dr. Jennifer Miller, University of Florida
PWSA (USA) Clinical Advisory Board member

Q: When my 5-year-old son's IGF-1 levels were very high (3x normal), we had more behavior problems with him, he did not sleep well, we had more food seeking issues with him, and he grew hair under his arms. When growth hormone treatment was stopped, the problems appeared to go away. Are these common problems if the IGF-1 levels are too high?

A: It makes complete sense to me that your son's behaviors, axillary hair, sleeping, and appetite were worse when he had a high IGF-1 level and that all of those things are now better off of GH.

IGF-1 pushes the adrenal gland to make androgens (the male hormones, including testosterone), and higher levels of IGF-1 cause higher levels of androgens. Androgens in a child his age are not normal and thus lead to behavioral problems as the brain is exposed to testosterone it is not supposed to be seeing at this age. The androgens also cause hair growth, advanced bone age, often significant weight gain and breast development in boys with PWS. Have you had a bone age measured recently? If not, it is worth doing to see how much it advanced during the time his levels were so high.

Additionally, IGF-1 levels go hand in hand with insulin resistance. Insulin resistance decreases satiety and leads to a higher appetite drive because insulin is a satiety signal. So resistance at the blood brain barrier will lessen the satiety signal to the brain.

High IGF-1 levels also cause swelling of tonsil/adenoid tissue and worsen/cause sleep apnea which leads to poor sleep, frequent awakening, and meltdowns during the day because of fatigue from not sleeping at night.

Therefore, his IGF-1 levels being 3x normal was likely the cause of most of the problems your son was experiencing (which you know because these disappeared when he stopped GH and his IGF-1 levels came back down). GH definitely has benefits for children with PWS, but as you have experienced, more is not always better. Most boys his age with PWS need very low doses of GH because their metabolism is slower and they have some insulin resistance due to the appetite phase. It is important for you to know that GH dosing needs to be adjusted for each individual and not based on standardized dosing for kids with PWS. If you want to restart GH (which I would recommend for the benefits it has for growth, body composition, and bone mineral density), I would start at 0.2 mg per night and check levels in a month or so to see if his levels are normal. ■

Comparing Studies on Growth Hormone

The difference between the Netherlands research which appeared in the March-April issue of the GV and the USA research cited below appears that the Netherlands research looked at 4-year long term therapy in children, while the USA research looked at 6-year long term therapy starting early in life. Both found long term therapy beneficial, but the USA study particularly noted benefits outweighed risks for starting it in infancy.

Long-Term Growth Hormone Therapy Changes the Natural History of Body Composition and Motor Function in Children with Prader-Willi Syndrome

Aaron L. Carrel, Susan E. Myers, Barbara Y. Whitman, Jens Eickhoff and David B. Allen, Department of Pediatrics, University of Wisconsin American Family Children's Hospital, Madison, Wisconsin; Department of Pediatrics, Cardinal Glennon Children's Medical Center, St. Louis, Missouri; and Colorado State University, Ft. Collins, Colorado

To assess the impact of hGH therapy begun early in life on the natural history of PWS, comparisons were made of height, body composition, and strength in similar-age children with PWS who had never been treated with hGH with those with PWS treated with hGH for 6 years.

Forty-eight children with PWS were studied: 21 subjects aged 6–9 years who had been treated with hGH for 6 years beginning at 4–32 months were compared with 27 children aged 5-9 years prior to treatment with hGH. Percent body fat, lean body mass, carbohydrate/lipid metabolism, and motor strength were compared.

Conclusions: hGH treatment in children with PWS, begun prior to 2 years of age, improves body composition, motor function, height, and lipid profiles. The magnitude of these effects suggests that long-term hGH therapy favorably alters the natural history of PWS to an extent that exceeds risks and justifies consideration for initiation during infancy.

[Note: For more detailed information, see The Journal of Clinical Endocrinology & Metabolism Vol. 95, No. 3 1131-1136, 2010] ■

Role of snoRNAs in Prader-Willi Syndrome

Stefan Stamm, Ph.D.
Department of Molecular and Cellular Biochemistry
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UPDATE ON STAMM GRANT

[Note: This is a PWSA (USA) sponsored grant.]

Publication activity

In the December report, we mentioned that our work was accepted for publication in Human Molecular Genetics. In the meantime the story was chosen as a cover for the journal, which increases visibility of the topic.

For HMG publication, we developed a method to clone and analyze dsRNA. This method is now being written up and will be submitted in April/May, as we are waiting for the results from high-throughput sequencing experiments.

Research Activity

PWS is caused by the loss of paternal gene expression between the two breakpoint clusters indicated. Recent evidence indicates that the loss of snoRNA expression is important in causing the disorder. The snoRNAs are found in expression units: they are released during the processing ('splicing') of the RNA. Humans possess over 50 copies of these particular snoRNAs.

The snoRNAs were identified in the year 2000. However, our recent re-analyis showed that the initially reported sequences were wrong/incomplete.

We sequenced the psnoRNAs using a newly developed technique. The major snoRNAs expressed from the region lack important features of snoRNAs. They act not like snoRNAs, but like a new form of regulatory nuclear short RNAs. Since they are short (73 nt), they can be made synthetically and could in theory be re-introduced.

The new property of snoRNAs (i.e. they are NOT snoRNAs, but a different form of RNAs), explained our earlier findings that HBII-52 expression can regulate processing of the serotonin 5-HT2C receptor. The serotonin receptor is involved in hunger signaling in the brain. In order to make a functional receptor, a critical exon needs to be included. This can happen in two ways: the RNA is modified, which generates a weak receptor, or the exon is 'pushed in' by the snoRNA. The modification 'weakens' the receptor and mice models show that only the snoRNA-dependent receptor prevents mice from hyperphagia. The serotonin receptor was the target of phen-fen, a weight loss drug. Phen-fen worked well for weight loss, but had side effects on the heart and was pulled of the market. HBII-52 works like a 'genetic phen-fen', but is not expected to have these side effect.

Substitution of snoRNA, therapeutic approach

Our earlier studies showed that the snoRNA can be re-introduced in cells using special constructs. The 'good' receptor increases when we add the HBII-52. The molecular analysis shows the mechanism: the HBII-52 expression unit generates a small RNA that binds to its target exon. This small RNA (psnoRNA for processed snoRNA) can be substituted by a chemically synthesized form. The drawback from this approach is that oligos do not cross the blood brain barrier and need to be delivered by a pump into the brain. The alternative route is to deliver the whole gene in a virus (lentivirus). Once induced, the virus stays forever in the cells. We constructed such viruses, and they make the correct psnoRNAs. These viruses are currently tested in cell assays. ■

Genetic Questions for Dr. Merlin Butler

PWSA (USA) Scientific Advisory Board Chair March 2010

Q: I have been hearing a lot about a DNA test that has been developed to identify rare diseases quicker and cheaper. Is PWS in this group?

A: There will be a time with advanced technology when genetic testing will be much more thorough, quicker and cheaper than currently available as illustrated in a recent report in the medical literature of a patient with Charcot-Marie-Tooth disorder, a genetic condition due to mutations of several different genes located on different chromosomes. All the known genes were screened for mutations in this patient to find the defective gene causing Charcot-Marie-Tooth disorder in the family. Although the approach used in this patient required DNA sequencing for all known genes with the next-generation-sequencing platform which is still quite expensive, it can be accomplished in only a few days to weeks while the initial DNA sequencing performed in the Human Genome Project required years and several billion dollars to complete. Therefore, it is now possible to sequence the entire genome illustrated in this patient using the newest technology if one has a genetic condition with known (or unknown) genetic lesions to identify, although still costly. In many rare or uncommon genetic disorders this technology may not be needed such as PWS, where we know the

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Butler, *continued from page 5*

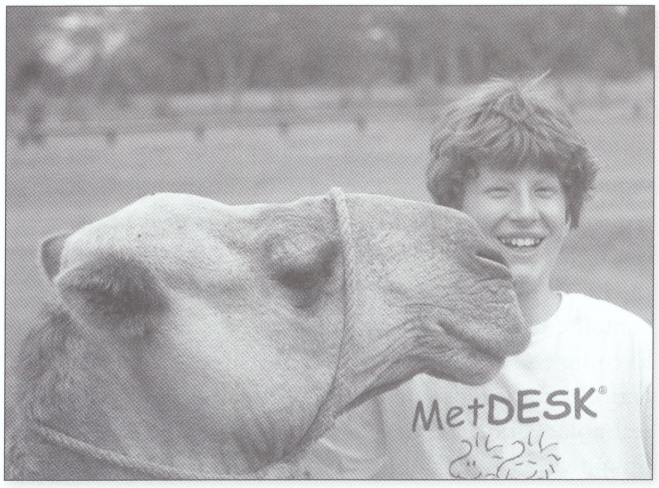
problem is located to a specific chromosome (chromosome 15 in PWS) and not located on the other 22 pairs of chromosomes or the rest of the genome.

There are 3,000,000,000 DNA base pairs in the entire genome and the PWS region contains about 5 to 8 million DNA base pairs (the size of the Type I or Type II deletion). With advances in genetic technology and high throughput (fast) testing, one can now sequence all of the known genes in one's genome for less than $50,000 and someday the cost may be $1,000 or the price of an MRI brain scan. If the costs continue to drop, it is also feasible to identify gene mutations or genetic risk factors for disorders at birth using the new technology through newborn screening but this opens up many ethical and health related issues. These may include what to do with the discovery in a newborn of having the Alzheimer gene or the gene for breast cancer. There are insufficient numbers of geneticists to date to address the current needs let alone the need for expanded genetics services in the future to explain, test and counsel family members with or at-risk for genetic disorders. The advanced testing and lower costs should be available in the next 5-10 years but the genetic infrastructure to supply services and decision plans on how to share the information and educate the public will need to be done before the testing is available for genetic conditions overall. How we use the new technology successfully will be an important and open-ended question to answer in the near future. However, at the current time, this new technology is not required for the diagnosis of PWS.

Q: Could someone really have both PWS and Angelman syndrome?

A: Yes, I have seen this before, and there are a few reports in the literature (John Hamerton and others reported a patient with both conditions in 1991). Generally, one of the causes is based on genetics (e.g., Angelman syndrome with the features and genetic findings seen in this condition); the second presentation of PWS may be due to brain injury of the hypothalamus leading to the PWS phenotype including a ravenous appetite, behavioral problems, growth deficiency and hormone disturbances and meeting the Holm et al. clinical diagnostic criteria. One would anticipate that only the AS genetic methylation DNA testing to be present. One could also envision a mosaic genetic pattern with an error in both the sperm and egg production or an imprinting defect contributed from both parents. Therefore, findings of two separate conditions can be present in one individual through different mechanisms. For instance, I recently evaluated a male with both PWS and 47,XXY (Klinefelter syndrome). There are about six cases in the literature of males having both PWS and Klinefelter syndrome including an individual we reported in the medical literature about 15 years ago. Therefore, having both AS and PWS in the same individual could happen but it would be very, very unlikely. One would anticipate only the genetic confirmation of AS or PWS but not both. ■

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Alex after riding a camel named Sammy near Mt. Kenya

Africa, *continued from page 3*

have been carrying water and heavy objects up and down these mountains their whole lives. When we got to the car, they all followed us and told the guide that he was a "very special boy." He had won all their hearts.

We had been thinking about a trip like this for a long time and with the boys finally old enough, decided to go! We had no major food or behavior issues with either kid. We were always well-prepared for normal needs, like snacks and naps, and did lots of sensory preparation and input throughout each day. IU House *[an apartment complex where they stayed]* had an open kitchen and cooked three meals a day for us. Alex helped ring the triangle to call everyone to eat, and everyone helped us watch him in the dining room. All of us enjoyed our trip and are looking forward to returning when we can! ■

Fundraising

by Jodi O'Sullivan

"Coming together is a beginning. Keeping together is progress. Working together is success."
~Henry Ford

Well Taught

Fifth grade students at Riviera Day School in Coral Gables, FL held a Mini-Mall on March 12. They were given a $40 loan to produce a cost-effective item appealing to school age children with intent to earn a profit. They donated $133.40 to PWSA (USA) from the interest on their loans along with a portion of proceeds. Great lesson all around!

Donating Comfortably

Marsha Stallings of MasterBrand Cabinets, Inc. sent a donation to PWSA (USA) raised from employees at the corporate office who participated in their "Denim Day" fundraiser. In all, their 2010 effort raised $220. A nice amount to be 'comfortable' contributing.

PWSA (USA) was the selected charity by Hospital Sisters Health System in Springfield, Illinois for their Friday Denim Days in March, thanks to **Judy Crespi**, mom to 17-year-old Sarah Crespi, who has PWS. Employees donated $5 to wear jeans, which by the end of the month, totaled to a $1,712 donation for the crisis program. Judy wrote, "I very much appreciate all the help PWSA has given me over the years with my daughter…since she was first diagnosed with PWS. This is just a small way of saying "thank you."

Nothing Fishy Here

The second annual Casting for a Cause fishing tournament was held the weekend of March 4-7, 2010 in Homestead, Florida. **Michelle Torbert**, President, Prader-Willi Florida Association, and member of the PWSA (USA) Board of Directors, reports that the tournament was a great success,



Rorri Peaton, Gavin Ayers and their guide, Captain Jim Hale

raising $30,000 for PWSA (USA) and $10,000 for PWFA. Plus, it promoted a lot of awareness for PWS. Rorri Peaton and Gavin Ayers, who have PWS and live in Gainesville, Florida in an independent living facility, won 1st place in the guided division with their Captain, Jim Hale.

Michelle says *"On March 5 we also held our 1st annual Prader-Willi Movie Night at Schnebly's Redland Winery. The movie "Cloudy with a Chance of Meatballs" was shown outside on a big screen and was attended by close to 300 people. It was a cool beautiful night and raised over $5,000 for PWFA. We are now in the process of planning our 3rd annual Casting for a Cause tournament to be held in 2011. See you next year!"*

A Grandmother's Love

Kate Loper, grandmother to nine-year-old Logan Buchanan, successfully completed another Bunko Tournament, Silent Auction, Raffle and Wine Tasting on March 27 in Kennewick, Washington. Kate devoted much time and effort, but the result was worth it. Her event netted over $4,190 for PWSA (USA).



Logan and mom Jenny Buchanan

Awareness Works

PWS Awareness Month of May is a prime time to educate about PWS Prader-Willi syndrome. We hope you took time to do something to help in this way. Please let us know if you did by emailing Jodi O'Sullivan at josullivan@pwsausa.org.

PWSA (USA) now also has new awareness items: red letter openers, bookmarks, and coolie cup holders. To purchase, please call the national office toll-free at 800.926.4797 or 941.312.0400. All items are $1 each and require a five-item minimum order, assorted items allowed.

Are You Aware?

National PWS Spokesperson, Clint Hurdle, and his wife, Karla, parents to Madison, 7 with PWS, continue their efforts to better the lives of those with PWS spreading more awareness in Texas. Hurdle is now hitting coach for the Texas Rangers. The Hurdles are still planning their 7th annual golf event in Denver, CO in July after a successful 6th annual event which netted over $80,000 for PWSA (USA) and PWSA CO.

For more information about the event, visit http:// pwsa.golfreg.com/. To read an interview with Clint by T.R. Sullivan, reporter for MLB.com entitled, "Hurdle and family embracing their 'treasure': Daughter of Rangers coach is living with Prader-Willi Syndrome," visit http://texas.rangers.mlb.com/news/article.jsp?ymd=20100413&content_id=9268468&vkey=news_tex&fext=.jsp&c_id=tex

In April, Senator Robert Menendez (D) of New Jersey agreed to introduce a resolution in the US Senate similar to the one that passed in the House in December 2009 recognizing May as National PWS Awareness Month to "raise awareness of and promote research on the disorder." In order to go forward, Senator Menendez expressed a desire to find a Republican co-sponsor. Please call your

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Until you Walk in my Shoes – Jazzy's Story

by Julie Sutton



Jazzy on left with family, 2009



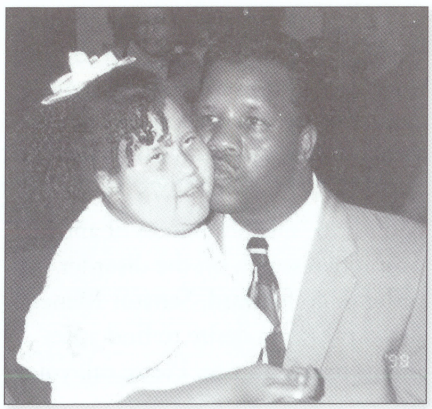
Mom and Jazzy at her highest weight 335 pounds, 2007

1st Stage, Infant: Jasmine Sutton (AKA Jazzy) was born January 17, 1990, in Dayton, Ohio to proud parents Darrell and Julie. A beautiful baby, she had complications right after birth and was in ICU for a week. She was tiny, about five pounds, pale, with very low muscle tone so she didn't move or cry much, and couldn't suck so she had a feeding tube

Jazzy was my second child, so I knew there was something seriously wrong. The doctors ran all sorts of tests but no answers. I was really worried about my baby girl…will she be okay, will she live, will she be disabled? When I finally was allowed to hold her, I cried. The doctors still had no answers, only that she had floppy baby syndrome with very weak muscle tone, a weak cry and no sucking reflex.

When she finally came home, she still couldn't eat much or hold her head up. I had to constantly check on her because she hardly ever cried, and when she did I could barely hear her. My strong faith-based family was deeply concerned and immediately started praying for our little Jazzy.

2nd Stage, Toddler: Small for her age and with low muscle tone, Jazzy



Dad and Jazzy, 8 years old

didn't crawl and even had a hard time sitting up in a chair or a highchair. So I constantly held her. Around three or four, she started progressing, walking, and really trying to communicate. Her speech was hard to understand so we took some sign language classes. Since she was delayed for her age, she attended special needs classes.

A happy child, she loved animals and her baby dolls. Too weak and not coordinated enough to pedal, she couldn't ride a big wheel or trike. So she did puzzles, colored in her coloring books and played with her baby dolls, putting their clothes on and off and doing their hair. She loved playing tea and looking at books with her older sister.

3rd Stage, Elementary school: Still small, she continued in MR/DD special needs classes. She enjoyed blocks and puzzles and loved pushing and feeding her classmates who were in wheelchairs. The teachers praised Jazzy for being the helper of the class. However, she started asking for more food, getting up in the middle of the night to eat, and hiding food in her book bag, dresser drawers, under her bed, even in her toy box. She was not diagnosed with PWS until she was around seven.

Her condition and constant craving for food took a toll on our marriage. My husband worked all the time, leaving me alone to care for the girls. He started saying that the doctors didn't know what they were talking about. I believe this was because he didn't have a perfect child. We divorced in 1996. I became a single working mom, raising my girls alone--but I didn't let that stop me from continuing to research and work with the doctors to find out what was wrong.

4th Stage, Teenage: By junior high Jazzy weighed about 200 pounds at 4'9". Imagine how she felt in school being so overweight. I met with her teachers about diet and not letting her talk them into giving her food. She could convince the kids to trade candy or chips for her fruit items. She had to walk to different classrooms and had difficulty keeping up with her classmates because she would be out of breath, so they often made fun of her.

One evening she passed out in my bathroom. The doctors said her heart couldn't handle the excess weight and we had to get her help immediately. She was approved for short-term treatment at The Children's Institute in Pittsburgh, Pennsylvania. She stayed there for two months and lost 60 pounds; they saved her life.

Upon her return home we joined a program for several months at the Children's Medical Center in Dayton to help with weight loss and maintenance. However, once she was back

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A Behind the Scenes Look at PWSA (USA)

Julie Doherty, Secretary, PWSA (USA) Board

If you're reading this article, your life has been touched in some way by the PWSA (USA) organization. At the very least, you're one of the 3,000+ who receive the *Gathered View* six times a year. Perhaps you are also one of the 200+ newly diagnosed families that received the Package of Hope, or were paired with a New Parent Mentor.

When you imagine the Sarasota office of the organization, do you picture a large staff that efficiently carries out these, and many more, functions? If so, allow me to give you a glimpse behind the scenes. Our staff is certainly efficient, dedicated and hard working, but they are few in number. It is truly amazing how much work can be done by so few – and always exhibiting such a pleasant and caring attitude!

What you may not realize is that there is a small army of volunteers who deliver services such as the writing of articles and editing of the *Gathered View*, conference planning, webinar presentations, chapter and support group leaders, new parent mentors, the dedicated professionals who are members of the Scientific, Clinical and Professional Providers boards, as well as the members of the board of directors and its officers. In fact, PWSA (USA) received over $680,000 in donated professional services in 2008. Our organization would not exist without these hard-working individuals. They embody the Gandhi quote, "Be the Change You Want to See in the World."

The next time you have contact with our office staff or one of many volunteers for PWSA (USA), take a moment to give them a word of encouragement and appreciation – and perhaps consider adding your talents at the state or national level. ■

Jazzy, *continued from page 8*

in school and around some of her friends and my family, she slowly started regaining the weight. The nightmare started all over again--hiding food, stealing food, going around the neighborhood begging for food. She couldn't help herself. We were back on the roller coaster ride with her weight.

5th Stage: In March 2007, Jazzy was approved for a group home thru an ICFRR Waiver/MRDD. At 335 pounds, she was morbidly obese, borderline diabetic with other complications. The hardest decision I've ever had to make was placing my beautiful child in a group home. I cried and felt so guilty because I felt I had let her down. Yet it was necessary to save her life again.

Two years later, I'm so proud of her because she's lost 125 pounds and continues to lose 1-2 pounds a week. She feels so much better about herself, and she loves the new Jazzy. When she comes home on weekend visits, we're given her menu plan, and she knows the rules and the plan. She's allowed to have only what's on the list for her breakfast, lunch, dinner and snack at certain times, no exceptions! She knows not to ask neighbors for food and not to ask at the store. She knows we have to pay close attention to calories and portion control.

I give praises and thanks to God because He answered our prayers and brought the right people to help: MRDD, the doctors, nursing staff, and--most important--wonderful support groups, PWSA(USA) and PWSA of Ohio. A special thank you goes to Dr. Zipf and his nursing staff and to Sandy Giusti for the knowledge about PWS and the love and support they gave me during those trying times, and to my family, my church family and my close friends.

After going through this experience, my advice to parents is: No one can understand what you go through with a child with a disability until he walks in your shoes. Pray. Ask for help. Remember "You'll Never Walk Alone". ■

Fundraising, *continued from page 7*

Senator to urge support. Additionally, if you know a Republican Senator willing to co-sponsor, please call PWSA (USA) at 800.926.4797. ■

2010 State Actions: Awareness Month

New York: Nina Roberto, chapter executive director, reported they were successful in securing a legislative resolution for a second time (also in 2008). It states, "…be it RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor David A. Paterson to proclaim May 2010 as Prader Willi Syndrome Awareness Month in the State of New York…"

Tennessee: Chapter Board member, Misti Love, reported a resolution passed in state Senate and is due for vote in the state House of Representatives very soon. Her state representative spoke for it, referencing her daughter, Emma. ■

Ask the Parents (2)

By Lota Mitchell, Editor

Parents on PWSA (USA) e-mail groups except 0-5 were asked the following question:

Q. If you have a high-functioning child or adult with PWS (low normal or even normal IQ), what are the problems you encounter and have you found any solutions to deal with them?

Last issue included a number of responses regarding food and behavior issues and problems specific to the high functioning individual; here are more.

"Our community has many social and recreational programs for people with disabilities. However, most of those who attend these are much lower-functioning than April. Besides limited physical mobility, many are non-verbal or unable to carry on much conversation, don't interact well with others."

[Another] "problem was standardized testing. She was smart enough, but the test-taking process, besides being very anxiety-producing, was sabotaged by her compulsiveness. [That] and love of long lists also made homework much more difficult than it might otherwise have been."

Katie, 30, comes from a highly educated family with background wealth, money and travel. "She had always felt both inferior (in the family, and when younger, fully expected to go to college) and superior (to the rest of the world). So she considers herself "better" than a lot of the world, much less PWS. Katie is very verbal and can absolutely run rings around most of her staff and for many years would lord her superior verbal ability, money, and life experiences over everyone, especially the poor staff members. (She has burned out a lot of staff.)

Darlene's daughter, 8, "gets all A's and B's in school in a regular class, no aid or any help… does get PT and speech therapy. Speech is her biggest challenge…She does like to eat but does not seek food and understands she must exercise to burn the calories off. The only trouble is that she does not like to have a routine changed and can get grumpy faster than most when tired."

Solutions

"Besides good paraprofessionals and teachers, the other thing that made high school very positive for April is that our school has a fine arts magnet program. It's designed for students who really excel in one area, but they let April do a "dabbler" approach, taking intro-level courses in choir, drama, and dance, all of which she loved and worked hard at".

"Our 'solution' is to have her in a small group home where she can have a pet (currently house with 3 residents, 3 dogs), extremely loving, supportive and 'smart' staff, and for us to set limits, especially on money and travel. Also, she needs to work every day - currently in a sheltered workshop. She also must have the right meds - tends to have psychotic episodes of hearing voices and needs meds to control."

"We have applied for DDD which has denied Storme, saying her IQ is 1 point too high (Washington says it has to be 69; Storme's is 70); we are appealing." Her parents have also applied for her to enter The Children's Institute of Pittsburgh for her severe behavior problems. Although her IQ is not that high at 70, she is being denied services because of it. They hope to find a safe, appropriate, therapeutic setting for her, and then, her mom says, "perhaps the rest of my family (14, 11, 8 and 5) can start to heal as well. I am so looking to give ALL my children a sense of normality, peace, happiness and safety."

"I have contacted PWSA and Evan (who I have spoke with many times in the past; thank God for PWSA and their ability to listen and understand) and asked for help, information, ordered materials, referrals, and any thing else they can and will give."

"Maggie, 7, did not do well in 1/2 special ed and 1/2 regular ed… she was too aware of how she compared to her peers; she is about 1 year behind in development." She had many behavior problems. "This year she is in a fulltime emotional support class where there are 6 kids, 1 teacher and 2 teacher assistants. She is the best behaved kid, learning…happy and her needs are getting met."

"I understand your frustration of feeling like the only friend to your daughter. I was, too, for a long time, but I found a young women willing to stay with my daughter overnight… There was some protest, but in the end they had fun. We are in a good place now and happy."

Impact on parents and family

"We try to structure her day as much as possible. *[Daughter, 20, has many activities.]* All this involves an enormous amount of driving her around and supervising her in every setting."

"Because of my daughter's PWS, my life radically changed. I moved out of a corporate career that I didn't enjoy and became an inspirational speaker, life coach and writer. I call Maggie, 6, my greatest teacher because she has been the stimulus for me to radically transform my life and the way I view people."

continued on page 11

Webinar presenter, past member of Board of Directors, current member of Scientific Advisory Board, and longtime member of PWSA (USA) says:

Thank you for all of the valuable work that you and all the other PWSA (USA) staff and volunteers do. This organization has changed from a "mom and pop" organization to a substantial professional and incredibly useful organization. You should be very proud indeed!

All the best,
Suzanne Cassidy, M.D.

Ask the Parents, *continued from page 10*

"… Katie's brother, 17 months younger and the only sibling, had almost been destroyed by the situation. We did the best we could to give him our love and attention, but he was definitely short-changed. The family dynamics were truly destructive for him. We mostly hear about our kids with PWS or siblings in young families where everything looks good. I'm sure others have had the experience my son has had and wish someone would look into this more. I don't know what we could have done differently, but at least these sibs should be on the lookout for fallout as they grow up."

"Virtually all [social] activities include a large eating component, e.g. game night with pizza, so one of her parents always has to go with her."

Christine's daughter, 7, is "completely disabled by the food factor. She cannot go on playdates without me, she cannot go to a home day care while I work, no one in my family will watch her, no birthday parties without me. I have never been away from her for more than a few hours since she was born because I have to constantly monitor her around food. She has a 1:1 aide at school to help navigate social situations at school. I worry about her quality of life and being independent when she grows up. Especially since she is so cognitively aware. It is hard. We have respite, but only for a few hours at a time.

"We're hoping son Jacob, 18, may be admitted to community college where he wants to study jewelry design. While we feel we're relatively lucky in PWSland, we don't know what the future holds. It's hard to imagine where our son would fit in other than in our care and home. This means that, since his mom works full-time and I'm a freelance artist, I end up doing the main care and supervision. I'm almost 60. We wonder how to make provision for his future, and how to plan for a residential arrangement that makes him comfortable and keeps him safe. The only group home in the Toronto area has people with far fewer intellectual resources, and we can't imagine sending him there. So while the present seems relatively stable and fulfilling (except for the fact that I have set aside a part of my career), the future looms with many difficulties and dangers." ■

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School in Greenville, South Carolina.

News and Notes from the Counselors Corner

On Tuesday, March 23, 2010, President Barack Obama signed the Patient Protection and Affordable Care Act into law. As with any changes in our health care system we urge families of people living with Prader-Willi syndrome to stay up to date on what is happening. With all the controversy surrounding this legislation it is sometimes difficult to know what the impact will be for people with disabilities. Below I am listing web sites of several of PWSA (USA)'s partner agencies you can visit to learn more about what some disability experts are saying about this new law.

http://www.thearc.org/NetCommunity/Page.aspx?pid=209

http://www.easterseals.com/site/PageServer?pagename=OPA_public_affairs

http://www.rarediseases.org/nord/washington/office

Several months ago PWSA (USA) offered a webinar on behavior entitled, "The Truth about Consequences." Participants who attended submitted many questions and some very good ones could not be answered during the webinar due to time constraints. We now have available a follow-up resource that answers all of those additional questions. If you are interested in receiving a copy, please e-mail me at efarrar@pwsausa.org

See you next time in the Counselors Corner!

~ Evan Farrar
Director, Crisis Counseling

Zoe, A Positive Story

Zoe Marks, affectionately known as our Prader-Willi Valentine baby, turned 13 on 2-14-09. The day before, Zoe swam the 1650 mile (66 laps) race in a USA sanctioned swim meet. She just swam another 1650 race on 1-29-10. What is so amazing is that Zoe only learned how to swim when she was 11.

During that summer, a friend said that if Zoe could swim 25 yards without stopping, she could join the swim team. I was pretty reluctant to say yes, but when Zoe heard the words "swim team," that was all she wanted. Zoe's vocabulary does not include the words "I CAN'T!"

Surprisingly, on the first day of swim practice, Zoe must have swum 20 lengths during the 45-minute practice without complaint. Zoe swam her first meet of 50-yard freestyle (2 laps) very slowly, with the crowd clapping her on to the finish. Zoe loved every minute. It must have taken almost 2 minutes to complete. Now she is swimming that same distance in under 40 seconds and also loves swimming the longer distances.

The great thing is that Zoe has not stopped improving. Things come at a much slower pace, but she does succeed at what she tries.

To look at Zoe, you would not know she has Prader-Willi. One of the most difficult things for her is socializing with her peers. Swim team has helped that so much, as well as with her confidence and independence. Last week her relay team took first place. Not uncommon for most of the girls, but for Zoe, that was her first. She was grinning from ear to ear when she got out of the pool. Zoe was on the middle school swim team this past year and loved participating with her classmates.

Knowing how to figure out the distances she is swimming helps her with her math skills. She is quite accomplished in counting by 25s, 50s, 100s. Zoe's school work improves, too. She is mainstreamed with help from a paraprofessionial in the classroom. Zoe is learning, just at a slower pace.

Zoe has also been doing karate for over 4 years. She is a brown belt in Ishanru style karate. Her technique might not be perfect, but she continues to memorize her very intricate katas. During a recent karate competition, Zoe broke 4 different boards with her foot.

Since fifth grade she has been playing the clarinet. This January, 2010, she received a second place medal for her solo at the Middle School Competition. Zoe wants to continue with the clarinet in high school to be part of the marching band. Rhythm seems to be the most difficult part of playing for her, but she continues to improve.

When Zoe was born, she had a fish probe test which came back negative. When she was 3, after many other studies, the University of Michigan genetics doctors retested her with a methalation probe test. It came back positive for Prader-Willi. Zoe has maternal dysomy, which would make the fish probe test negative. Knowing why our little girl was always hungry and overweight with very poor muscle tone came as a relief.

She was started on growth hormone shots immediately with great results. By watching her food intake and adding walking to her everyday routine, Zoe became a very active and lean child. She loved taking gymnastics at that time, which helped with upper body strength and coordination.



When Zoe was a newborn, my girlfriend whose husband is a pediatrician told me, "You don't want to read about Prader-Willi; it is too devastating." If you saw Zoe now, you would not think that.

Zoe is learning every day how to manage her food. She loves to cook and hopes to go to culinary school. Seems crazy for a person with an eating disorder. But that is her dream, and I bet she succeeds at it. Remember to keep up the faith. ■

~ Terri Marks, Zoe's mom,
Dexter, Michigan

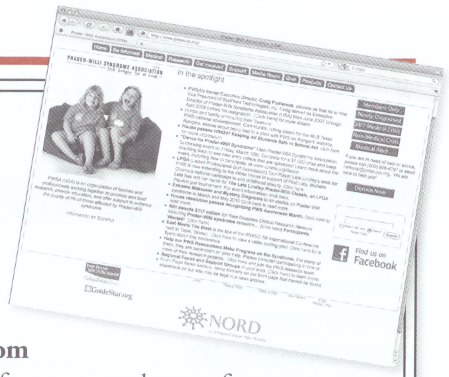
CHUCKLE CORNER

I picked Justice Faith up from school and we ran home for a quick lunch. After lunch I told her we had to run some errands. She looked up at me with her big blue eyes and said very seriously, "Mom I can stay home by myself now. I am in Kindergarten."

~Kristi Rickenbach
Blaine, Minnesota

VISIT OUR ENHANCED WEB SITE!

by Barb McManus, Webmaster



We have added some new features to our PWSA (USA) web site (www.pwsausa.org) and would like to share with you some of the highlights!

1. The tabs at the top of the main web pages are different.

a. A "Medical" tab has been added – It contains much medically relevant information and links.

b. Family Support is now "Support" – It encompasses Family, Provider, Educator and other non-crisis support information and links. Our People with PWS registry link is on this page, too.

c. "Products" tab has a list of logo items for you to purchase. Two new items: letter opener and beverage sleeve (coolie cup). Order your items for Awareness Month while supplies last.

2. A side menu is now on many of the pages without the top menu for easier navigation. Click on one of the links on any page and see the blue side index bar.

3. Two new videos have been added.

a. On the "Medical" tab – under the heading Comprehensive Management, a new video **Endocrinology video overview on Prader-Willi syndrome by Mayo Clinic.** Mayo Clinic has given PWSA (USA) permission to add this very informative video to our web site.

b. Webbabies.com has a video designed for message therapy for babies with PWS. It is located under support, links and resources, For Parents and Families, **Developmental massage for newborns with PWS - video demonstrations!** Janice Agarwal stated, "I think this is a great video on some massaging and working with all of our children. While we don't know this therapist personally, he does a brilliant job of demonstrating effective techniques that our parents and their therapists can copy!"

While you are visiting our web site, take a look at some older very useful sections of the site. The awareness section is on the **"Get Involved"** tab. It is full of very useful information for ways to spread awareness about PWS.

You can type any word or phrase on the home page Yahoo Search to find information on our web site.

On the **"Products" tab** you can look at many of the publications we offer at PWSA (USA). ■

Chapter View

by Barbara McManus, Family Support

Good News!

Chapters in good standing will now have access to PWSA (USA) membership lists of families in their state. This will facilitate the sharing of information between national and states, as well as enhance support and create further opportunities to work together.

Idaho had a focus group meeting in March, well attended with discussions of many topics. A long-term goal is to have a clinic in Idaho, and a short-term goal is to have a presentation by a behavior specialist. Cheri Gordon stated: "I was so pleased with the participation and many things I learned from other parents and grandparents. I hope that everyone else left with the same feeling."

New York held its 20th Annual Conference on May 1-2 in Albany. A special awards dinner was held to honor Janalee Heinemann, B. J. Goff and Dr. Moris Angulo for their dedication and professional support of people with Prader-Willi syndrome. Speakers were nationally known experts who presented very informative sessions.

Texas hosted its very first PWS conference on April 10 in Houston, with an excellent turnout of over 50 parents, caregivers, doctors, therapists and group home directors. YIP/YAP was provided for almost 25 children and adults with PWS. The new chapter unveiled an exciting TXPWA web site to be launched this year and kicked off their first official membership drive. Especially interesting was a breakout session where adults spoke about their experiences growing up with a sister or brother with PWS. The day was jam packed with wonderful information and opportunities for networking and making lifelong friendships. Thanks to all who were involved!!

In the last few months I have been creating e-mail support groups for individual states with and without active chapters. Currently we have 28 Yahoo groups representing 28 states. Our goal is to have one in every state by the end of this year. The communication that takes place on a state e-mail group is state specific, with topics like placement options, IEP help, fundraising, advocacy, awareness, workshop notices, focus group meetings, chapter conferences and meetings. A list of state chapters and Yahoo support can be found at www.pwsausa.org/links/chapter.htm. If you do not have access to e-mail or web pages, please call me at 800-926-4797 for information for your state. ■

Contributions

Thank you for Contributions in February and March 2010 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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WE REMEMBER

Donald R. Armento, M.D., died March 9 at age 78. A previous member of the Board of Directors of the Prader-Willi Syndrome Association (USA), his interest in PWS came about because of granddaughter Brook Pfeiffer, age 10, from Blue Bell, Pennsylvania, who has PWS.

California is grieving the loss of **R. Glenn Roe,** whose life was cut short at age 58 on February 16 in a tragic car accident caused by a drunk driver.

Bill and Judy Castle write, "For more than 20 years Glenn has been a part of our lives. We first met Glenn when Alta California Regional Center contracted with TTSR (Training Toward Self Reliance) to work with our son Jason, who has PWS. In the mid-1990s a new contract and relationship developed with Glenn and TTSR when he led a team including his long-time friend Paul Wurst to develop and manage a supported living program for Jason. Glenn and Paul had already successfully developed and implemented the very first PWS supported living program in California for a Sacramento area client which continues on today. Glenn managed Jason's program for over 11 years, first through TTSR, then Glenn and Paul's company and finally with Glenn's company.
Glenn was especially in tune with the needs and idiosyncrasies of folks with PWS."

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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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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Cindy Beles, Triage Advocate
Kate Beaver, Alterman Crisis Counselor
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E-mail Support Groups:
We sponsor nine groups to share information.
Go to: www.pwsausa.org/egroups

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Medical information published in *The Gathered View* is not a substitute for individual care by a licensed medical professional.

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

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