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

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

Executive Director View

Making a Difference

In the month of October something wonderful happened. PWSA (USA) received a "generous donation" from the estate of Joe McErlane. Be sure to read the story of "Big Joe", written by his daughter, Erin Bale. This donation, to be used for research and the betterment of lives of persons with PWS, was made in honor of his grandson, Braden, born in May 2007, with the syndrome.

Each week our national spokesperson Clint Hurdle, manager of the Pittsburgh Pirates baseball team, sends out inspirational emails to a big list of people. One of his quotes, "There are souls in this world which have the gift of finding joy everywhere and of leaving it behind them when they go." (Fredrick Faber, 1814-1863, theologian and hymn composer) seems to fit quite well the person that Big Joe was.

Big Joe was a devoted grandfather and successful businessman who was also a member of the PWS community, which sometimes we like to call our PWS family. And as a member of the PWS family, he appreciated the help that his own family had received from PWSA (USA) and chose to give back.

The PWS family includes grandparents, uncles and aunts, parents, siblings and others involved. It is a big family and growing, and its needs are growing, too. In 2014 alone PWSA (USA) served 1,641 families and children – and 8,000 during the years of its existence – providing support, crisis and medical assistance, information for new parents, and more.

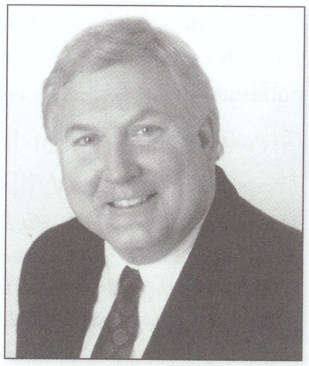
If all of that big extended PWS family would follow Big Joe's example, during their lives or in their wills, with donations large or small, PWSA (USA) could not only continue to provide all of its present services but also expand to meet the ever-increasing needs of those with or involved with PWS.

Clint Hurdle always ends his emails with "Make a difference today"– a message for all of us. ■

~ Ken Smith, PWSA (USA) Executive Director

A Very Special Legacy from a Very Special Man

By Erin Bale, his daughter, and the McErlane family



Joseph "Big Joe" McErlane

Born and raised in Philadelphia, Joseph "Big Joe" McErlane was the youngest of three children in a modest family that valued community and each other. Following his two sisters, Joe attended Villanova University where he studied political science with a mathematics minor, was active on campus with various groups and manager for the basketball team. During a dance his freshman year, he literally bumped into a sweet, bright-eyed girl named Florence (whom everyone calls "Fluff"). They fell in love and married a year before Joe's graduation in 1970. Ultimately the two grew a large family of five children.

With many mouths to feed and a growing family, his career was important. In 1974 Joe moved his brood to Minneapolis. He worked very hard, embracing the entrepreneurial spirit, and with a few of his colleagues opened their own insurance company in the early 1980s.

Big Joe was very proud of his family and had been known to give a toast or two. He cherished every holiday and loved the spirit of Christmas, making every Christmas exciting and magical. He made everything special--graduation parties, birthdays, super bowl Sunday, or simply a Tuesday. He was a very giving man, not only to his family but to various charities, schools, and organizations.

In 2000 shortness of breath doing light activities alarmed him enough to visit his physician. His doctors suspected Idiopathic Pulmonary Fibrosis (IPF), a rare and fatal lung disease. The life expectancy for someone with IPF is 2-4 years after diagnosis. Joe's zest for life didn't change; he still enjoyed the things he loved. His disease, which typically progresses rapidly, stayed idle for many years.

His two granddaughters he showered with love. In May 2007 grandson Braden was born. The family knew right away that something was wrong. He was very weak, unable to drink from a bottle, and lethargic. On Braden's fifth day of life, doctors told my husband Eric Bale and me that he had Prader-Willi syndrome. Also suffering from a terrible lung infection and a hole in his heart, Braden remained in the hospital for over a month and had multiple procedures. At three months Braden had open heart surgery. This was a difficult time for everyone.

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Volume 40, Number 1 ~ January-February 2015 ~ Our 40th Year of Publication

Growth Charts for Prader-Willi Syndrome Published

By Janalee Heinemann, M.S.W.; PWSA (USA) Coordinator of Research & International Affairs

Thanks to funding from the Prader-Willi Syndrome Association (USA) and in collaboration with the natural history study of the Angelman, Rett and Prader-Willi Syndromes Consortium, which is part of the National Institutes of Health Rare Diseases Clinical Research Network, the following was published in the well-respected ***Pediatrics*** journal:

Growth Charts for Non-Growth Hormone Treated Prader-Willi Syndrome

Merlin G. Butler, M.D., Ph.D., Jaehoon Lee, Ph.D., Ann M. Manzardo, Ph.D., June-Anne Gold, M.D., Jennifer L. Miller, M.D., Virginia Kimonis, M.D., Daniel J. Driscoll, M.D., Ph.D.
DOI: 10.1542/peds.2014-1711; Pediatrics; originally published online December 8, 2014

The goal of this study was to generate and report standardized growth curves for abstract weight, height, head circumference, and BMI for non–growth hormone–treated white male and female US subjects with Prader-Willi syndrome (PWS) between 3 and 18 years of age and develop standardized growth charts. Growth data were collected from 120 subjects with PWS (63 males, 57 females) with genetic confirmation of PWS and no current or previous growth hormone treatment.

Although just published, Dr. Butler has been receiving several emails and requests including international, so it is attracting worldwide attention. Thanks to Dr. Butler and statistician Jaehoon Lee, there will also soon be growth charts on those treated with growth hormone therapy sponsored by PWSA (USA). These growth charts have been more challenging because of all of the variables to take into consideration (How long should they have been on growth hormone? Differences due to ages started, etc.) Individually and comparatively, these growth charts will be significant for the treatment of those with the syndrome.

A big thanks goes to all involved – especially Dr. Butler and Jaehoon! We have a great team of world renowned researchers and clinicians working with PWSA (USA), for which we are grateful. ■

Special Man, *continued from page 1*

We called PWSA (USA) before leaving the hospital, needing guidance. They gave us reassurance that things would be ok and put us in contact with other families in the area. We had a million emotions after getting the diagnosis, but as my Dad always said, "The sun will come up tomorrow." He reminded me that today may be tough but give it time and things will be ok.

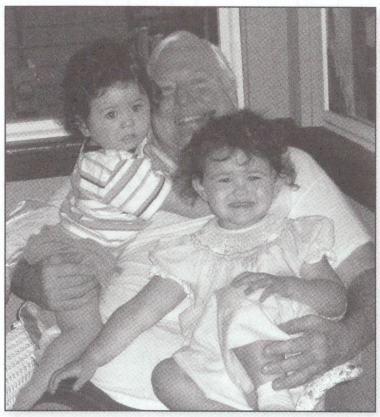
Joe was keenly aware and supportive of the care Braden needed at the time and for the future. He saw what it takes to take care for a child with special needs. He provided support for Eric and me as we worked with all the therapists, specialists, teachers, doctors, home care nurses, and navigated within insurance companies. Joe ensured that we would have appropriate medical coverage for Braden.

In 2009 Joe added an estate trust to his will. He specifically wanted to allocate funds to PWSA (USA) for research to help find a cure or ways for families to financially manage PWS. He also wanted to acknowledge PWSA (USA) for their hard work and dedication to the PWS community. This donation would be made a few years after his death.

As Braden continued to grow and get stronger, so did the bond he shared with his Grandpa Joe. They developed a beautiful relationship and enjoyed spending time with each other. They watched cartoons, played at the beach, went on pontoon rides, read books, played with trains, and went on joy rides in Joe's car. My Dad was so proud of Braden and found him quite remarkable. We not only celebrated the big milestones like everyone else, but we celebrated the small things and cherished them.

In January 2010 while on a trip to Disney World with Braden and the family, Joe's illness started to progress. The bond between Braden and Joe grew even stronger. Braden would help Grandpa Joe with his breathing machines, and Joe would work with Braden on reading and coloring. They were quite a pair.

Sadly in February, 2011, at the age of 62, Big Joe lost his battle with IPF. His passing had a profound effect on Braden and the entire family, a devastating and overwhelming loss. Although we will always mourn the loss of Big Joe, we find ourselves grateful that his legacy continues to support the efforts of PWSA (USA). As with PWSA (USA), we keep IPF close to our hearts and hope one day they also find a cure.



Big Joe with Braden and Kamea

It has been almost four years since Big Joe's passing and per his wishes a generous donation has been made to PWSA (USA). I will always be proud of my Dad, but I am so amazed that even after his passing he continues to make an impact. The Joseph McErlane Research Fund will be established in his memory. My hope is that other families will follow suit and recognize all the great work PWSA (USA) is doing. ■

A Chance to Make a Difference in Prader-Willi Syndrome!

BestPWS Clinical Trial (Beloranib Efficacy, Safety and Tolerability in PWS)

Prader-Willi syndrome and the hyperphagia that defines it can have a devastating impact on patients and families, disrupting everything from daily household function to long-term social, educational and job-related prospects. While there is no cure, the bestPWS clinical trial is providing an unprecedented opportunity to offer hope to those who are dealing with this challenging disorder. bestPWS is a randomized, double-blind, placebo-controlled, Phase 3 trial to evaluate the safety of an investigational drug called beloranib for subcutaneous injection and its effect on total body fat mass and food-related behaviors in obese volunteers with Prader-Willi syndrome. It will involve 84 volunteers at sites across the United States.

At a Glance

- Obese PWS volunteers aged 12-65
- Placebo-controlled
- Medication administered by a home health nurse
- Option to receive active study medication during 6-month open-label phase
- Travel costs will be reimbursed

For more information about bestPWS, go to www.clinicaltrials.gov and search Zafgen PWS Double-Blind, Placebo Controlled, Phase 3 Trial of ZGN-440 (Beloranib) in Obese Subjects With Prader-Willi Syndrome (bestPWS)

Our Clinical Trial Experience

By Alice Virolsav

Although we live in Texas, Olivia and I travel to the clinical trial site in a different state once a month to participate in the clinical trial with a new experimental treatment for PWS. We come in the night before the clinic visit and return home that afternoon or evening. We actually look forward to our short trips together; we go out to eat or to a movie the night we arrive, and visit friends and local attractions while we're in town. The visit at the clinical trial site itself lasts no more than a couple of hours, and is sometimes less than two hours depending on the week. We go to a private room, where Olivia has blood drawn and provides a urine sample before breakfast; sometimes there is additional testing (e.g. electrocardiogram, psychological screening). Then we have the opportunity to mix and mingle with other PWS families, which we really enjoy.

We are aware that not everyone is on the drug, some of the people that participate will get placebo. Even if Olivia is on placebo, it is just for a limited amount of time, and in the big scheme of things, that is no time at all. We understand that it's very important that some people get placebo to prove that the drug has an effect.

Although we were a little nervous going in, so far, participating in the clinical trial has been easier than we expected. It has actually been pretty fun! We were most worried about the blood draws, since Olivia has had trouble with those in the past, but the nurses at the clinical trial site have a tremendous amount of experience with drawing blood and have made it easier for Olivia.

We're pleased and excited to be helping with a possible treatment for PWS.

Yes, You CAN be a Part of Something Big

By Elizabeth Roof

I have been involved in the Prader-Willi syndrome research field for 20 years, seeing more than 300 children and adults with PWS. Over that time, I have heard countless pleas from desperate parents to help our child with PWS. Although we could be sympathetic or help with some of the issues, we couldn't fix the main problem of extreme hyperphagia and the anxiety that went along with being so hungry and obsessed with food every hour of every day. There was simply no treatment that addressed it effectively and it was so frustrating to me. I wasn't sure I would ever see it in my career, but I am so excited to be a part of multiple clinical trials in PWS in the last year.

...all of the families we have seen at our site have had a positive experience...to help their child and others with PWS. They love (to)...be a part of something bigger than themselves.

Many professionals and families have worked tirelessly alongside pharmaceutical companies for many years to bring these treatments to a point where they could be tested in individuals with Prader-Willi syndrome. It seems hard to believe that some parents aren't beating down the doors to participate in these trials; no one was more surprised than me.

Many families *may* think it is a hassle and inconvenient to participate in a clinical trial since it involves study visits and drug administration for months. However, I am pleased to let you know

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Something Big, *continued from page 3*

that all of the families we have seen at our site have had a positive experience being involved in these trials. They are so excited for this opportunity to be able to help their child and others with PWS. They love meeting other families, sharing stories that make them laugh until they cry and be a part of something bigger than themselves. **With all the structure and positive praise we supply, patients in the study are happy to see us and tell us how they are doing. They get more follow-up and monitoring than they would as a regular patient and trust that the people seeing them really know PWS.** We make the visits fun (doing puzzles, watching movies, playing games) so that every visit is positive. Many patients look forward to seeing their new friends with PWS again and again and some have never met anyone else with PWS. I often describe it as suddenly finding out you were adopted and then meeting your birth family and seeing how much you have in common with them.

Several families that I called said they didn't have time, were scared to try a not yet FDA approved study drug, or that traveling with their child was hard; true. Many drugs never get FDA approval. However, if there aren't enough people willing to donate their time and participate in these vital trials, we will not know if these new drugs work. My team is at the hospital every morning by 6:30 am getting everything set up to make the day run smoothly for each visit and I never think about it being inconvenient for me or my family. Tired at the end of my crazy busy days, sometimes seeing 5 patients at one time, it feels so worthwhile to be part of team PWS. I believe I am doing something that will ***make a difference in the life of someone with PWS.*** After so many years of only being able to listen and sympathize, now I can actually be a part to make sure that their lives with PWS are brighter. ■

Zafgen Clinical Trial Sites for Beloranib

As of December 9, 2014

California

University of California, Davis
- Not yet recruiting
Sacramento, California, United States, 95817
Contact: Majid Mirmiran, M.D., Ph.D.
916-734-4790
majid.mirmiran@ucdmc.ucdavis.edu
Principal Investigator: Dennis Styne, M.D.

UCSD: Rady Children's Hospital
- Recruiting
San Diego, California, United States, 92123
Contact: Rachel Winograd
858-966-8453
rwinograd@rchsd.org
Principal Investigator: Lynne Bird, M.D.

Colorado

Children's Hospital of Colorado
- Recruiting
Aurora, Colorado, United States, 80045
Contact: Megan Brocato
720-777-8864
megan.brocato@childrenscolorado.org
Principal Investigator: Christine Chan, M.D.

Florida

University of Florida
- Not yet recruiting
Gainesville, Florida, United States, 32610
Contact: Christine Keeling
352-294-5280
ckeeling@peds.ufl.edu
Principal Investigator: Jennifer Miller, M.D.

Kansas

Kansas University Medical Center
- Recruiting
Kansas City, Kansas, United States, 66160
Contact: Humaira Masoud
913-945-6689
hmasoud@kumc.edu
Principal Investigator: Merlin Butler, M.D.

Maryland

National Institute of Child Health
- Not yet recruiting
Bethesda, Maryland, United States, 20892
Contact: Sheila Brady
301-451-3783
bradys@mail.nih.gov
Principal Investigator: Jack Yanovski, M.D.

Massachusetts

Children's Hospital Boston
- Not yet recruiting
Boston, Massachusetts, United States, 02115
Contact: Andrea Hale
617-919-2867
Andrea.Hale@childrens.harvard.edu
Principal Investigator: Diane Stafford, M.D.

Minnesota

Children's Hospital and Clinics of Minnesota
- Recruiting
St. Paul, Minnesota, United States, 55102
Contact: Christine Benoit
651-220-6254
christine.benoit@childrensmn.org
Principal Investigator:
Jennifer Abuzzahab, M.D.

Missouri

Saint Louis University
- Recruiting
St. Louis, Missouri, United States, 63104
Contact: Barbara Whitman, PhD
314-268-4027
whitmanb@slu.edu
Principal Investigator: Susan Myers, M.D.

New York

Winthrop University
- Recruiting
Mineola, New York, United States, 11501
Contact: Marilyn Richardson
516-663-9582
mrichardson@winthrop.org
Principal Investigator: Moris Angulo, M.D.

Ohio

University Hospitals Case Medical Center
- Recruiting
Cleveland, Ohio, United States, 44106
Contact: Audrey Lynn
216-844-7124
Audrey.Lynn@UHhospitals.org
Principal Investigator:
Shawn McCandless, M.D.

Tennessee

Vanderbilt University
- Recruiting
Nashville, Tennessee, United States, 37235
Contact: Elizabeth Roof
615-343-3330
elizabeth.roof@Vanderbilt.Edu
Principal Investigator:
Robert Steven Couch, M.D.

Texas

Texas Children's Hospital
- Recruiting
Houston, Texas, United States, 77030
Contact: Farida Khetani
832-824-3388
fxkhetan@texaschildrens.org
Principal Investigator: Sarah Barlow, M.D.

Utah

University of Utah
- Not yet recruiting
Salt Lake City, Utah, United States, 84112
Contact: Heather Hanson
801-587-9017
Heather.Hanson@hsc.utah.edu
Principal Investigator: Dave Viskochil, M.D.

Washington

Seattle Children's Research Institute
- Not yet recruiting
Seattle, Washington, United States, 98105
Contact: Sue Kearns
206-987-1758
sue.kearns@seattlechildrens.org
Principal Investigator: Parisa Salehi, M.D.

Team Up For Treatment

PWSA (USA) Promotes Awareness & Collaboration at Obesity Week 2014

Boston, MA, Nov. 2-7 2014 ~ Boston Convention & Exhibition Center

All of the PWS events at Obesity Week sponsored by PWSA (USA) were a huge success! The impact was significant regarding raising the awareness and education of the syndrome with researchers and medical professionals who would not otherwise have much knowledge of the syndrome. Also, the invited dinner, which was attended by those who had knowledge of the syndrome, achieved the goal of connecting multiple disciplines "including pharmaceutical companies" with researchers.

Prader-Willi Syndrome (USA) Agenda:

PWS Symposium

"Prader-Willi Syndrome: A Model for Understanding and Treating Hyperphagia and Obesity":

Session Chairs: Joseph Tam; Jack Yanovski

Session Agenda:

1) Food Behavior Modulation with Non-Invasive Brain Stimulation by Felipe Fregni;

2) Broad Overview Of Prader-Willi Syndrome And Current and/or Emerging Therapies by Jennifer Miller;

3) How Animal Models Enhance Our Understanding of Prader-Willi Syndrome by Rachel Wevrick

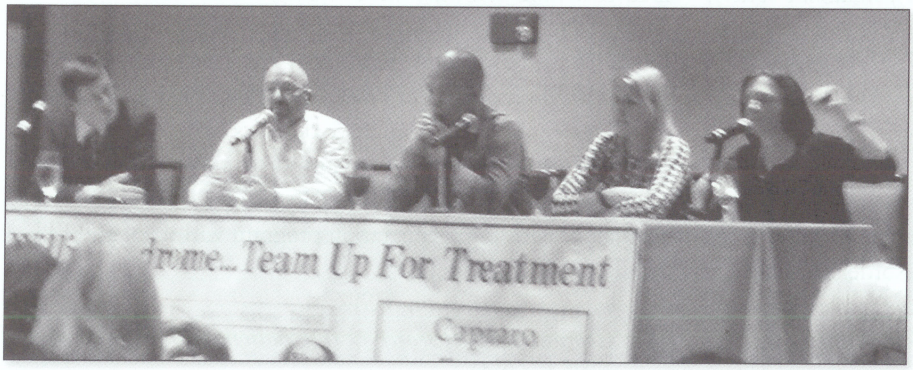
The symposium was well attended by several hundred people.

PWSA Scientific Invited Dinner and Reception – the theme was Team Up For Treatment" and was chaired by Dr. Merlin Butler with a panel on "How to do research studies with the PWS population." Afterwards, there was a poster session with dessert and drinks. Travel grants were awarded for trainees and junior faculty selected to present a poster, with a $1000 award to the best poster presented which went to Lisa Cole Burnett. Her topic was "Using Induced Pluripotent Stem Cells to Investigate CNS Neuro-molecular Phenotypes of Prader-Willi Syndrome." These awards are made available through the generous support of the Jay Headley Family

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L to R: Lisa Cole Burnett, Kerry Headley, Dr. Merlin Butler



L to R: Dr. Merlin Butler, Dr. Tony Goldstone (UK), Dr. Denis Kim, Dr. Jennifer Miller, Dr. Ann Scheimann

In Awe of the Brainpower...

By Andrea Glass

As what is probably typical of a parent of a child with PWS, I follow the travels of PWSA (USA) with avid interest, as they are always "On the Move", no grass growing under their feet! This time PWSA (USA) was exhibiting at Obesity Week/ Boston. It was an almost week long convention with two symposiums and a dinner/panel discussion hosted by PWSA (USA). Attending the dinner, I was in awe of the IQ gathered in such a small space, and all focused on PWS research and treatments! Over the past 15 years, I have followed the research, the scientists, the medical professionals and the potential treatments. It is amazing what is happening now. At the dinner, I met the scientists, excited by their research in PWS-related subjects. I met CEOs of small pharma companies interested in bringing their drugs into the PWS population for drug trials. I met representatives from an Israeli firm that has developed gene therapies for Cystic Fibrosis and thinks their technology may work with PWS. The outreach by PWSA (USA) in the area of research, pharma, and FDA advocacy has been phenomenal. I was completely unaware that this effort had reached this level of cohesiveness between the research world, the pharmaceutical world and our Association. We are fortunate to have a group of parents and professionals that have dedicated their lives and resources to solving the mysteries of PWS and developing effective treatments. I left the dinner knowing that with this brain power, interest and resources, we are close to effective treatments for our family members with PWS. ■

PWSA (USA) Medical and Research View – Making a Difference!

Obesity Week, *continued from page 5*

Foundation.

Rob Lutz wrote after the event: "Awesome turnout at the lunch and well organized dinner with great dialogue amongst people during cocktails and the panel. Great work!" This invited dinner significantly enhanced our relationship with several pharmaceutical companies and researchers.



Janalee Heinemann and Ken Smith

The Obesity Society-Pediatric Obesity Section (POS) luncheon & business meeting – PWSA (USA) provided key sponsorship. It was attended by several hundred people. Dr. Dan Driscoll did an excellent job on his overview of the syndrome.

PWSA awareness booth at the conference – Janalee Heinemann and Ken Smith partnered in hosting the booth. Over two hundred memory sticks were given out with extensive PWS information and the medical alert in 16 different languages.

Clinical Advisory Board Meeting – Chaired by Dr. Dan Driscoll, a time for the advisory board to have an open and healthy discussion on specific PWS medical issues.

The following is one of the thank you emails received:

It was my pleasure to attend the PWSA Scientific dinner and have the chance to present my work and talk about it during the poster session.

You all did a great job! The session during the afternoon was very good and I appreciated a lot the overview about the disease, more from a clinical point of view, and the update about the state of the art regarding clinical trials and the available models. The panel discussion after dinner was really interesting for me and during the poster session I had a chance to talk about my project, get feedbacks and a lot of suggestions and ideas. It was a very enriching experience and I hope I'll have the possibility to come to other events.

So thank you very much for inviting us and give me the chance to attend and present my work!

Best regards, Cristina Grande, Ph.D.

Coordinators: Janalee Heinemann, Kerry Headley, Ian Hassan, Jim Kane, Debi Applebee, and Dr. Merlin Butler with special thanks to local Boston PWS volunteers - Andrea Glass and Mary Raymond.

A very special thank you to the conference financial sponsors:

Gold Sponsor
- Bill & Tina Capraro – proud parents of Lea

Silver Sponsor
- James Hervey Johnson Charitable Educational Trust
- Zafgen pharmaceuticals
- Ferring pharmaceuticals
- Healthbridge Children's Hospital
- The Private Foundation of Maryland
- Jay Headley Family Foundation

Bronze Sponsor
- The Coca Cola Company

Friendship Sponsor
- Novartis Pharmaceuticals

Positive Results from Phase 2 Clinical Trial of Beloranib

We are happy to announce some exciting news about the results of a recent clinical trial by Zafgen on beloranib, the drug that is currently in a phase 3 clinical trial with Prader-Willi syndrome. This clinical trial was done on people with hypothalamic obesity (which we informally call Acquired PWS).

At PWSA (USA), we have received many calls over the years from people dealing with a loved one who has hypothalamic obesity, and often I have found that their hyperphagia (drive to eat) is even more dramatic than most people with PWS. We are happy for the breakthrough for this population, and excited about the current clinical trial for PWS, which we have posted for recruitment extensively.

Zafgen, a biopharmaceutical company dedicated to significantly improving the health and well-being of patients affected by obesity and complex metabolic disorders, announced January 7, 2015 that ZAF-221, a randomized, double-blind, placebo-controlled Phase 2 clinical trial of beloranib, a MetAP2 inhibitor, in 14 adults with hypothalamic injury associated obesity, or HIAO, met the primary efficacy endpoint of weight reduction ($p = 0.01$). In addition, beloranib treatment was well-tolerated and improved cardiovascular disease risk factors.

"We are extremely pleased with these results, which differentiate beloranib from other weight loss agents. Beloranib's impact to restore balance to production and utilization of fat is further validated with these findings," said Dennis Kim, M.D., Chief Medical Officer of Zafgen. "With these results in hand, we plan to pursue HIAO as an extension of our work in Prader-Willi syndrome, or PWS. We believe beloranib shows tremendous potential to improve the lives of those impacted by HIAO and PWS, and for whom there are limited effective pharmaceutical alternatives. In 2015, we aim to establish the regulatory path for a registration program with U.S. and EU regulatory authorities." ■

~ Janalee Heinemann, MSW
Coordinator of Research & International Affairs
PWSA (USA)

Development Update

By Jack Hannings

As the new Development Director for PWSA (USA), I look forward to working with our volunteers and families. In the two months that I have been on board, I have been touched by the commitment and passion of our volunteers and staff who work tirelessly to meet the needs of the Prader-Willi syndrome community. The Development Department has developed a plan to generate the resources necessary to meet these needs and challenges.

The Fund Development Committee, led by the chairman Rob Lutz, has recently approved the fund development plan for PWSA (USA) for 2015. The plan includes a focus on establishing our development resources and systems.

The main components of the development plan include multiple focus areas. The plan establishes priorities that utilize best practices in fundraising. Strategies are developed for the annual fund, membership, special events, major gifts and conference sponsorship support. In order to meet the revenue goals in these areas, it is essential that a "Culture of Philanthropy" be established. Fundraising will become a higher priority for our volunteer leadership and in our communication and branding awareness activities.

I am happy to announce a new addition to our development staff team, Leanne Gilliland. Leanne is a longtime resident of the Sarasota area. She is a graduate of Florida Gulf Coast University and was in sales for Aramark during school and immediately after graduation. She then moved back to Sarasota where she worked for the Diocese of Venice as the Special Events and Alumni Coordinator at a local high school. During her tenure at the school, Leanne was involved in a number of events including golf, galas, and alumni engagement activities. She also worked with a fundraising database at the school. Most recently Leanne was employed in outside medical sales. Please welcome Leanne to PWSA (USA).

Our Angel Card campaign continues to receive generous support from our donors. We have to date raised $126,338 by the end of December and additional donations will continue into 2015 to help us achieve our goal from the program. We will soon be contacting our PWSA (USA) members to renew your benefits and dues. A focus for our development team in early 2015 will be to reach out to our volunteers who conducted fundraising events in 2014. We look forward to working with our supporters to confirm event dates and activities for 2015; we will provide you with the support and materials necessary to make your event successful!

If you want to join with us to hold a local fundraising event to help save and transform lives, please contact me at jhannings@pwsausa.org and we will work with you to make your event a success. ■

Carolyn Loker Joins PWSA (USA) Staff Team!

By Janalee Heinemann, M.S.W.; PWSA (USA) Coordinator of Research & International Affairs

As many of you know, Carolyn has been actively involved as a volunteer with PWSA (USA) for over 15 years, since her daughter Anna, who has PWS, was a little girl. The New Parent Mentoring Program and Packet of Hope are thanks to Carolyn's vision and dedication – amongst several other projects. Currently, Carolyn and her husband Jim Loker (a pediatric cardiologist on our clinical advisory board) are working diligently on our study of deaths. They will continue to do so on a volunteer basis.



Carolyn with daughter, Anna

Fortunately, with me stepping out of the medical counseling portion of my role with the Association, Carolyn has agreed to take on a very part-time (8 hours a week) role to supplement the larger part-time role of Bonnie Shelley, Ph.D., who is handling the medical calls four days a week. Carolyn will be on call the fifth day, and also work with us on reviewing and revising our current medical information, and creating new medical information. PWSA (USA) has created the largest amount of practical medical booklets, brochures, articles, etc. on the syndrome than anyone else in the world! It is important we keep this information current, and Carolyn is the ideal person to help with this massive ongoing project.

I am very proud of our counseling team. Thanks to your financial support, PWSA (USA) saves lives! ■

CHUCKLE CORNER

My son is 8 and has a slightly twisted sense of humor. As I was finishing up some work at home, I told Mathias my battle with the flu left me sick and dying. "Dying?", he asked with sweet concern. I restated: "sick and dying". Mathias then added: "Do you think you could fix me some lunch before you die?" That's my little boy.

~ John & Denise Hipes
Panama City Beach, FL

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

Postoperative Monitoring of Patients with Prader-Willi Syndrome
Treatment Recommendations

The following recommendations have been reviewed by members of the Clinical Advisory Board of the Prader-Willi Syndrome Association (USA) with special acknowledgment to Dr.'s Moris Angulo, Mary Cataletto and Mary Lyn Quintos-Alagheband of Winthrop University Hospital, Mineola, NY (which cares for over 300 patients with the syndrome) for their contribution to this document. The unique health needs of individuals with this disability must be carefully researched and evaluated by all health care professionals. For questions or consultations, please feel free to contact the PWSA (USA) office at 1-800-926-4797 from 10:00 am to 5:00 pm EST weekdays.

BACKGROUND INFORMATION:

Patients with PWS are known to have increased morbidity after surgery due to:

- Abnormal physiological response to hyercapnia 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
- Decreased pain sensation is common in persons with PWS

Patients with PWS may experience greater challenges with compliance to pre- and postoperative treatment procedures due to:

- Extreme food seeking behavior and hyperphagia due to hypothalamic dysfunction.
- High incidence of gastroparesis and slow motility of the intestinal tract.
- Extreme skin picking which may interfere with wound healing.
- Altered temperature regulation – fever may be absent in the presence of infection. There does not seem to be a higher incidence of malignant hyperthermia.

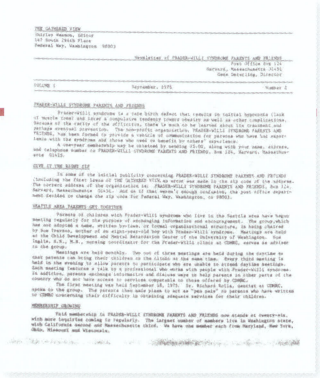
RECOMMENDATIONS:

- Patients with PWS who undergo deep sedation and general anesthesia should be recovered overnight in a monitored unit.
    - Infants and children may require intensive care monitoring
- Continuous monitoring of pulse-oximetry for 24 hours postoperative with attention to airway and breathing.
- A conservative approach to pain management and use of narcotic agents.
- Full assessment of return GI motility prior to initiation of intake by mouth because of the predisposition to ileus after surgery.
- Scheduling procedure as early in the day as possible to prevent prolonged time period where food seeking could take place.
- Direct supervision (1:1) to prevent foraging postoperatively.
- Monitor for picking at wounds and/or incisions. May require additional dressings and other barriers to prevent access to wound.
- Close observation of wound for signs of infection.
- Utilization of respiratory therapy interventions to prevent atelectasis and/or postoperative lung infection.
- Due to the hypotonia and obesity the individuals with PWS are at risk for deep venous thrombi (DVT) and pulmonary embolism. Patients should be under the guideline for DVT prophylaxis.

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MA-1050
12/2014

40 Year Flashback



2015 is a milestone year for *The Gathered View* as we recognize (and celebrate) our 40th year of publication.

Where was *The Gathered View* 40 years ago? Even more inquiring – where was PWSA (USA) then? In the beginning, it was the labor and dedication of families and doctors looking for answers. Readers and healthcare professionals have shared experiences and knowledge over the years.

Thanks to efforts from families like the Deterlings, and support from doctors like Zellweger and Holm, the organization was established in 1975. It was truly a passionate grassroots beginning. I cannot fathom the good this organization has achieved in the past 40 years, for the love of the children with the syndrome.

In each 2015 issue, *The Gathered View* will feature a special retrospective column: "40 Year Flashback". These articles will feature a glimpse back through the eyes of the *The Gathered View*, plus highlights from staff, families, counselors and professionals who have made great contributions to help all *The Gathered View* readers learn more about the syndrome.

In 1975, "Prader-Willi Syndrome Parents and Friends", soon renamed "Prader-Willi Syndrome Association", was established by Gene and Fausta Deterling, parents of a son with PWS, with the support of Dr. Vanja Holm, of the Child Development and Retardation Center and Shirley Neason (the first GV editor whose son had PWS) in Seattle, Washington.

In 1977, PWSA officially incorporates, with Gene Deterling as first President, and Delfin Beltran as first Chairman of the Board.

Janalee Henimann noted: "Dr. Hans Zellweger did the initial research on Prader-Willi syndrome before doctors Prader, Willi and Labhart. He described PWS as …*One of the two most grave ailments I have encountered -- the other being Huntington's Disease.* Fortunately, thanks to the advancements in awareness, education, and research, we are confident that he would not make that statement today."

Everyone CAN make a contribution; yes YOU can make a difference, and we look forward to sharing your *The Gathered View* memory and "throwback moments" with the GV readers.

Following is an except from a presentation by Dr. Andrea Prader in 1984…

I am delighted to be with you… It is impressive to see how much progress in medical knowledge and in practical management has occurred in the 28 years since my colleagues Dr. Alex Labhart, Dr. Heinrich Willi and I have given the first short description of this syndrome. On the other hand, we realize painfully how much we do not yet know and how little we can do.

I am deeply impressed by the successful activity of your association. You were the first Prader-Willi Syndrome Association in the world, which has brought together parents, doctors, other health workers and teachers... It is one of the most admirable qualities of American people to develop very powerful private initiative; to have a strong will to help each other, not to be ashamed to have a so-called abnormal child and to go public in support of these children. It is a great experience for me to see what you are doing, how you advise and help each other, how you bring together experts from various fields who can contribute to help these children, and how you have founded and organized special residences which is probably the ideal solution for many adult patients… As a pediatrician, I know how much we can learn from the observations and the experiences of parents and we hope that parents can also learn from us.

Do you have a story, comment or observation to share? We would love to hear how *The Gathered View*, or even a particular story, has personally impacted you. ■

~ Sara Dwyer, Editor



L to R: Hans Zellweger, M.D., Gene Deterling, Vanja Holm, Faussta Deterling, Dr. Prader, Delphin (Sam) Beltran, M.D.

There are a million different things that you could learn today. Don't be overwhelmed by it all. Just choose one thing. If you do that day in and day out you'll be amazed at how quickly it all adds up.

Win Your Day!

Steve Gilbert

Contributed by Clint Hurdle

Sibling View



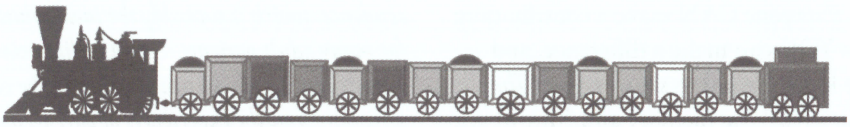
By Rockie Penta, 19, the younger sister of Victor Penta, 21.
Tucson, Arizona

Growing up with an older brother with special needs has always been hard, but I would never change that for anything. It's always made me realize to stay strong because these kids do it every day!

I now have a job helping families who have kids with special needs, and these two kids I treat as my own blood. So it has opened my eyes more and made me realize how darn strong all these parents are. Yes, there are some parents who could care less about helping their child with special needs, but then there are these parents who would go through hell and back a million times to try and help their child.

To the parents who have a baby, a kid, or an adult who has special needs, you are a hero. Not to just me in my eyes, but to your kid(s). Being a sibling, knowing no different, I turned out all right, and so will your other kids. They will realize having a sibling with special needs is a blessing. I promise. ■

[Mom's note: Rockie is a respite provider here in Tucson. She has several clients, including three with PWS. The parents absolutely love her, because I think they know she "gets it." A few weeks ago she took all three with PWS bowling. She said they had such a great time, but told me that she totally understood how worn out parents can get! She's a good kid, deciding if she is going to go into health care or into law enforcement like her mama. And oh yes, we all just celebrated Victor's 21st birthday by going to Las Vegas!]



Part I of a Series

Implementing the TRAIN

By Linda M. Gourash, M.D. and Janice L Forster, M.D. of the Pittsburgh Partnership, Specialists in Prader-Willi Syndrome

The TRAIN (Tool for Reducing Anxiety, Insecurity and Noncompliance) is an eco-environmental tool to manage symptoms of cognitive rigidity, perseveration, and stress sensitivity that are associated with the PWS behavioral phenotype. A visualized, linear schedule informs the PWS person what activities and tasks are expected to occur throughout the day. By arranging the daily schedule along a linear queue, the "engineer" or caregiver alternates the order of activities from non-preferred (resistance) to preferred (reward, i.e., mealtime). This flow of activities manages transitions to keep the person with PWS moving through their day, resulting in greater productivity, mastery and improved self-esteem.

Relevant background

Studies show that persons with PWS have certain cognitive characteristics that suggest that visual display of information can improve on-task behavior. Individuals with PWS have deficient working memory, the cognitive skill that allows all of us to hold multiple tasks in mind in order to execute multi-task objectives. In addition, individuals with PWS are mostly visual learners, so a visual display of sequential tasks helps the person know what to do next, reducing uncertainty and anxiety. Finally, individuals with PWS do not have a good sense of quantity, time or space, which leads to problems with arithmetic and perception of amount of time passing. However, they are able to understand calculations on a number line and a sense of time passing on a time line. Hence the linear, visualized schedule, defining the order of activities across the day, compensates for phenotypic deficiencies, and allows the person with PWS to focus on the activities at hand without preoccupation with what might happen next. Identifying when meals, snacks and preferred activities will occur during the day not only helps to define psychological food security but keep all else secure as well.

When people with PWS have food security, they can focus their minds on other adaptive tasks. ■

As featured in the Prader-Willi Syndrome Association of South Africa newsletter "People with Strength"

¡HOLA!

By Nina Roberto, E.D. of the New York Association and on the State Chapter Leaders Team as representative to Spanish-speaking families with PWS.

¡Hola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi. Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que nececitan informacion y ayuda. Les quiero directar a www.pwsausa.org donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, ninaroberto@verizon.net. ¡Hablamos pronto! ■

A Message from the Coordinator of Medical Affairs

Throughout my professional life, I have been privileged to work in the fields of developmental disabilities and mental health. While the value of my exposure to conditions, diseases, and competent providers is beyond measure, the families and consumers have taught me the meaning of commitment to a cause. Across the board, parents are driven by their desire to improve the lives of those they love. These kind, good-hearted people sacrifice every day to provide the best *they* can and, more often than not, also must assume the role of advocate to insure the best treatment, education, medical care or residential care for their family member.

Since joining PWSA (USA) in August, I have spoken to many who possess this same drive and motivation to help their family member with PWS. The complexity of the syndrome and the potential for medical, psychiatric, and/or behavioral complications take stress to a higher level for families as well as medical and other providers. Anticipatory stress of what may be and is not yet is often reflected in their voices or in conversations of parents of a newly diagnosed infant, a young child beginning to show too much interest in food, a teenager presenting behavioral challenges, or a young adult requiring inpatient treatment or residential placement. In addition, as interventions have improved the lives of those with PWS, we see aging parents express concern about making provision for the "child" who is now an adult. These parents fear what will happen to their offspring if they leave this world first. These are natural feelings; we all experience them at one time or another regardless of the situation or who we are caring for. These feelings and thoughts go hand-in-hand with a loving, sensitive person who also is a caretaker.

What is the downside for those loving and sensitive caretakers? Nothing, as long as you are willing to care for this loving, sensitive person who is YOU. In our fast paced, high tech world, the additional responsibility and resulting stress for caretakers is substantial and I hope each of you will assess your personal well-being. Because I can compete for first place for any award given for worrying and I have walked the walk as a long-term caretaker, I can take the liberty to encourage each of you to care for yourself with the same commitment that you care for your child or family member with PWS. The negative effects of caregiving stress eventually do catch up with you. It is just a matter of time. These negative effects wear many cloaks and present as symptoms, including, the common cold, depressed immunity, cardiac issues, hypertension, diabetes, pain, even anger, depression and anxiety. They may serve as the catalyst for conflict in your lives, broken relationships and marriages, even financial woes. For professionals who work in a caregiving profession, we see symptoms of compassion fatigue produce similar negative effects. I have often told people the effects of stress on our lives are like water on rock – we are not aware until the surface is worn smooth and the texture is no more.

Do just **one** thing for **YOU**

Each of you deserves to be happy and to embrace your own life, an important life. It includes, even requires, that you attend to your own physical and mental health needs. To do so is not selfish; it is wise. Love and appreciate yourself before the damage of not doing so is done. While it may seem unrelated, caring for you is also caring for those who depend on you. Imagine what their lives might be like if you are not present.

If you approach each day believing you will do the very best you can within the limits of the situation or day, then that is all that is asked of you. We each have a healthy definition of what it means to care for ourselves, and if you don't, please ponder this concept of "healthy" and begin to do just one thing for YOU during the course of the day. Do one thing that brings you joy or pleasure and enriches your body, mind and soul. This may seem so foreign to you it will require you to think outside the box. And, you can if you give yourself permission to think about YOU. ■

God bless each of you for just BEING, not just for your DOING.

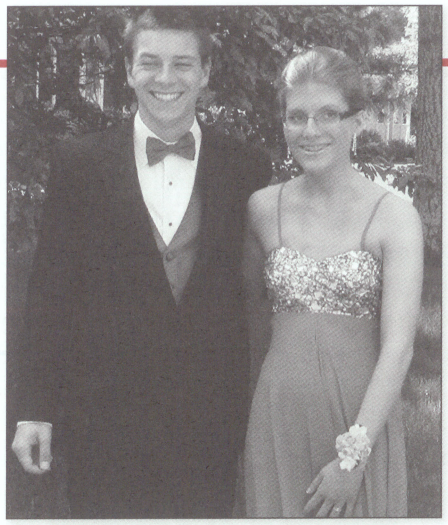
~ Bonnie L. Shelley, Ph.D.
Coordinator of Medical Affairs

ATTENTION Federal Employees!

If you work for the Federal government, the Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all." **PWSA (USA) CFC ID # is 10088**

For more information about the CFC program and how it works, go to their Web site at http://www.opm.gov/cfc/index.asp, or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee. ■

From the Home Front



Brenna Siegfriedt of Westford and Patrick Conway of Acton before heading out to the Westford Academy prom at the Sheraton Hotel in Boston on May 31.

WESTFORD -- When Patrick Conway knocked on her door a week before the Westford Academy prom armed with balloons spelling out an invitation to the dance, Brenna Siegfriedt almost couldn't control her excitem ent.

"Patrick left and she was giddy for an hour. She couldn't stop laughing for an hour," said her mother, Michele. "I had just never seen her so happy in my life."

For Brenna, an 18-year-old from Westford, with PWS, the prom was a teenage milestone she didn't think she would ever get to experience. But thanks to the help of her long-time mentor and friend Mackenzie Brewer, Brenna found her Prince Charming. Conway, a senior at Acton-Boxboro High School, heard from Brewer, who was a close family friend, that Brenna was in need of a date to the prom. As someone whose own family has been closely affected by a different genetic disorder, Conway had no doubts about stepping in. "I have a sister that has Down syndrome, and so when she was in high school she kind of went through the same thing of not necessarily being included," Conway said. I just thought everybody deserves to be able to do what most people do."

Brenna spent the day of prom, May 31, getting her hair and nails done, but said her favorite part of the preparation was buying her dress, a bright blue gown with a sparkly top. The couple took pictures on the Westford Town Common along with hundreds of other students that night.

Conway's parents, Patricia and Peter Conway, came along for that part of the evening. Their support, Michele said, along with his mother Patricia's statement that she wanted to make sure Brenna had the ultimate prom experience, was enough to bring Michele to tears.

Her favorite parts of prom night itself, Brenna said, were dancing and seeing her friends. With more than 400 students there, it was the largest social event she'd ever attended.

For Michele, Conway's willingness to go out of his way to help Brenna showed how a much of a difference a stranger's compassion can make. "People don't understand what one little act of kindness can do for someone that isn't able to take part in everything as freely as other kids," she said. She said she hopes Conway can serve as an example for others.

"I just think more people back away with people that are challenged and I would just like to see the opposite," Michele said. ■

Reprinted from The Lowell Sun by Chelsea Feinstein

Follow Chelsea Feinstein on Twitter and Tout @CEFeinstein.



Supported by PWSA (USA)!

Welcome to the Revolution

Thanks to our international organization IPWSO, you can now put Prader-Willi World in your pocket and never be without help or information about the syndrome. You can use this app to find facts, show others, and to keep up with the world of Prader-Willi syndrome. The first app of its kind, Prader-Willi World links you to websites around the world. It also shows you where else in the world other families live. This app will be especially helpful for PWS families living in countries with little or no support. It is in English and Spanish – and is free! It is designed for android devices, but eventually will be made available for Apple devices. Check out the Prader-Willi-World web page: http://www.prader-willi-world.com/ and sign up. ■

Janalee Heinemann, MSW
Vice President, IPWSO
PWSA (USA) Coordinator of Research & International Affairs

Did You Know....

For $15 you can give a gift auxiliary membership providing a one-year newsletter subscription to your child's doctors, teachers, and family members?

An Angel Among Us ~ Tribute to Scarlett Leigh Meade

"Those whom we lose in the springtime of their lives we shall meet again where there is no winter."



Our beautiful Scarlett was born on January 24, 2014. She provided many surprises throughout her short life including the day she was born. My 39th birthday was the day before. I was 7 months pregnant. At 10PM that night my water unexpectedly broke and Scarlett was born 3 hours later. With the premature birth, Scarlett was whisked off to the NICU for immediate treatment.

Almost immediately, the doctors expressed concern that Scarlett was very sleepy and hypotonic. I thought she was just traumatized from being born 2 months early. Scarlett was tested for a slew of potential disorders and a few weeks later, Scarlett was diagnosed with the UPD version of Prader-Willi syndrome. Her father and I were devastated. What we read on the internet regarding Prader-Willi was horrifying. Luckily, we found the Prader-Willi national organization, PWSA (USA) and ordered the Package of Hope. As we became more educated on the disorder, we felt more confident that we could handle it. Scarlett didn't seem like a "special needs" baby, she was just Scarlett.

We did everything we could to make sure Scarlett had all the early intervention tools that she needed. We organized all of her specialist referrals through her pediatrician. She was set up for regular appointments with a physical therapist, occupational therapist, ophthalmologist, gastroenterologist and endocrinologist. Scarlett was making great strides in her development. She got off her feeding tube at 5 months. She started growth hormone at 7 months. She was an incredibly easy going baby who hardly ever cried. Keeping up with all of the intervention therapies was a lot of work for her father and me, but it became a new normal for us. We were in love with our baby Scarlett and everything we did for her was worth it.

Scarlett was never sick until she was about 9 months old. It started with 2 weeks of diarrhea, which the doctors initially thought was from a type of baby food that was introduced. Then she got what seemed to be a cold but turned into something more when she became feverish and just wanted to sleep all day. We took Scarlett to the emergency room and she was diagnosed with Para influenza Type IV. She recovered a week later and we took her home. Unfortunately a few days later we had to take her back since she became sick again. This time the diagnosis was worse – ALL T-Cell Leukemia. Scarlett had to go on chemotherapy immediately in the hopes of eradicating the cancer. Just like with having Prader-Willi, we were fully prepared to work with Scarlett to get through this crisis, which we thought would just be a temporary setback. We reached out through the Prader-Willi Association (USA) to connect Prader-Willi experts with Scarlett's oncology team. Scarlett took the chemotherapy treatments in stride. She never complained and was still a happy baby for the first few weeks. Unfortunately, she contracted another respiratory virus that her little body could not fight off because the chemotherapy and Leukemia wiped out her immune system. Scarlett had to go on a respirator in order to get enough oxygen to her infected lungs.

The doctors did not think Scarlett was going to make it on Christmas Eve, but she continued to hold on for an additional 3 days. Because she was such a fighter, her big sister was able to have a Christmas morning opening gifts from Santa. We had the love and support of family and friends who stepped up and offered help in our time of need. So many people prayed for her. Unfortunately we did not get our miracle. On December 27th, Scarlett's little body shut down and she died peacefully in our arms.

We had 11 months and 3 days as Scarlett's parents. While we are grateful for that time with her, we are also sad for all the things we will miss from not seeing her grow up. We were ready to deal with all of the difficulties that Prader-Willi would bring later on. We had ideas about diet plans, teaching her yoga for exercise, starting speech therapy, going to a regular school, and the list goes on.

Scarlett's life was full of only love and goodness. We did not see her as special needs. To us she was just special. We will miss her every single day for the rest of our lives. We are grateful for the support we received from the Prader-Willi community throughout Scarlett's short life. ■

By Jennifer & James Meade

(Note from Janalee -- It is highly unusual for a child with PWS to also get cancer. I have informally followed all of the known cases of cancer with PWS around the world since 2004, and know of only one other young child with PWS that had leukemia, which is the most common cancer in children. I want to personally thank Jennifer for sharing the life of their precious angel.)

Contributions

Thank you for contributions in October-November 2014. We try to be accurate in recognizing contributions above $25, and apologize for any errors or omissions. If you notice an error, please tell us.

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Want to Share YOUR Story?

PWSA (USA) is accepting stories and pictures of your child/adult with PWS for use in the "From the Home Front". Individuals of all ages, both genders, and all ethnic backgrounds are welcomed.

We have professional writers available to interview you and assist in crafting your story. For consideration or questions, please contact us at pwsaeditor@pwsausa.org. We'd love to hear from you!

Photos should be a MINIMUM of 1000 pixels high OR wide, in a JPG format. To complete a Permission Form visit: http://www.pwsausa.org/photo%20release%20fieldform%20PWSA2010-08.pdf, and email the completed form and photo to news@pwsausa.org.

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

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

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The Gathered View (ISSN 1077-9965)
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To purchase for $30, please contact the national office in Sarasota: (800) 926-4797, email: sales@pwsausa.org, 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238, and watch for announcements in social media and on the website. ■

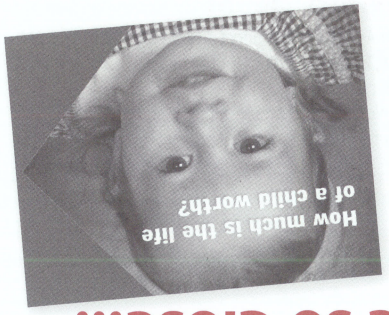
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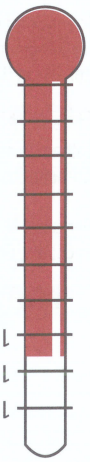


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