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

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

*In the November-December 2012 issue of **The Gathered View**, the focus was on history. In this November-December 2013 issue, the focus is on Research. Since its earliest days, PWSA (USA) has been involved with research in a variety of ways – attracting the interest of top-notch researchers to PWS, working on their collaborations, providing seed money, publicizing results and recommendations to our membership, and, of course, sponsoring Scientific Days at the national conferences and the Hyperphagia conferences. PWSA (USA) is now doing even more. For this issue – and this issue only – the Medical and Research View will be retitled **PWSA (USA) Research – Making a Difference!***

~ Janalee Heinemann
PWSA (USA) Director of Research & Medical Affairs

Rob Nicholls' Ride For Research… "One man. One bike. One ride across America for a cure"

Rob Nicholls
Ride for Research



As we go to press, Rob has pedaled 593 miles across the HUGE state of Texas with another 247 miles to go before he gets to a Rest Day in Houston. He is on his way from California to the national conference in Orlando, Florida, where he anticipates arriving on November 5, after a total of almost 3000 miles.

Since beginning his incredible ride on October 10 from Chula Vista, California, to raise money and awareness for PWS research, Rob notes that the first four days were the most challenging of his life. "… every day so far, we had roads on the map and GPS that didn't exist, and other roads with different names than the maps."

By Day 7 he had made it to West Texas where the pattern continued— "As in New Mexico, in west Texas, once outside the city of El Paso, a number of side roads either didn't exist or were dirt and sand." As of October 22 he had lost some time due to a bike repair situation, but expected to be back on schedule by October 24.

You can read about Rob's Ride for Research — and donate — on www.robsrideforresearch.com. It is not too late to give. The goal is to raise $500,000, so he has a long way to go, both in miles and in money! ■



Our Angel: Lee

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Volume 38, Number 6 ~ November-December 2013 ~ Our 38th Year of Publication

Things Are Changing.

by Melanie Ledgerwood

After 33 years on the PWS life-tour, it's comforting to see that this generation of young parents has the ability (like never before) to communicate and share information in a way never before dreamed possible!

I'm hopeful about the future.

To illustrate how far the PWS movement has come in 33 years, let me tell a little bit of my daughter Lauren's story:

I was a single mom, 20 years old. No insurance. Husband M.I.A. Lauren was born at Parkland Hospital in Dallas. I was on the free pre-natal care plan for the poor. Nobody said it was a bad thing that I lost weight while pregnant. Nobody asked if I felt her move - and I never did.

When she was born in a room full of curious medical students, I heard the doctor say, "This is a floppy baby", and then they swept her away. The next day I still had not seen my baby. I timidly asked the male nurse about this and also why I had not been taken into surgery for the tubal ligation I had scheduled. He responded, "Nobody told you? There is something wrong with your baby!" Yeh, he really said that...

Fast forward a couple weeks when I insisted that I was taking my baby and GOING HOME! They scheduled me to stop by Scottish Rite Hospital so that Lauren might be evaluated there. The diagnosis was more grim than PWS.

You all will carry this torch until one day you kick this disease in the "you-know".

Thank goodness they were wrong and she did not have muscular dystrophy.

Fast forward again and she's about 4. I've gone from being a mom who was counseled to encourage and coax my failure-to-thrive baby to eat -- to being a mom scolded for allowing my toddler to become obese. It was at that point that the neurologist entered the exam room with papers he had xeroxed from his medical journal. These papers were complete with photographs of people diagnosed with PWS. Prognosis: Morbid obesity and death around age 17 or 18. Black and white photos showed



Lauren last spring at the State Special Olympics

400-pound people. The pages spoke of increased mental retardation as the patients' weight increased. He said "We only treat orthopedics here. This is not an ortho problem." "Where do we go now?" I said. And he replied, "I don't know..."

Okay - there is way more to the story than that!!! After some very rough spots along the way, Lauren at 33 is doing better than I ever dreamed she could. All I really want to do is show that THINGS ARE CHANGING. I know that hearts break when parents learn your babies are not neurotypical - but I promise - it is getting better. You all will carry this torch until one day you kick this disease in the "you-know". I want to be around to be your biggest cheerleader. ■

~ Melanie (the mom) and Lauren (the champion)



Lauren enjoying a sunny day in Tennessee



2012 is so last year; keep your eyes open! Watch for the Angel Campaign coming soon.

ANOTHER PWSA (USA) FUNDED RESEARCH PROJECT

Study To Understand The Genetic Reasons For Restrictive Repetitive Behavior In PWS

by Soo-Jeong Kim, M.D., Associate Professor Division of Child and Adolescent Psychiatry, Department of Psychiatry, University of Washington, Seattle Children's Research Institute, Seattle, WA 98101

We are very grateful for the PWSA (USA) support for our research project entitled "Genetic Underpinnings of Restricted Repetitive Behavior (RRB)." Through this project we have gathered highly valuable preliminary data from our gracious study participants.

- We have confirmed genetic diagnosis of PWS using an independent molecular genetic technique and also interpreted the types of deletion in participants with deletion subtype. Part of this result was published in Kim et al. (2012).
- We gathered phenotypic data regarding various neurobehavior, such as adaptive behavior, cognitive ability, level of social communication skills/deficits, level of challenging behavior and restricted repetitive behavior from our participants. Part of this result was published in Flores et al. (2011).
- We are currently expanding our scope of research to identify secondary hit events contributing to variable expressivity of atypical neurodevelopment across individuals with PWS. We will submit an NIH R01 application utilizing the data generated from this study.
- We are conducting DNA methylation studies to identify global effects of aberrant DNA methylation arising from PWS region.

Thank PWSA (USA) very much again for allowing us to conduct this interesting study and gather important pilot data. We are confident that the preliminary data we obtained from this project will help us to achieve our goal to understand underlying genetic factors that may explain the variability of PWS symptoms.

Publication from this project

Flores CG, Valcante G, Guter S, et al. Repetitive behavior profiles: Consistency across autism spectrum disorder cohorts and divergence from Prader-Willi syndrome. J Neurodev Disord. Sep 1

PWSA (USA) Sponsors Three New Fellowships

The Future of PWS Research Depends on the Commitment of the Next Generation of Researchers

PWSA (USA) has been sponsoring two fellowships a year through the Rare Disease Clinical Research Consortium (RDCRN) since 2010. The decision was made that for this funding period 2013/2014 we would increase the sponsorship to three fellowships for $25,000 each. I'm including two of the recent Fellowship reports to give you a concept of how important this funding is to grow our future generation of researchers who have a special interest and commitment to Prader-Willi syndrome. As you will read, their work has been phenomenal!

~ Janalee Heinemann

PWSA (USA) Fellowship Award

Ann Manzardo
Kansas University Medical Center, Kansas City, Missouri

Annual report 2013

I would like to thank the Prader-Willi Syndrome Association (USA) and the families affected by Prader-Willi syndrome (PWS) for supporting my research and training in the genetics of PWS and obesity-related syndromes and for continuing to champion the cause for medical research in rare diseases, particularly in light of the current economic challenges. This is an extraordinarily difficult period in the history of American medical research, and the support of community organizations like PWSA (USA) is increasingly important for continued scientific discovery and the development of treatments.

Over the past several years I have had the privilege to work with and learn from the best mentor in genetics and PWS possible, Merlin G. Butler. Focused training as a PWSA (USA) Fellow has significantly advanced my understanding of the personal and scientific challenges associated with PWS and increased the effectiveness of my research efforts to improve the health and quality of life for those living with PWS. The fellowship has also increased my exposure to medical experts and researchers in the field of PWS and obesity, allowing me to participate in larger obesity-related research projects. I look forward to continuing in the development of research protocols to tackle issues of importance to PWS.

We explored several important scientific questions of relevance to PWS treatment over the past year including a common genetic polymorphism or variant in the growth

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hormone receptor (GHR) gene. The effects of growth hormone on height and lean muscle mass result from binding to the GHR protein located in the cell membrane. A common GHR gene polymorphism produces a different version of the GHR protein, one with substantially increased 'affinity' or binding strength to growth hormone.

We hypothesized that this increase in binding affinity may influence the response to growth hormone treatment impacting growth trajectory and risk for side effects such as scoliosis. We examined growth trajectories of 69 subjects with PWS in the presence and absence of growth hormone treatment to determine the possible impact of the GHR variant on treatment response. We found a clear increase in the rate of growth among subjects with the protein variant. Fortunately, this did not appear to be associated with an increased likelihood of scoliosis. But more research is needed in this important area as the majority of children and infants with PWS are undertaking growth hormone therapy.

…the support of community organizations like PWSA (USA) is increasingly important for continued scientific discovery and the development of treatments.

The data supported our hypothesis that GHR gene subtype influences growth and response to growth hormone in PWS and is an important consideration in the management of growth hormone treatment. The results of this study have increased awareness of the importance of GHR subtyping of PWS infants prior to initiation of growth hormone treatment.

I have also been involved with the collection and sorting of data on weight, height and head circumference for the development of growth charts for PWS between 3 to 18 years as was done previously in infants with PWS (Butler et al., 2011). These charts should help physicians monitor growth trajectories and reduce the occurrence of side effects.

I assisted Dr. Butler in the validation of new structural DNA microarray technology designed to increase the sensitivity, precision and accuracy of PWS diagnoses and subtype identification. The use of high density microarrays provides a detailed examination of deletions, duplications and regions of homozyogosity in the genome, enabling the identification of very small deletions and the confirmation of maternal disomy 15 (UPD) status in many cases. This technology was used to evaluate and verify PWS subtypes in 50 subjects and found to be effective, although questions remained regarding the interpretation of negative findings and the relevance of very small deletions and duplications. The advanced procedures appeared to be particularly helpful in discrimination between UPD and imprinting defects when one or both parents are not available for testing. These results will also yield useful data in our genotype-phenotype correlation studies when comparing the impact of the differential genetic subtypes on clinical findings.

We are currently working with other PWS experts to obtain funding to study psychiatric syndromes in PWS and evaluate long term outcomes such as mortality to optimize treatment and promote long term success and life quality.

The results from our current investigation into gene expression disturbances associated with obesity, "Probing the Genes for Hyperphagia", will be presented at the 27th annual PWSA (USA) Scientific Day. I look forward to the opportunity to meet and interact with the experts and families that work so hard to further research in this important area.

PWSA (USA) Fellowship Award

Frederick A. Kweh, Ph.D.
University of Florida, Gainesville

Annual report, October 2013

I have had the privilege to train with two of the most prominent researchers in the field of Prader-Willi syndrome (PWS) in Drs. Dan Driscoll and Jennifer Miller. This unique opportunity was made possible to me largely through the financial support of the Prader-Willi Syndrome Association (USA) and the participation of the families affected by PWS in our PWS Natural History Study project. I would like to thank PWSA (USA) for their support and the affected families for their commitment and participation in our study and their willingness to share their experiences and knowledge of the disease with us. Learning about the challenges of living with PWS directly from them has been key in my development as a researcher in this field. It has furthered my understanding of not only the scientific challenges associated with PWS, but also the even bigger personal challenges faced by the families daily. Their stories serve as a constant reminder to me that what we do matters, and we must work even harder to improve the quality of life for those with PWS.

The fellowship we received from PWSA (USA) allowed us to investigate hyperphagia and obesity in individuals with PWS and others (non-PWS) with early-onset morbid obesity (EMO). We explored the question of ghrelin levels in infants and young children with PWS and its role in the development of hyperphagia and obesity in PWS. We hypothesized that if hyperghrelinemia were responsible for hyperphagia in PWS, then infants and young children with PWS in the early non-hyperphagic nutritional phases (1a & 1b) would have significantly lower ghrelin levels than children in the

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later hyperphagic nutritional phases (2a, 2b & 3). However, we found that ghrelin was significantly elevated in infants with PWS as early as five weeks old, long before the onset of hyperphagia. In fact, the highest ghrelin levels were in infants in nutritional phase 1a, which is characterized by poor appetite. Thus it is highly unlikely that ghrelin alone is responsible for the switch to hyperphagia in PWS.

However, the hyperghrelinemia is probably contributing to the increased body fat beginning in young infants with PWS. Recent research has shown ghrelin can promote lipogenesis and fat deposition independent of its effect on appetite. This would explain why young infants with PWS have significantly elevated body fat relative to their weight-for-length percentile and why older children and adults with PWS have elevated body fat relative to others of similar Body Mass Index (BMI) standard deviation (Z) scores.

We also examined prominent cardio-metabolic risk factors in subjects with PWS and compared them to normal weight sibling controls and also to others (non-PWS) with early-onset morbid obesity (EMO). We found that individuals with PWS in better weight control (BMI-Z<2.0) have significantly lower C-reactive protein (CRP), TNF-alpha, cholesterol, triglycerides, white blood cell count and body fat than individuals with PWS of poor weight control (BMI-Z>2.0). However, we found that obese individuals with PWS have lower leptin, CRP, IL-6, triglycerides and insulin than EMO subjects of similar BMI-Z scores. Thus it appears certain cardio-metabolic risk factors are lower than expected in obese subjects with PWS and are further reduced with good weight control.

The findings of our studies are important to both the PWS community and the general population.

The findings of our studies are important to both the PWS community and the general population. Understanding ghrelin's contribution to obesity outside of appetite control and why certain cardio-metabolic risk factors are lower than expected in obese subjects with PWS would benefit not just individuals affected by PWS, but also others with obesity. We hope to use these results as preliminary data for a much broader study involving metabolomics analysis in individuals with PWS and others with early-onset morbid obesity.

The results of our ghrelin study in children with PWS have been submitted for publication. The results of our study of cardio-metabolic risk factors in PWS will be presented at the 27th annual PWSA (USA) Scientific meeting in November 2013. It will also be written up in a manuscript for subsequent publication. I look forward to sharing our findings with the PWS community and meeting the many families who participated in our research. ■

Eight Years of Growth Hormone Treatment in Children With Prader-Willi Syndrome: Maintaining the Positive Effects

Setting: This was a multicenter prospective cohort study.

Methods: They followed 60 prepubertal children for 8 years of continuous growth hormone treatment.

Conclusion: This 8-year Dutch study demonstrates that GH treatment is a potent force for counteracting the clinical course of obesity in children with PWS.

(JClin Endocrinol Metab 98: 0000–0000, 2013)

J Clin Endocrin Metab. First published ahead of print September 3, 2013 as doi:10.1210/jc.2013-2012
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Comments from Dr. Moris Angulo on GH and body composition:

Moris Angulo, M.D., Winthrop University Hospital, Mineola, New York

(Endocrinologist who pioneered the original studies on PWS and growth hormone and a member of both the international (IPWSO) Scientific Advisory Board and PWSA (USA) Clinical Advisory Board)

This study above confirms again not only the growth promoting but the significant anabolic effect of growth hormone (GH) treatment in children with PWS. It is somehow difficult in many children with PWS to find the right balance between GH dose, clinical response and serum IGF-1 levels. In USA, growth hormone has been approved for short stature/growth failure in children with PWS; therefore their response should be based on growth velocity and ideal body weight to calculate their GH dose. There is improvement on weight and body composition but to a lesser degree than growth velocity and final adult height, which normalizes after GH treatment. Considering the achievement of better weight and body composition as the main reason for GH treatment could mislead its use. As in any naïve growth hormone deficient

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child, GH response may vary regardless of their serum IGF-1, and caution should be taken to prevent overtreatment and development of complications including type 2 diabetes mellitus and acromegaloid features. ■

Report on Study Examining Swallowing Function in PWS VOLUNTEERS NEEDED

PWSA (USA) is sponsoring a research grant that is a pilot study examining swallowing function in persons with PWS. The principal investigators are Roxann Diez Gross, Ph.D. and Gregory Cherpes, M.D., at The Children's Institute in Pittsburgh. The study is examining the phases of swallowing and assessing for evidence of risk factors associated with aspiration and choking. The six-month interim report has already revealed some striking preliminary findings that could change how we look at eating and drinking in persons with PWS. At this point, 16 of the participants have already completed the research procedures. The goal is to have 30 participants with PWS.

If you would like to learn more about this study, or if you are willing to consider your person with PWS (ages 4 to 55) as a participant, please call the study coordinator, Ronit Gisser, MSc at 412.420.2249. There will be some compensation for your time and expenses. This study will have important and immediate implications for PWS care. ■

Using The Internet

By Janalee Heinemann, M.S.W. [PWSA(USA)], Jennifer Miller, M.D. [University of Florida], Theresa Strong, Ph.D. [FPWR]

The Internet has proven a valuable place to learn about PWS, share experiences, and find out what other parents are doing to manage their child's health. However, applying information gathered over the Internet to your child's medical care can end tragically if the proper precautions aren't taken. Here are some suggestions:

- **Know Your Sources:** When considering advice about medicines, supplements, or diets, consider the qualifications of the person or website providing the information. For individuals, what is their education, training and/or experience? For those giving medical advice, are they licensed, active in their field and well respected by colleagues? For organizations, where are they drawing the information from and are there any conflicts of interest (for example, could they benefit from the sale of a related product)?

The Genetic Alliance has a "Trust It or Trash It" tool that's a good resource to help you weigh the quality of Internet materials http://www.trustortrash.org/#. Some examples:

- **Think about TRUSTING IT if:** The medical information is based on research of many people.
- **Think about TRASHING IT if:** The information is based only on someone's opinion or individual experience.
- **Look for Clinical Trials:** Medical interventions (e.g., medicine, supplements, diet) might seem logical on paper and may be reported as beneficial by one or a few individuals, but until well designed clinical trials are performed, the safety and effectiveness of any intervention is unclear. Unexpected safety issues may arise, or it may turn out that anecdotal findings don't hold up when evaluated in a rigorous clinical trial. Ideally, decisions will be guided by the results of clinical studies published in peer-reviewed medical journals.

Information about clinical studies can be found at http://clinicaltrials.gov/ or in the medical literature http://www.ncbi.nlm.nih.gov/pubmed/

- **Inform Your Doctor:** To properly care for your child, it's critical that your doctor have a clear overall picture of all aspects of your child's health. Thus, he/she needs to be fully informed of medications, supplements and dietary interventions you are using or would like to consider. Any changes should be discussed ahead of time, so you can fully understand the risks and benefits in the context of your child's health. If you are uncertain or don't agree with your doctor's recommendation or plan, seek a second opinion from a qualified medical professional.
- **Take Care with Supplements:** Keep in mind that the Food and Drug Administration (FDA) does not regulate supplements in the same way as it does drugs. FDA-approved drugs undergo a rigorous review process to demonstrate safety and efficacy. In contrast, there are no requirements for manufacturers of supplements to demonstrate either safety or efficacy prior to marketing. Some supplements can be toxic if given when not necessary or in too high of doses. In addition, while FDA approved drugs undergo strict quality control to ensure lot-to-lot consistency, there is no formal oversight

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process to test the composition of supplements and ensure that it matches the label. Independent testing sites, such as ConsumerLab.com, or the NIH Office of Dietary Supplements (http://ods.od.nih.gov/), provide unbiased information about supplements. ■

Recommended Websites:

- **General Medical Information:** WebMD, MedScape, MayoClinic, NIH MedlinePlus Medical Encyclopedia and University-based websites are usually good sources for general medical information.
- **Prescription Drugs:** The US National Library of Medicine Drug Information Portal http://druginfo.nlm.nih.gov/drugportal/drugportal.jsp

How Our Organization Helped

Matthew and Sodium Levels

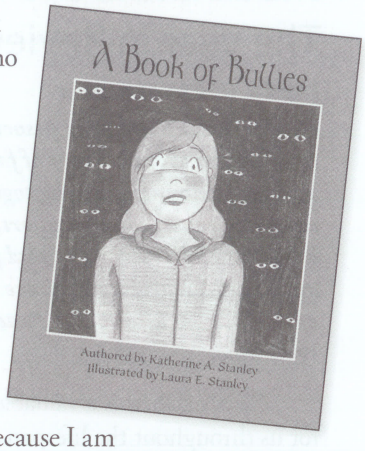
by Denise Servais

Judy Chapman from Flowery Branch, Georgia, had received some good news. Her son Matthew, 29, had been accepted into The Children's Institute's PWS program in Pittsburgh, Pennsylvania. But there was a problem. The lab test results ordered by Matthew's endocrinologist, Dr. David Robertson, came back showing that Matthew's sodium levels were too low. "We were getting ready to go to Pittsburgh, when Matthew's tests results came back," said Judy. "We had to find out what was causing the low sodium or else he couldn't go." Judy reported that she was told that Matthew's participation in the exercise program in Pittsburgh could lead to seizures if he had low sodium levels.

Judy called Evan Farrar at PWSA (USA) and asked for help. Evan sent out a notice to endocrinologists around the country to get their opinion as to what could be causing Matthew's low sodium levels. One of the responses that came back suggested that drinking excessive amounts of water might be causing the low sodium levels. "When I heard that," Judy said, "I knew that was it…I remember seeing a lot of empty water bottles in his room. When we cut back on his water, his sodium went back to normal."

Judy reported that Matthew did go to the Institute last year and lost about 50 pounds. He came home and continued to lose weight. Judy now monitors his water intake. Matthew lives at home with his mom and is quite active in sports and social programs offered through his county. Judy expressed appreciation for her local PWS chapter and PWSA (USA) for all the help she received. ■

Some Excellent New Publications for You



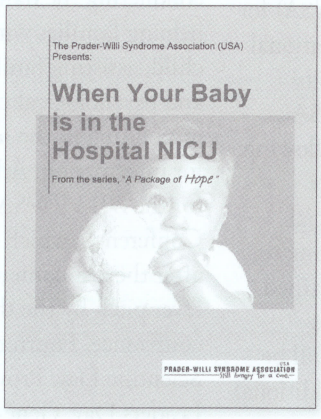
Especially exciting is a book written by Katherine Stanley, who is 17 and has PWS. The book, entitled ***A Book of Bullies*** and partially sponsored by PWSA (USA), is illustrated by her older sister, Laura. In her Author's Notes, Katherine says:

"I write because I have something to say that I believe children need to know. I was born with a condition called Prader-Willi syndrome. Because I am different, I have unfortunately become an expert on bullies. I have experienced just about every kind of bullying you can think of. I have used that bad experience to create something positive—this book.



"I hope that through this book my message will reach young children and help them understand how hurtful bullying is. I hope it will make people want to be kinder to each other. I also hope this book will convince other children with special needs to never give up on themselves. Many people thought I could never get a book published, but here it is!"

Retail cost is $16.95. It will be available at the conference and on our national store afterwards. Katherine and her mother Cyndi will be attending conference, with Katherine doing a book signing. ■



From the series, *"A Package of Hope"*

The Prader-Willi Syndrome Association (USA) presents:

When Your Baby is in the Hospital NICU

Written by Colette, R.N. and Eric Joncas, R.N. (parents of a child with PWS) and reviewed by many members of the PWSA (USA) Clinical Advisory Board

And it's FREE! ■

This is Your Association

The year in Review



Dale and Dottie Cooper
Interim Co-Executive Directors

PWSA (USA) 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.

PWSA (USA) is a valuable resource for us throughout the lifespan of the individual with PWS. Families with infants and young children are supported through programs such as our Parent Mentor program and information on medical and therapeutic interventions. Families of adolescents are helped through our emphasis on meeting special education, medical, and behavior challenges. Parents of adults with PWS are bolstered by information on supported living and employment, as well as physical and psychological changes occurring as our young adults are now living longer. **PWSA (USA) is a hub through which the knowledge gleaned from the medical and provider professional communities, in addition to National, Chapters, and the real life experiences of families, come together.** Thank You, PWSA (USA).

All over the country (and even the world) families come to PWSA (USA) for guidance and information. Our national organization takes this responsibility seriously. Just this year alone, PWSA (USA) has been engaged in the following:

- Special Education Advocacy initiatives – the Wyatt Special Education Advocacy Training was launched with 10 people trained specifically to address issues related to PWS, and who will be instrumental in training additional advocates. Our new e-letter "School Times" and our new video on YouTube for teachers and families, "Tips for Teachers" show our growing outreach.
- New initiatives for research and new medical discoveries – investing in research and providing up-to-date and timely information regarding progress, findings, and recommendations
- Webinars scheduled regularly to focus on topics of interest -- already Special Education Advocacy, Gastroparesis, and Rob Nicholls' research
- New Website – easier to navigate, informative, easy-to-find chapter pages, a library, a robust eCommerce site, and more
- New Social Media communications infrastructure – comprehensive use of e-Bulletins, Facebook, Twitter, and blogs
- New Accounting system – clarifying the financial stream of our national office, as well as chapters
- Volunteer initiatives -- A strong volunteer program very successful in our national office is being passed along to chapters.
- New Fundraising initiatives – PWSA (USA) has developed fun opportunities for families to bolster the support our organization can provide to those affected by PWS.

All of this has been done while conducting the daily business of helping families with a newly diagnosed child, assisting families with medical and psychological challenges, and responding to the numerous requests for information. Add the planning for the 2013 PWSA (USA) National Conference, which started a few months after the last conference and reaches a fever pitch by the three months before conference. Fourteen committees plan Scientific Day, Providers Day, Chapter Leaders Day, General Conference, YIP (Youth and Infant Program), YAP (Young Adult Program), and Sibling program, plus the various Clinical Advisory Board, Scientific Advisory Board, Rare Disease, and Professional Providers Advisory Board Committee meetings –all occurring in a four-day period! Not to mention Rob's Ride for Research, culminating at the National Conference -- a Herculean effort of bicycling coast to coast to bring awareness and funding for PWS research.

So much has been done just this year and so much more we can do together as we increase funding and volunteer support. With such a robust 2013, we can't wait to see what 2014 will bring. It will surely be guided by what we hear from chapter leadership and attendees at the National Conference, as well as our on-going communications with families, individuals with PWS, and professionals from around the country. At PWSA (USA) we are listening to you. After all,

THIS IS YOUR ASSOCIATION. ■

Contributed by Clint Hurdle:

"When I was 5 years old, my mother always told me that happiness was the key to life. When I went to school, they asked me what I wanted to be when I grew up. I wrote down, 'happy.' They told me I didn't understand the assignment. And I told them they didn't understand life."

~ John Lennon

Make a difference today.

Board News

Effective 9/1/13, following the election, we welcomed four new board members, Sybil Cohen, Rob Lutz, Rob Seely, and Michael Troop, and one returning board member, Michael Alterman. We look forward to their participation and contributions to the life of PWSA (USA).

Heartfelt thanks and gratitude are in order for the three hard-working board members, John Heybach, who served from 2004-2013; Mary K. Ziccardi, who served as secretary from 1998-2000 and as a board member from 2000-2009 and 2010-2013; and Steve Leightman, who served from 2004-2013. All have completed their terms and are going off the board. If you see any of them, be sure to express your appreciation for their dedication.

At the board meeting at the end of September, Ken Smith was elected Chair of the Board and Michelle Torbert as Vice Chair.

…and a farewell

Sincere thanks also go to Dottie and Dale Cooper for their valued service to PWSA (USA), serving as Interim Executive Directors. They will be transitioning out at conference. John Heybach noted that they brought the exact skill set our organization needed, at a time when it was badly needed. Lisa Thornton said that they were inspirational and motivational and it was a pleasure to work with them. The board as a whole acknowledged that we all owe them a debt of gratitude. ■

¡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! ■

The Value of Life

by Patrice Carroll, Manager of PWS Services, Latham Centers, Brewster, Massachusetts

In May we celebrate PWS awareness. In October we celebrate Down syndrome and Spina Bifida awareness. Is celebrate the right word? Yes, I think it is. Do we, as a society, celebrate the birth of infants who are not typical? No. But I believe that we should. Human life should not be celebrated or valued based on what an individual may contribute to society--but rather for who a person is, what he or she brings to the lives of his or her families and those that love them.



Why do we assume that those born with different challenges are suffering and therefore are somehow lesser than those without "syndromes" or "disorders"? How do we as individuals define quality of life, and why do we assume that our definition is correct? Quality of life is defined as having meaningful relationships, meaningful work and leisure activities that bring us joy. The definitions of "meaningful" and "joy" are deeply personal and not transferable from person to person. I often ask the people that I work with who are diagnosed with PWS what they want people to know about what it is like to live with PWS. Here are some of my favorite responses:

"I want people to know that I'm not as sick as everyone thinks I am. I feel pretty good" – Anthony, age 17.

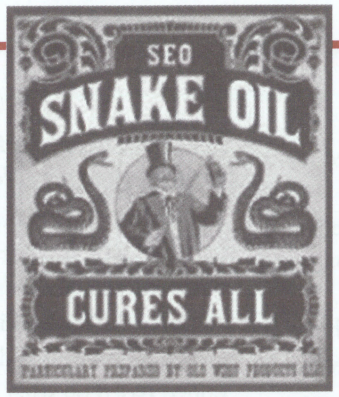
When asked what, if anything, he would change about himself, Ben, age 16, said, "I wish I didn't have to wear glasses." I then asked if he would want to take away having PWS, and he said: "No, I like myself."

Leona, age 22, said, "It would be great not to feel so hungry all the time, but you get used to it. I have a boyfriend and a lot of friends and I'm in college. I have a job. I do more than a lot of other people who don't have PWS."

Just as the definition of meaningful is not universal, neither is the definition of suffering. We make so many assumptions about people with disabilities, and one of the biggest assumptions is that they are suffering and would change if given the choice. Instead of focusing our energy on pity and trying to make people with developmental disabilities change to fit our definition of normal, we need to open our hearts and minds to the idea that there is intrinsic value in all life regardless of how we define quality of life, happiness and success. ■

SNAKE OIL

by Lisa Peters



If you are initiated into the world of special needs parenting, there are some very unusual skills you must develop. One of these skills is an ability to evaluate and implement the growing list of new vitamins, supplements, important medications and therapies that may improve the quality of life for your child.

Unfortunately, however, in developing this skill, we become particularly vulnerable to the sales efforts of a legion of carpetbaggers, charlatans and pharmaceutical drug reps.

As a parent of a child diagnosed with an incurable disease, there is a very convincing inner voice that whispers in your ear.

"You must try everything. If there is a chance to help your son in any way, you must take it. If you look like a fool, it does not matter. There is nothing more important than the health of your child."

But staying abreast of the "latest new thing" is a daunting responsibility.

You must sign up for countless yahoo groups, facebook pages and twitter feeds. You must join national organizations, befriend PWS experts and participate in conferences. You must read every blog and every comment ever posted about PWS.

If you are a special needs parent, the ability to jump on the band wagon is not just a frivolous pursuit to keep up with the Joneses; it becomes an important way of life, a means of keeping informed of important new treatment options for your child.

The tricky part is learning to discern which treatments are good medicine and which are nothing but snake oil.

In our PWS community, it begins with a "buzz word" that starts to reverberate throughout our desperate ranks. Unusual words like CoQ10, carnitine, melatonin, vitamin B12 and PharmaNAC are ease-dropped into our daily conversations. Slowly at first, and then building in intensity until they are spread through our airwaves like viruses.

Of course, each of these products serves a different function. Some propose to give our children more energy, others will help them to sleep better, and there are even those that claim they will help control appetite, anxiety or skin picking activities.

My job as a "good parent" is to evaluate them all or face the unwanted scorn of my fellow parenting colleagues and PWS professionals. So, in an effort to remain in good standing within my small community, I try them all.

I must admit, at times I feel like a desperate and gullible mother, bringing her child to the wild witch doctor who waves his magic feather wand over my suffering child and proclaims with spiritual reverence and mad man intensity....

"Be gone evil spirits, be gone!"

I have spent countless dollars on countless boxes of vitamins and supplements that now sit untouched in the dark confines of our bathroom medicine cabinet. But I have also discovered important therapies and treatment options that have made a significant difference in the quality of life for my son, treatments such as growth hormone, Abilify and Provigil, medications that have enabled my son to overcome obesity, manage anxiety and sharpen his cognitive focus.

So, I will continue my quest as the ever-evaluator of snake oils. I will buy every magic pill recommended by my fellow comrades-in-arms. I will fulfill my role as a "good parent" until one day perhaps we will find a legitimate cure that will enable my son to live a happy and healthy life, free from the effects of a terrible disease. ■

Rob Nicholls
Ride for Research
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Counselors Corner

by Kate Beaver

A new resource is coming out this fall called "The Older Child E-Book". This is going to be an e-book that was created to help parents, grandparents and others raising children with PWS. The articles are one- and two-page handouts that provide practical strategies to help with food and behavior in the home. There is also a section on marriage and family, the basics for school information, a medical section, plus more. The e-book will be on a zip drive and include the exercise DVD; families can also purchase the exercise DVD to go with the thumb drive so children can watch it on a TV. The e-book will debut at our National Conference in Orlando in November. ■

Sarasota's Mediterranean Night



On September 29, 2013, PWSA (USA) kicked off the season of giving with a board-hosted fundraiser in the backyard of our national headquarters, Sarasota, Florida. The event, Mediterranean Night, was held at the prestigious Prestancia Country Club and was well attended by local community supporters as well as PWSA (USA) staff and board members.



A Mediterranean theme, supported by the backdrop of the venue's exquisite terrace, was the common thread of the evening. There was a Tuscan hors d'oeuvres table, cocktail hour and a grand silent auction that even included a villa for four in Tuscany.

Local musician John Reven entertained the crowd with his vocal and piano playing talents throughout the evening. Carolyn Davis, another local artist, joined John in an impromptu duet of "Midnight Train to Georgia " dedicated to our own executive director team, Dottie and Dale Cooper.

A special note of gratitude goes to Angela and John Fain and the entire Grapevine Communications team for helping PWSA(USA) with the promotion of this event.

The evening was a huge success and we wish to thank all of our sponsors and attendees. We look forward to next year and making this event an annual PWSA (USA) tradition. ■

Erase The Picking

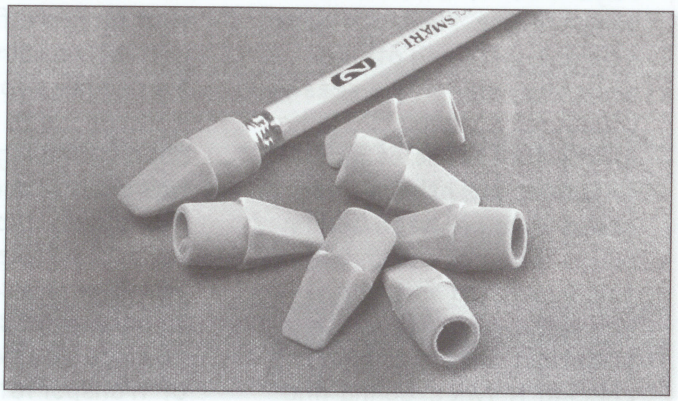
by BJ's Grandmother, Retired English Teacher Lovetta Currence

After years of hard candy, plastic balls, rubber tops, anything rough, smooth, prickly edges--nothing worked; the picking continued until deep scars on his legs linger as a reminder of the days before Daniel Brian Currence, Jr. (BJ), 15 years old with PWS, found his answer to the perpetual picking problem of PWS patients---**erasers.**

When asked how he got started with erasers for relief of his need to stimulate his hands, BJ said, "I just thought one day--I'm going to try to use the top of this pencil—'the eraser' instead of picking. I told my Dad about the idea, and the next thing I know, Dad brought in a whole pack of caps (that go on top of pencils). Of course, the mother lode was when he got the big solid erasers not attached to a pencil (**I never knew erasers came in so many shapes and sizes**)." They felt really relaxing; the "disintegration" of the eraser is as effective as the rubbing, hands together--constant, easy motion.

When asked by his doctor at Duke University about the picking issues, BJ's response about the erasers brought a reply from the doc, "Unique approach"—**whatever works**.

Teachers at school have joined in the effort to help find pencils, on the floor, in the yard, on the pathway. His fellow students chimed in when they could with, "Here's a pencil, BJ, let's get the eraser." One teacher, Mrs. McKenzie, remarked about such great friends to help find erasers. She had even moved BJ to a different seat in the classroom (picking had become an issue for other students – not any more – regular ed English class by the way).



At first at Granny's house there was much concern when pencils about the house were missing erasers—then BJ explained---small price to pay for the wonderful results; no blood on sheets, under fingernails, on socks, and--just a look of relief on BJ that this is one of our problems--**solved**.

BJ's after-school provider, Miss Tara, said the new discovery was working well and that she could see such an improvement in stress level. Another great aspect to the erasers is the convenience. BJ just puts some in a plastic bag, keeps them in his pocket (**at all times**), and there they are when he gets anxious.

BJ explains that he works with the eraser until it has the "right feel". He wants to share his story with other kids with PWS so they might just try it and "**erase the picking**." ■

CHUCKLE CORNER

A Holiday Chuckle

Does Santa Claus have Prader-Willi syndrome?

Background: Through the centuries there have been numerous anecdotal accounts and written legend describing the physical and behavioral characteristics of the person called **Santa Claus**, aka St. Nicholas. As you will see in the following case study, there is a possibility that Santa Claus may have Prader-Willi syndrome.

Case report: Physical and behavioral characteristics are consistent across anecdotal reports. He always wears fur trimmed outer clothing "... from his head to his foot..." regardless of the ambient temperature. He stays awake all night, watching others while they sleep: "He sees you when you're sleepin'..." He has an absolute sense of moral judgment **for others:** "He knows if you've been bad or good..."Then he documents this by writing lists that he repeatedly checks for accuracy: "He's making a list, checkin' it twice, gonna find out who's naughty or nice...." Currently, he is described as having a pleasant disposition and a fondness for children of all ages. However, by earlier accounts his temperament was not always so congenial. He has held grudges for as long as one year, placing a lump of coal in a person's Christmas stocking instead of a small gift!

Unfortunately, there is nothing known about his family, pregnancy, developmental or medical histories. It is said that he is married, but there have been no children born to this union. He is thought to reside in a rural setting where he cares for animals; reindeer are among his favorites. He is employed in a workshop where his primary tasks are assembling toys from their component parts and packaging items for delivery. He has a long history of home invasions, he enters other's domiciles through the chimney, and once inside, he forages for milk and cookies.

Anecdotal accounts indicate that he has a fair complexion with white hair and blue eyes. He requires corrective lenses. References to his truncal obesity are legendary: "He was chubby and plump...a little round belly that shook when he laughed like a bowl full of jelly." He is also described to have small stature with reliance on alternative forms of transportation like ..."a miniature sleigh and eight tiny reindeer..." placing into question his exercise tolerance, his ability to ambulate even short distances, and his motor coordination. Frequently it is noted that he falls down the chimney "...with a bound." Despite his rough landings, he never appears to experience discomfort.

Results: The author has applied the Holm criteria (Holm et al, 1993) to a meta-analysis of reports describing **Santa Claus.** Based upon the information available, only 2 of the 8 major criteria are met: **hyperphagia and obesity** (HO). However, 6 of the 11 minor criteria are met: **hypopigmentation and ocular problems** (HO); sleep disturbance, short stature, small hands and feet, and behavior problems. His notorious, vengeful behaviors appear to have diminished with age, and generally, he is now regarded to have a pleasant disposition. Several supportive criteria are also met, including temperature instability/ insensitivity, **high pain threshold** and unusually good **object assembly skills** (HO).

Discussion: Although his genetic status may never be discerned, there is ample evidence that Santa Claus displays the physical and behavioral characteristics of Prader-Willi syndrome. (HO, HO, HO!) ■

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SPOTLIGHT ON

PWSA New England

by Andrea Glass

The Prader Willi Syndrome Association of New England (PWSANE) has made significant strides in its ability to advocate, educate, and be socially active. Both officers and members have spearheaded projects that have had tremendous impact on the New England PWS community. Members have helped the newly diagnosed, the child or adult in crisis, a family looking for residential or day placement, negotiation of our department of developmental disabilities services, medical and dental referrals, legal issues, security, and school referrals. Local connections give strength to all our members.

Having been a member for the past 16 years, I have seen the Chapter grow and prosper. Our current team of officer volunteers include President Eileen Rullo, Vice President Mary Raymond, Treasurer Peggy Forbes, and Secretary Cindy Wells. Eileen spends about five hours a week on Chapter business. Jarrod Wells maintains the pwsane.org website and facebook page. On a weekly basis the officers field phone calls and emails from parents seeking local information. The Chapter has members in Massachusetts, New Hampshire and Maine. Each state has different disability legislation, educational policies, housing opportunities, and financial resources. Since the officers are all from Massachusetts, the expertise of the Chapter mainly regards Massachusetts.

Both Eileen and Mary Raymond (VP) recently guided the efforts of a hired lobbyist to change the Massachusetts legislative rights of adults with PWS in our community. HB 78 which, if passed by the Massachusetts House and Senate, will list PWS as a qualifying diagnosis for adult services in Massachusetts. This effort is funded by several fundraisers including the Annual Walk for Prader-Willi Syndrome spearheaded by Jarrod and Cindy Wells each June in Borderland State Park and the Annual Hunter Lens Golf Tournament at the Back 9 in Lakeville, Massachusetts, sponsored by Lori and John Lens. Without these significant and highly energetic fundraisers the Chapter would not be able to pay for this important lobbying effort. These fundraisers bring our PWS families together to generate funds, increase awareness, and foster a sense of community.

The Chapter now co-sponsors with Latham Centers a 1 ½ day educational conference with nationally recognized speakers. The conference this past September had seminars by Dr. Linda Gourash, Dr. Janice Forster, Dr. Diane Stafford, Dr. B.J. Goff, and presentations from parents, residential staff and an occupational therapist. The quality of this conference compares with our National conference on every level. The cost to participants was partially offset with Chapter funds.

Through the years there have been parent sponsors of holiday festivities, picnics, horseback riding, swim parties, indoor playground parties, and sibling workshops. The Chapter has hosted dances, holiday parties and parent meetings and dinners. As part of the national PWS community, many of our members have been parent and educational mentors to others. Information is shared via facebook, webpage, email, phone calls and meetings.

Several years ago Sandra Strazzulla, one of our New England parents, had a goal to establish a Prader-Willi medical clinic in Boston. We had not had a clinic since Dr. Robert Wharton passed away. She organized a clinic at the Franciscan Hospital in Brighton, Massachusetts. The clinic, which runs every 3 months, has an endocrinologist, a geneticist, physical therapist, orthotics, nutritionist and psychiatrist.

According to the current Board, the Chapter has many issues to tackle in the future, including advocacy/awareness, standards for care in residential placements, crisis support, research, housing and growth hormone for adults. The Chapter makes donations of wish list items to residential facilities, National, and has raffled trips to the National conference. For more information regarding the PWSANE, contact any of the officers whose contact information is on the www.pwsane.org website. ■

The best part of the season is remembering those who make the holidays meaningful.

We wish you all the love and happiness this season can bring, and may it follow you throughout the coming new year.

WE REMEMBER

Ethan's mom, Rhonda Cottrell, writes:



Ethan was diagnosed with PWS when he was first born. He would light up a room when he walked in. Ethan had scoliosis and was treated at Shriner's Hospital in Chicago. The staff was wonderful and loved Ethan. Ethan was two years old. He was a quick learner with a beautiful smile. Ethan loved everyone. He had GI issues for almost five months. On Dec. 22, 2012, Ethan was having breathing issues. He took his last breath in my arms. Once we got the autopsy report back we found he had lesions of bowel obstruction. What took his life was that his small intestines twisted and caused a blockage. There was no way of saving his life. It was something that happened suddenly and quick and it does not happen over time.

I owe a big thanks to Little Surf and Sand Daycare a big thank you for taking the time to allow Ethan to be part of their daycare. Mrs. Sonya Andre, the owner, contacted me and told me she could take on the difficult task to provide care to my son so that I could keep my job. She was the only person that was willing to do it, and she loved Ethan like he was her own child. She never treated him any different than any other of her daycare children. She was willing to learn everything she could about Ethan having PWS.

Ethan loved his sister Riley and enjoyed playing with her. She loved being a big sister to her little brother. We love and miss him so very much. He was my inspiration and my life. Such a big hole left in my heart. **We were able to donate Ethan's brain for research. We hope it will be able to give other families and researchers some answers on PWS.** ■

NOTE: A special thanks from PWSA (USA) and the researchers for the gift of Ethan's brain.

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

TRIBUTE TO MARGE WETT

I was saddened to hear of Marge Wett's passing. Muriel and I have the fondest of memories of Marge, who was always there with information that was unavailable anywhere else and was always willing to go the extra mile. If it were not for Marge and her encouraging words, I don't know how we would have survived those early years. We lived in New York City, and you would think that the best doctors at the best hospitals would be able to help. No one knew or could explain what it was that my daughter was suffering from. PWS was a unknown syndrome. Marge and the Association were our only hope and source of information that gave us hope. God bless you, Marge, for all those years of sacrifice for our children.

~ Harry Persanis, New York

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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. ■

Due to the increased activities within our organization and important information regarding research and support that we want to share with all of our readers, we struggle with limited space in *The Gathered View*. Therefore, we have discontinued publishing a list of our donors – for whom we are eternally grateful and with whom we will continue to acknowledge and communicate on a personal level – and without whom our association might not survive. We thank you for your support and dedication to PWSA (USA) and the individuals, families and all those involved with PWS that we serve.

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PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

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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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Note: If you have difficulty logging in, please contact info@pwsausa.org.

E-mail Support Groups:
We sponsor nine groups to share information.
Go to: www.pwsausa.org/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; June 1; Aug. 1; Oct. 1

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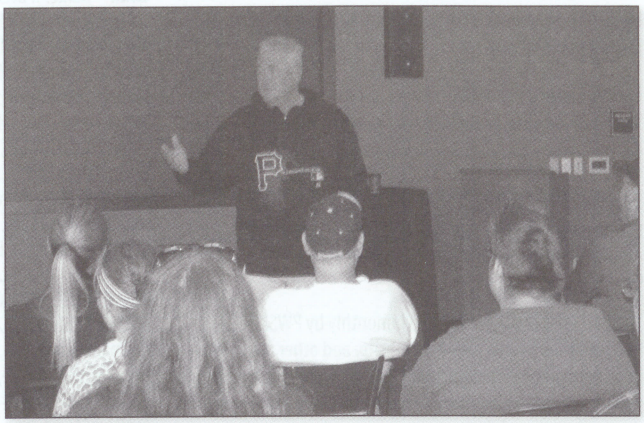
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Clint Hurdle "Brings it Home"

In the summer of 2011, Clint Hurdle, manager of the Pittsburgh Pirates baseball team, national spokesperson for PWSA (USA), and father of Maddie, age 11 with PWS, held a Meet and Greet for Pennsylvania chapter families before one of the games. During his talk to them he said, "I will bring it home to you, I promise."

Fast forward to 2013! The Pirates had their first winning season in 20 (yes, 20!) years, finishing with 94 wins, sending five players to the All-Star Game, beating the Cincinnati Reds in the wildcard playoff, and going 2-2 in the division series against the St. Louis Cardinals until losing in the fifth game. The discouragement that the 'Burgh baseball fans felt during those 20 drought years was gone.

Pittsburgh is filled with delighted, re-energized fans, waving the Jolly Rogers skull and crossbones flags and wearing Pirate gear. Thank you, Clint, for your unfailing optimism, inspiration and encouragement that has helped to bring the team and the city to this. And thanks, too, for bringing those same qualities to those who, like him, struggle with the daily issues of PWS. ■



Quotation contributed by Clint:
"Those who are lifting the world upward and onward are those who encourage more than criticize."
~ Elizabeth Harrison, 1849-1927, Educator

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