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

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

Twenty Questions

By Lisa Peters, Georgetown, Massachusetts

Happiness is the longing for repetition.
~Milan Kundera

Children diagnosed with Prader-Willi syndrome often experience repetitive patterns of speech. They will focus on certain words, phrases or conversations and use them over and over again. Experts claim this is part of the obsessive/compulsiveness tendencies associated with the syndrome.

For my son Nicholas, it is a tool he uses to feel secure and gain a tiny bit of self control over a life ruled entirely by thoughts of food. I believe that folks diagnosed with PWS feel overwhelmingly repressed by the tyrant appetite that rules their every thought...every moment of every day.

As a parent of a child diagnosed with this syndrome, it is difficult to answer the same line of questioning, again and again. It requires a superhuman level of patience that can only come from the unconditional love a parent has for their child who is suffering.

When my son was born, I was educated about this and other aspects of the syndrome. I wondered about this bizarre symptom and how I would withstand a constant barrage of repetitive questions from my child. Could I handle the same questions asked over and over again...for the rest of my life? My stomach ached as I thought this sounded like a lifetime of hell to me. I questioned my ability to be a good parent to my son.

It has been nine years since my son was born and diagnosed with Prader-Willi syndrome. In that time, we have developed some interesting lines of conversations. They go something like this...

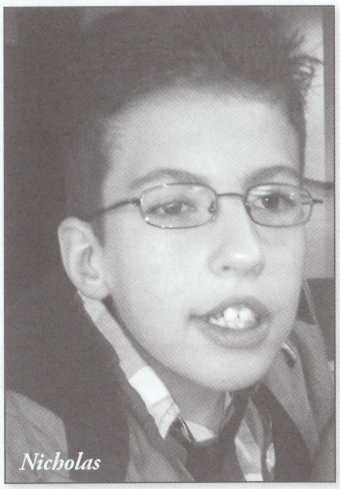
"Mom, did you have trouble putting the car into the vanilla house garage?"

(The "vanilla house" is a term Nicholas uses to describe a vacation house we visited on Cape Cod.)

"Yes, Nicholas, I did," I reply as I realize the game is officially on!

"Why was it hard to do?" he asks.

"Because it was a tight fit, wasn't it?" I answer.


Nicholas

"Yes, it was," he exclaims, now starting to smile brightly. On his face is a look of welcomed relief, like I have just started to scratch a bothersome itch that was slightly out of his reach.

"But you did it though!" he says proudly.

"Yes, I did it!" I answer triumphantly.

"Why was I able to do it?" I ask. I smile at my son, knowing exactly what is about to happen next. He is shining and almost bursting with torturous anticipation. Like a comedian waiting for the perfect timing to deliver his punch line, Nicholas answers....

"***Cuz, you're a good driver!***" He shouts, laughing hysterically. He is overjoyed and pleased with his expert ability to deliver his much-anticipated line on cue. He beams with pride, remembering his superhero mother's ability to maneuver a large vehicle into a small garage, a feat that seemed impossible to him. Our familiar dialogue about this event comforts him. His eyes sparkle as he looks at me with love, seemingly thankful for my willingness to indulge him in his blinding passion for sameness.

Although this routine gets very old for me, particularly when I am stressed, I also realize that my worst fears have been realized. I am superhuman, at least in my son's eyes. And although my life is indeed monotonous and hellish at times, it is also as if I am living in a world where I am the hero, the champion, the unconditional love of my son's quirky life, a person who is willing to empower him and acknowledge his

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In this Issue

Volume 37, Number 1 ~ January-February 2012 ~ Our 37th Year of Publication

Full Service

By David Crump
Interim Executive Director

Recently we received a thank-you from the mom of a 10-year-old with PWS. Although we have had contact with her numerous times since his birth, a little over a year and a half ago she contacted our support team again with several challenges looming--issues with her child's school and a critical health concern. Some family circumstances made everything more complicated.

That call would be the first of many to take place over the next eighteen or so months. Sometimes our team provided personal support and encouragement to the sobbing mom. Other calls were with the teachers and administrators of the school, advocating on behalf of her child. Another call recommended a doctor who has experience and expertise with the PWS-specific health issue her child was facing, and more calls helped make that connection and ensure that the proper follow-up care was provided. Medical resources were sent that she could give to their family physician. A consultant was also sent, in partnership with the local state chapter, to provide hands-on training for the school staff. This same consultant provided countless hours of follow-up after the training, reviewing IEP goals and objectives and talking sometimes weekly with teachers to answer questions and address new concerns.

Nearly two years later, this mom is feeling hopeful again. She writes, "I truly don't know how I would have made it through this most difficult year and a half without you. If you all had not been there with your support, expert advice, advocacy and guidance we may have made the wrong medical decision and my child would very probably have been out of school. We thank you all from the bottom of our hearts for all you have done for us!"

Serving as Interim Executive Director the last few months, I have gained a deeper appreciation for all that this organization does. I believe that stories like the one shared above best express the *feeling* of what PWSA (USA) is about.

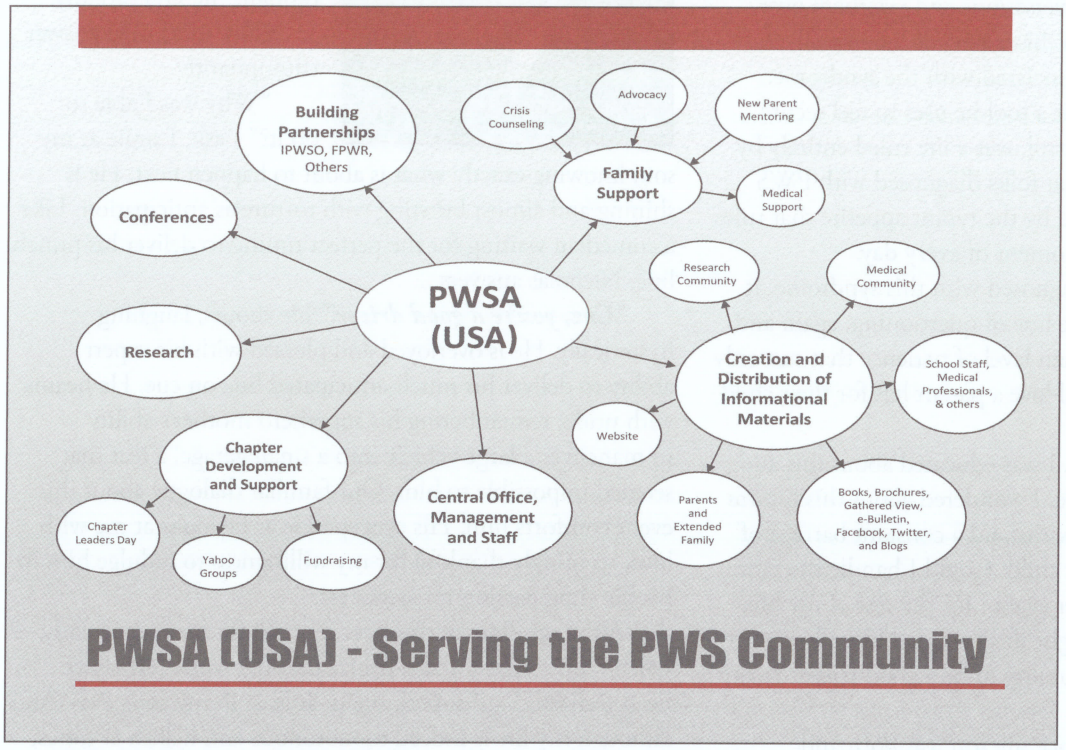
I am a relative new-comer to PWSA (USA) but I have come to think of the Association as a *full-service organization.* Besides **working with state chapters** to build local connections, communication webs and awareness, we also provide a whole range of services most appropriately accessed at the national level. There are the **direct family support services**, like the ones highlighted in our story. There are **conferences** –large, family conferences like the one held last fall, as well as smaller, more focused research conferences (another conference on hyperphagia (the hunger drive) is already in planning for 2012).

David Crump

And **research**! It's in our logo: "*Still Hungry for a Cure*!" PWSA (USA) is committed to research, funding thousands of dollars in research grants each year. Currently we are supporting five grants focused on the hunger drive.

Resources! The Association is recognized as the largest repository of up-to-date resources and information on PWS in the world: books, brochures and packets, a website packed with information, DVDs, write-ups in *The Gathered View* newsletter, as well as technical and professional articles.

Several resources have been revised and updated this past year, including a brand new Second Edition of the *Growth Hormone and Prader-Willi Syndrome* book. There are materials for Moms, Dads, and grandparents, as well as for professionals, including doctors, school officials, residential program staff and others. **We are *full service***, as our



mission says: "to enhance the quality of life of each person affected by Prader-Willi syndrome."

I overheard someone say that they don't care about organizations; what is important to them is the PWS community. I agree wholeheartedly about the central place of our community. That is why we exist! If there were no PWS community there would be no need for a PWSA (USA). In my way of thinking, our Association is critical, because without PWSA (USA), the services, resources and research we provide would not exist for our community. In interviewing folks for the "This is My Association" videos (see www.thisismyassociaton.org), one question asked how their lives would be changed if there were no PWSA (USA). Over and over, the responses were similar: "I would be lost;" "I don't know what we would do for our child;" "We would feel so alone."

Almost four decades ago, a small group of families and professionals met and decided to create what eventually became the Prader-Willi Syndrome Association (USA). Since then the Association has grown in its mission of serving the PWS community. We are here for you and we are here because of you. So I invite and encourage you to take advantage of what PWSA (USA) has to offer. Do not hesitate to contact our staff at 800-926-4797 or at info@pwsausa.org. This is *your* Association, and we are here *for you*! ■

Our Wonderful Volunteers

By Denise Servais

Volunteers are at the heart of many organizations, and PWSA (USA) is no exception. In this issue we highlight two very special volunteers, John Butler and Ann Seigel. Both have been volunteering at the national office for 13 and 10 years, respectively. They help out as needed, from putting packets together for mailing to folding brochures. Both work once a week for six months when they are in Sarasota. The other six months of the year John lives in Scottsburg, Indiana, and Anne lives in West Hartford, Connecticut.

John reported volunteering for the organization because he has two grandchildren with PWS—Lindsay, 28, and Meghan, 25. In 1998 he discovered the national office in Sarasota and met with Janalee. He started taking care of the maintenance needs of the office. Anne says that she came across the PWSA office while walking down the street one day and remembered something about PWS from her days as a special education teacher. She stopped in the office and asked if they needed volunteer help and was told yes!

John, originally from Indianapolis, moved with his wife Mary 10 years ago to Scottsburg. They have four children, 12 grandchildren, and a new great-grandson. John worked for 34 years at Ryerson Steel as a maintenance leader. Anne, a Brooklyn native, and her husband have lived in West Harford for the last 45 years. She was a special education teacher before she retired. She has also spent many years involved in a national organization that focuses on helping people with learning disabilities. She became interested in special education when her son was diagnosed with Asperger's syndrome.

When asked what they like best about volunteering, both commented on how friendly the office staff was and that they felt good about volunteering for such an important cause.

Thank you, John and Anne, and to all the other volunteers, who give so much of their time. You are greatly appreciated! ■

Twenty Questions, *continued from page 1*

desperate need for structure…*without any questions.*

As I am lost in this thought while writing this post, I hear a tiny voice over my shoulder say…

"Mom, did you have trouble putting the car in the vanilla house garage?"

And so it begins again…

Satisfaction lies in mindful repetition, the discovery of endless richness in subtle variations on familiar themes.
~ George B. Leonard

May is Prader-Willi Syndrome Awareness Month. To learn more about PWS or to make a much-welcomed donation, please visit www.pwsausa.org.

To read more about our family adventures, please visit our blog at: www.onalifelessperfect.blogspot.com.

Presentations at the 25th Annual PWSA (USA) Scientific Meeting in Orlando, FL – Nov 2011

The 2011 Scientific Co-Chairs

Merlin G. Butler, M.D., Ph.D.
Kansas University Medical Center, Departments of Psychiatry & Behavioral Sciences and Pediatrics, Kansas City, KS

Jennifer Miller, M.D.
University of Florida, Department of Pediatrics, College of Medicine, Gainesville, FL

Keynote speakers:

Maïthé Tauber, M.D., Ph.D., *Toulouse, France spoke on* *"The French Reference Centre for PWS and Pertinent Endocrine Issues in PWS"*
Cary R. Savage, Ph.D., *Kansas University Medical Center spoke on* *"Functional MRI studies in PWS and Obesity"*

Following are the titles of all of the abstracts presented at our conference and the key results that I thought would be of interest to our lay audience readers. **In this issue is The Genetics Review and The Poster Review.** The March-April issue will include the Behavior/Neuropsychiatry Review and the Medical/Nutrition/Endocrine Review. The complete abstract booklet can be bought by calling the PWSA (USA) office at 800-926-4797 or emailing Cindy Beles at cbeles@pwsausa.org. The cost is $10 for members and $15 for non-members.

~ Janalee Heinemann

The Genetics Review

Phenotype-Genotype Correlation of Two Patients with de Novo Imbalanced Chromosomal Rearrangements Misdiagnosed as Prader-Willi Syndrome

M.A. Angulo, G. Blaber and M.M. Zak
Department of Human Genetics, Winthrop University Hospital, Mineola, NY, USA

Introduction: We report on the 17-year old female and a 27-year old male with distinctive facies, intellectual disabilities, hypotonia, short stature, initially diagnosed at another institution with Prader-Willi syndrome (PWS) at the age of four and seven years respectively, based on chromosomal analysis and clinical picture. They had poor growth velocity associated with excessive weight gain, temper tantrums related to food and mild mental retardation.

Conclusions: Our findings suggest that patients with partial trisomy 14q32 or monosomy 2q11 can be easily misdiagnosed with PWS during early childhood, however, the typical features will change during adolescence. Utilization of new genetic tools accompanied by genetic counseling is imperative in appropriate diagnosis of these microduplication/microdeletion syndromes and may aid in predicting associated characteristics and medical management.

Mechanism of MBII-52 and MBII-85 snoRNA Processing

Marina Falaleeva, Manli Shen, Justin Surface and Stefan Stamm
University of Kentucky, Lexington KY, USA

Introduction/Background: MBII-52 and MBII-85 RNAs are localized in the Prader-Willi critical region and have all canonical sequences elements of C/D box snoRNAs. A crucial difference between conventional C/D box snoRNAs and MBII-52 and MBII-85 is that the later are further processed into smaller RNAs that we termed psnoRNAs for processed snoRNAs (1,2). Recent analysis of high-throughput sequencing data indicate that a large number of

C/D box snoRNA expressing units give rise to metabolically stable fragments of snoRNAs, suggesting that psnoRNAs represent a large class of new RNAs (3).

Conclusion: The Prader-Willi critical region expresses predominantly processed snoRNAs, not canonical C/D box snoRNAs that associate with different proteins and have different functions in gene expression. psnoRNAs share the importance of C/D boxes, k-turn motif and intron release with canonical snoRNAs. They differ in their dependency on proper intronic localization and their subnuclear localization. They are not dependent on components of the miRNA pathway and most likely the result of RNase actions.

Molecular Function of psnoRNAs Derived from HBII-52 and HBII-85 Expression Units

Marina Falaleeva[1], Justin Surface[1], Manli Shen[1], Pierre de la Grange[2] and Stefan Stamm[1]

[1]University of Kentucky, Lexington KY, USA; [2]Hopital Saint Louis, IUH, Centre Hayem, Paris, France

Introduction/Background: C/D-box small nucleolar RNAs (snoRNAs) are small, non-protein coding RNAs that have been mainly implicated in 2'-O-methylation of pre-rRNAs in nucleoli. SnoRNAs found within Prader-Willi region (MBII-52 and MBII-85) do not posses binding sites for rRNA and their function is poorly understood. We showed that RNAs from these C/D box snoRNA expressing units are further processed into small RNAs that we called psnoRNAs (processed snoRNAs). In contrast to canonical snoRNAs, psnoRNAs associate with common hnRNPs and have different function in gene regulation.

Conclusion: Our results indicate that MBII-85 and MBII-52 derived psnoRNAs regulate the expression of multiple RNAs, consistent with their association with a syndrome. The deregulated genes are enriched in biochemical pathways regulating fat/energy metabolism, cell-cell interactions and signal transduction. The strong influence of psnoRNA overexpression on gene expression further underlines that these RNAs have different function of canonical C/D box snoRNAs. Transfection experiments indicate that MBII-52 and MBII-85 act synergistically on some RNA targets, which should be taken into account for the design of rationale therapies.

Direct Cloning of Double-Stranded RNAs from RNase Protection Analysis Reveals Processing Patterns of C/D Box snoRNAs in PWS Critical Region and Provides Evidence for Widespread Antisense Transcript Expression

Manli Shen[1], Eduardo Eyras[2], Serene Josiah[3] and Stefan Stamm[1]

[1]Department of Biochemistry and Molecular Biology, College of Medicine, University of Kentucky, Lexington, KY, [2]University Pompeu Fabra, Catalan Institution for Research and Advanced Studies, Passeig Lluis Companys, Barcelona, Spain, [3]Shire Human Genetic Therapies

Introduction/Background: The Prader-Willi syndrome is likely linked to the loss of expression from the maternally imprinted small nucleolar RNA (snoRNA) SNORD116 (HBII-85) in the PWS critical region. As an orphan C/D box snoRNA, the biogenesis and biological function of SNORD116 still remains largely unknown. Similar to the downstream snoRNA SNORD115 (HBII-52), SNORD116 also contains tandemly repeated copies and is processed into shorter RNAs (psnoRNAs). In order to further understand this snoRNA, we cloned the processed snoRNAs from one SNORD116 expression unit using a newly developed technique to directly clone dsRNAs from RNase Protection Assays

Conclusion: The data suggest a conserved processing pattern for PWS critical region C/D box snoRNAs and abundant expression of longer, non-coding RNAs in the cells that can potentially form dsRNAs. The considerable conservation of the cleavage patterns of snoRNAs indicates that psnoRNAs are generated by a processing pattern and are not the result of random degradation. Thus, the data show that the PWS critical region gives rise to short processed snoRNA, not just canonical C/D box snoRNAs, which should be the target for therapeutic intervention.

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School student-sponsored "Spirit Week" Fundraiser in Greenville, South Carolina.

Loss of the Prader-Willi Syndrome Candidate Gene *Magel2* Impairs Leptin Signaling in Mice

Rebecca E. Mercer[1], William F. Colmers[2] and Rachel Wevrick[1]

[1]Departments of Medical Genetics and [2]Pharmacology, University of Alberta, Edmonton, Alberta, Canada

Conclusions: Our results demonstrate that *Magel2* is essential for the centrally-mediated anorexigenic effect of leptin on food intake *in vivo* and for the activation of anorexigenic neurons in the hypothalamus. This leptin insensitivity results in increased fat mass and reduced activity in mice lacking Magel2. Our data further suggest that loss of MAGEL2 contributes to increased fat mass, reduced satiety, and reduced voluntary activity in PWS. We hypothesize that Magel2/MAGEL2 is an adaptor protein within an intracellular signaling cascade in subtypes of hypothalamic neurons, including neurons that are normally activated by leptin. We propose that defective leptin signaling in hypothalamic neurons mechanistically links the severe obesity present in individuals with leptin receptor, SH2B1, or MC4R mutations with obesity and lack of satiety in Prader-Willi syndrome.

Supported by a "Big Ideas Grant" on Hyperphagia from the Prader-Willi Syndrome Association (USA).

Progress Report from the Prader-Willi Syndrome Research Strategy Workshop

Theresa V. Strong[1,2] Jennifer Miller[3], Elisabeth M. Dykens[4], Rachel Wevrick[5], Merlin G. Butler[6], Janalee Heinemann[7] and Daniel J. Driscoll[3]

[1]Departments of Medicine and Genetics, University of Alabama at Birmingham, Birmingham, AL, [2]Foundation for Prader-Willi Research, Los Angeles, CA, [3]Departments of Pediatrics and Molecular Genetics & Microbiology, University of Florida College of Medicine, Gainesville, FL, [4]Departments of Psychiatry and Pediatrics, Vanderbilt Kennedy Center, Vanderbilt University, Nashville, TN, [5]Department of Medical Genetics, University of Alberta, Edmonton, Canada, [6]Departments of Psychiatry and Behavioral Sciences and Pediatrics, University of Kansas Medical Center, Kansas City, KS, [7]Prader-Willi Syndrome Association (USA), Sarasota, FL.

Introduction: *The Prader-Willi Syndrome Research Strategy Workshop* [November 15-17, 2009], brought together a diverse group of clinical and basic scientists to discuss the strengths, opportunities,

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Presentations, *continued from page 5*

gaps in knowledge, and resources needed to advance the science of Prader-Willi syndrome (PWS). Workshop participants focused on five areas of emphasis relevant to PWS: Emerging Clinical Issues, Obesity and Energy Balance, Mental Illness and Psychopathology, Molecular Genetics, and Animal Models. For each area, the current state of knowledge was reviewed, and basic and clinical research questions were prioritized. One overarching theme of the Workshop was the lack of uniformity in assessment of phenotypes in both animal models of PWS and patients. A strong need to develop standardized measures was emphasized.

Conclusion: Successful completion of these goals, and the development of additional targets and funding to expediently advance PWS research will be best achieved through the continued engagement of a broad array of stakeholders in this initiative.

The Poster Review

Biochemical and Molecular Characterization of the Serotonin Receptor 2C (HTR2c) Alternative Splicing

Manli Shen[1], Serene Josiah[2], Ronald Emeson[3] and Stefan Stamm[1]

[1]Department of Biochemistry and Molecular Biology, College of Medicine, University of Kentucky, Lexington, KY, [2]Shire Human Genetic Therapies, Lexington, MA, [3]Center for Molecular Neuroscience, Vanderbilt University, Nashville, TN

Introduction/Background: The serotonin receptor 2C is crucial for the control of appetite and energy balance. HTR2c-knockout mice develop hyperphagia and obesity and mice with altered serotonin 2C receptor RNA editing display characteristics of Prader-Willi syndrome. HTR2c transcripts undergo extensive processing in the region spanning the competing alternative splicing donor sites of exon5. The RNA then forms an extensive base-paired structure that is subject to RNA editing and regulation by the HBII-52 psnoRNA. Since the regulation of the serotonin receptor is influenced by a psnoRNA missing in PWS, we analyzed its regulation in detail with the aim to identify molecules that influence its processing and possibly influence appetite.

Conclusion: The alternative splicing of the HTR2c appears to be regulated by its structure, which can be influenced by drugs, suggesting a therapeutic avenue for PWS. It is possible that psnoRNAs derived from the HBII-52 cluster generally function by changing the structure of target RNAs.

Outcomes of Adenotonsillectomy in Prader-Willi Syndrome Patients

Stacy Meyer, Mark Splaingard, Kathyrn Anglin, David Repaske, Steven Chung, Joan Atkin, William Zipf and Kris R. Jatana

Pediatric Endocrinology, Pediatric Pulmonology/Sleep Medicine, Pediatric Genetics, Pediatric Otolaryngology-Head and Neck Surgery, Cincinnati Children's Hospital Medical Center, Ohio State University, Columbus, OH

Background: Due to reports of sudden death in children with Prader-Willi syndrome (PWS) on growth hormone, detection of sleep disordered breathing by polysomnography (PSG) has been recommended. However, there is limited data regarding the outcomes of upper airway surgical intervention in PWS patients.

Conclusion: We conclude that adenotonsillectomy, while effective in most children with PWS who demonstrate mild to moderate AHI, may not be curative in children with severe OSA. An increase in central apneas can occur in some PWS children post-operatively, and it is important to repeat PSG after upper airway surgical intervention.

The Australian National Prader-Willi Syndrome Database 2011

Elly Scheermeyer [1,2], Mark Harris[3] and Peter Davies[1]

School of Medicine, University of Queensland, Brisbane, Australia[1], School of Medicine, Bond University, Gold Coast, Australia[2], Diabetes & Endocrine, Mater Hospital, Brisbane, Australia[3]

In collaboration with the PWS subcommittee of APEG: P. Crock, C. Verge, G. Ambler, G. Werther, P. Bergman, J. Couper, C. Choong, M. Van Driel, P. Hofman, F. Frazer and I. Hughes

Introduction/Background: The national Prader-Willi syndrome (PWS) database was initiated to follow up children with PWS following endorsement of PWS as a specific indication for subsidised growth hormone (GH) treatment up to 18 years. The database aims to provide a reliable estimate of the Australian paediatric population and genetic subtype, collect prospective outcome and safety data of children on GH and looks at various endocrine aspects besides height and weight. This collaboration will facilitate meaningful assessments regarding quality of health interventions and research in the heterogeneous phenotype of this population.

Conclusion: The PWS database was successfully established with data on body composition and various hormone functions. Our incidence estimate has been refined. The database is continuously growing with the assistance and collaboration of the clinics and the Ozgrow team. Annual reporting and discussion with the team assists in identifying concerns and in optimizing care and best practice of managing PWS in Australia. ■

In the journal, *Current Genomics*, May 2011, the focus is "Genomics of Childhood Obesity" with the chair of PWSA (USA) Scientific Advisory Board, Merlin G. Butler, M.D., Ph.D. as the guest editor. Merlin wrote us the following:

"I thought you might be interested in our recent editorship of a special journal issue entitled "Genomics of Childhood Obesity" for *Current Genomics*. I identified several experts relating to this topic or theme to help in preparing this journal issue. You could consider this special issue as an 'off-shoot' of the 1st Hyperphagia Conference as some of the authors selected and topics presented were directly related to the conference and discussions. The conference allowed me to renew older but established relationships (Dr. Hagerman) and establish new relationships (J. Marshall) pertinent to the theme of genomics of childhood obesity. I came up with this theme after attending the conference and made the commitment of time (and energy) shortly afterwards to undertake this task." ■

Editors Note: Please read the announcement on the outside cover regarding the 2012 Hyperphagia Conference.

In-Patient Psychiatric Treatment and Weight Gain: Breaking the Cycle!

By Janalee Heinemann, PWSA (USA) Research and Medical Affairs

The following is an email I received from a mother. The situation is typical.

Hello Janalee,

I talked to you over a month ago about my son who was admitted to the psych ward, telling you how unhealthy and fattening the food was. It was a real struggle to get them to feed him less food, let alone anything healthy. He gained 9 pounds in about 10 days-- with me calling them daily, begging them to give him a healthier choice and monitoring his food access. I called the hospital administrator to intervene and explained that my son has a life-threatening condition. I then had you fax over a letter on PWS, and you told them it was life-threatening. If you hadn't have done that, I don't think they would have taken it seriously. It was still difficult as most of the staff hadn't read the fax and didn't seem to want to be bothered. It was one of the more horrifying experiences I have gone through. My son would tell me about the food he was given. One time it was potato chips for an afternoon snack. He told them he would prefer an apple. He was freely given brownies and snack foods you would never give someone with PWS. He would have probably gained even more weight if we had not continuously intervened.

The staff was rude to me and would hang up the phone because I was always asking them to take away food. In the afternoon they had rest time, when you go in your room and sit. One of the staff had told him to go to bed. This is after sitting all day with no exercise. This whole experience was such a nightmare. It will probably happen again. We've already been through this three times. There has to be a better way.

Thank You for all your help, Nancy

For several years we crisis counselors at PWSA (USA) have been frustrated with the dramatic amount of weight our people who have PWS gain when admitted to psychiatric units – in spite of how much information we give the hospital staff and forewarn them of the seriousness of weight gain for PWS. (It also happens during general hospitalizations but not as often or as dramatic.) In this last year, in spite of my position at PWSA (USA) and my14+ years of working with the syndrome professionally, plus providing information and meeting personally with hospital staff, it even happened with my own son; he gained a dramatic amount of weight in the two weeks that he was admitted to a psychiatric unit – weight that his supportive living staff is still trying to get off of him.

All such situations are difficult, and the weight gain is dangerous for our people with PWS. This was demonstrated in a call I received from a mom who had an adult daughter with PWS who died from a stomach perforation, presumably due to being allowed too much access to food in the psychiatric unit. Of course, now the hospital is being sued. What is it going to take for hospitals to take the dangers of food access and overfeeding with PWS seriously?

To add to the problem of the actual weight gain is the reality that when our people with PWS are in this situation and get much more food than typically allowed, they are then motivated to try to get back into the psychiatric unit!

So how can we begin to break this destructive cycle? The following are suggestions from our crisis counselor, Evan Farrar:

With information. Go to our web site at www.pwsausa.org, and in the medical section get the article, "*Medical Alert for Inpatient Care*". Also, have some extra copies of the PWSA Medical Alert book set aside to share with staff at the facility.

With advocacy. Advocate yourself, but also enlist the support of others. Talk to your child's medical provider(s) in advance to make sure they understand you will need them to contact the facility directly if your child is admitted. This type of doctor-to-doctor communication can make a big difference in breaking through the wall of resistance some facilities present. Also, are there others who could advocate for your child's needs? A counselor? A Chaplain? A Case Manager? The more voices expressing concern about food security and other PWS-related issues, the more likely it is the message cannot be ignored. The key is to have these folks ready to advocate as soon as you need them, and that requires advance planning.

With training. Do some research to find out where in your area it is likely your child might be taken in the event of a psychiatric emergency. Find out who is in charge! Make sure to get them information about PWS, and offer an in-service training for staff. PWSA (USA) can help you with resources to use such as the DVD "Food, Behavior and Beyond". This will help you to build relationships you can utilize if your child becomes a patient of the facility. If this task seems too daunting to take on yourself, maybe your local chapter can work together to educate and train facilities in your area.

With PWSA (USA) support. Remember to call us if your child is admitted to a psychiatric facility. We can fax or e-mail helpful information directly to the unit so that information about food security and behavior is delivered promptly. We find facility staff are often more willing to listen to parent concerns when they know that an outside agency like PWSA (USA) expresses concern and monitors the situation.

With perseverance. We can't give up on this important issue. This is a hard cycle to break, but working together we can make a difference facility by facility which – in the end – will help people with PWS across the country who find themselves needing psychiatric care at an in-patient facility. ■

National Conference 2011

By Andrea Glass

I'm sure you will enjoy all the photos from the Orlando conference (for more, go to www.pwsausa.org/conference/2011). Both the kids and older adults had a great time in the Survivor Camps. As a parent whose PWS child had a really difficult time at the last Orlando conference, this conference was such a relief. As I peeked in on my son in the YAP program, I saw him giggling, full of energy and engaged. I sure would like to see that all the time! The Survivor camps kept the YIP/YAP and Siblings busy from 9-4:30 each day and gave them a great party on Saturday night. My son was the one asleep at the table by 9:00 Saturday night as the party went on around him! Sound familiar?

The conference sessions were excellent as always. The wealth of information was truly incredible. I always say that if I take home just one useful PWS management idea from a conference then it was definitely worth the trip. There were sessions which addressed every stage of life. I particularly took away two new strategies for dealing with my darling 16-year-old. And did I mention, the new friends from around the country with kids who have the same issues as my kid. Amazing!

Here's a few highlights of what the conference attendees are saying about the sessions:

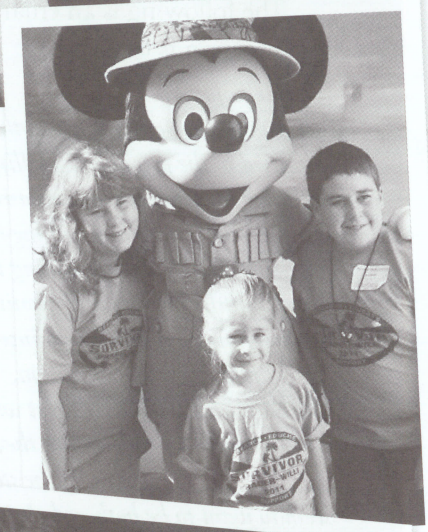
Keynote Speaker, Clint Hurdle: "Loved that he spoke to the Dads in the audience, telling them to let go of their egos." Clint also talked about the importance of fathers listening to their wives' feelings—and expressing their own.

'Food and Behavior': "Excellent session by Dr. Gourash that gave me a new perspective."

'Growth Hormone': "Dr. Miller really opened my eyes as to the importance of growth hormone".

'Faith': "Took comfort in knowing we do not struggle alone."

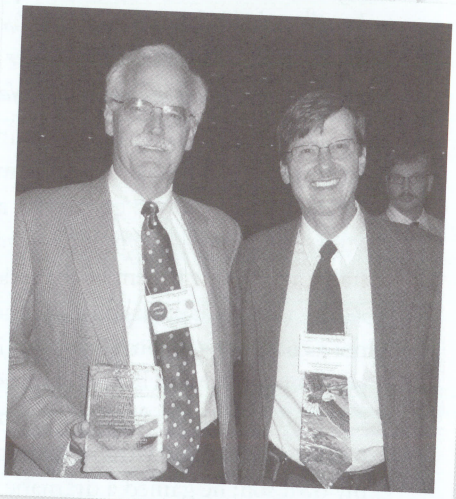
'Sensory Integration': "I always get new ideas from Janice Agarwal that I can use right away." ■



Nicole Burns, who has PWS, presented Janalee Heinemann and John Heybach with a gold gift box with $1500 inside in checks for PWSA (USA) which she raised making jewelry.

First row, Conference attendees from South America. Back row, Linda Gourash, Joan Gardner, and Janalee Heinemann.

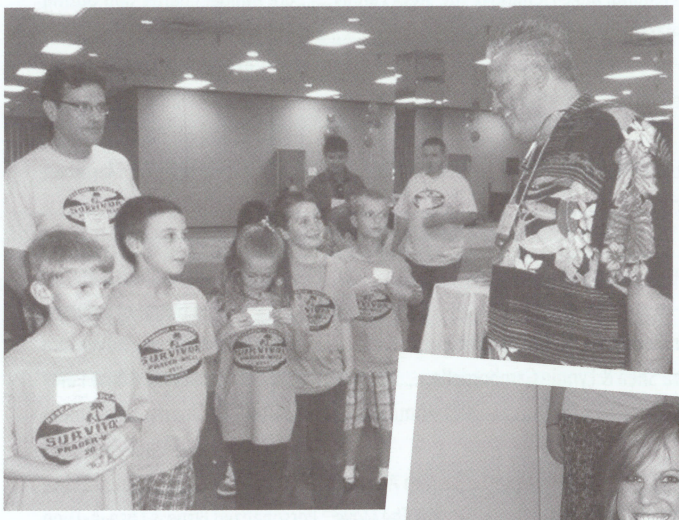
Barb McManus and Clint Hurdle with volunteers from The Villages. Approximately 179 volunteers serviced the YIP, YAP and Sibling programs, plus provided AV support, worked at registration and in the store. An army of very generous folk!



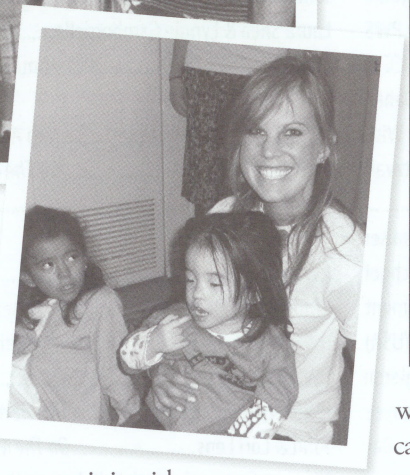
Jim Kane, who received a Lifetime Achievement Award, with Dr. Merlin Butler. Joan and Jim Gardner also received this award.

"Survivor" tribes in their colorful T-shirts perform for closing ceremonies

Janalee met with Moms from Alaska - they want to start a chapter!



Clint Hurdle, Keynote speaker with "Survivor" tribe.



ATTENDEE	COUNT
Aunt/Uncle/Relative	27
Exhibitor	22
Gala Only	40
General	5
Grandparent	34
Parent	289
Physician/Scientist	42
Professional Provider	81
People w/PWS	133
Sibling	50
Student	2
Volunteer	179
TOTAL	**904**
Scientific day	93

Over 900 people attended, from 44 states and 10 different countries!

A GRANDPARENT'S VIEW

Being the grandparent of a 2-year-old with PWS, my objective in going to conference, as it is with all things concerning Madeline, is to support her parents in whatever I can do to make life better for them and her. I was delighted to see that the message I heard was consistent among all the presenters.

Most of the sessions I attended dealt with behavior issues. I learned that most of the families attending these annual conferences have children from about 6 to 16, and this is their most pressing concern. I learned that most children with PWS have high anxiety over just about everything, and this leads to behavior problems when they don't know what to expect each day. Having an exact and unchanging schedule where they know exactly what is going to happen, when it will happen and that it does happen exactly as planned can lessen behavior issues. Of course, there is much more to it than that, but it was a consistent message from the presenters.

The other important and beneficial time I spent was in talking to people with PWS and their families. I met other families from as far away as Brazil and Japan.

I learned much and came away with much I can share and hopefully make a difference in Madeline's life and the lives of other families in Texas dealing with PWS. I highly recommend that if you have not been to a national convention that you consider going to the next one. There was something there for everyone. ■

Joel W. Crenshaw, Grandparent
Treasurer, Texas Prader-Willi Association

Fundraising

By Jodi O'Sullivan, Development/ Communications

It's time to get moving and start planning your **Prader-Willi Syndrome *On The Move*SM** event this May! The campaign, now in its second year, promotes movement-based activities that make others aware of PWS while funding state organizations and the PWSA national association. That means the more events there are, the more people know about our syndrome. Don't wait to make a difference. Call your PWSA state chapter or the national office (800) 926-4797). PWSA (USA) has many resources for you to make it great, including an ***On The Move*SM** Information Packet, event guides, and personalized online registration and fundraising website option. Visit www.pwsausa.org for more information. Now move! ☺

Before we move further into the new year, though, PWSA (USA) wants to gratefully acknowledge the many event organizers and their committee members who threw memorable events in 2011 for PWSA and those who supported them. We cannot highlight every person and fundraiser in *The Gathered View*, but we do want to recognize them*. If you know someone below, remember to thank them and consider following their lead with a fundraiser of your own. PWSA does more with your help. Thank you! ■

Prader-Willi Syndrome MOVE On The Move

NAME	EVENT
Mike & Lori Kuna; Tina Kuna, Living the Dream Foundation	Cruiser Bike Ride
Tracey & Bart Lombardi	Caring for Cole
Lisa Thornton and fundraiser supporters	Light a Candle - Be a Light for PWS
Hillarie Van Zanten	Thirty One Gifts Fundraiser in Honor of Emerson Parker
	Jewelry fundraiser in Honor of Nichole Burns & Suzanne Burns
David Chirico	Illustrated Properties Benefit In Honor of Cameron Wallace
Lori Guthrie	Lori Guthrie's Birthday Wish for Anna Kathryn
Michelle Torbert & PWFA	3rd Annual Casting for a Cause Fishing Tournament
Eileen Higgins	Round Table Pizza Fundraiser in Honor of Donovan Higgins
Palmer Trinity Private School	Shred Your Threads for Prader-Willi Syndrome
Barbara McManus	Weight Loss for PWS
The Nursery School Children	Rosenthal JCC of Northern Westchester Fundraiser in Honor of Brandon Dahan
Sybil Cohen	Sybil's Birthday Wish
Susan Fisher & Aaron Carvajal	Aaron Carvajal's Bar Mitzvah
Ms. Susan J Kirkham's class, University of Wisconsin-Oshkosh	University of Wisconsin Oshkosh Fundamentals of Speech Fundraiser
Fran Baehr	Awareness Month Bracelet Sales at the West Babylon School
Kerry Headley	1st Annual Jay Headley Memorial Golf Tournament
Michele Shingleton & Shawna Bush	5th Annual Walk-a-thon for PWSA (USA) in Honor of Carter Shingleton
MasterBrand Cabinets, Inc.; Marsha Stallings	MasterBrand Employee Dress Down Day
Sherry Reeves	Joe's Pizzeria Fundraiser in Honor of Lexie Reeves
Allison Bartelstone	Fundraiser in Honor of Makenna Lamb
Dominique DeLeage	Putt for PWS
Thomas and Valeris Jornlid	Charity Pumpkin Patch
Chris Dingley	Hartford Marathon Road Race for PWS
Karen Gill	Dancing Waves 2011 Summer Camp in Honor of Gavin Gill
Nikki Oplie	Grayson Oplie's 10th Birthday
Eileen Higgins	Eileen Higgins PWS Fundraiser
Lisa Tucker Pollard	Lisa Tucker Pollard's Birthday Wish In Memory of Julie Michelle Tucker
Emily Sprague & St. Paul's Catholic School	St. Paul Catholic School Dress Down Day for PWS
The Private Foundation of Maryland	PWS Pool - March Madness

NAME	EVENT
Bill Fleming, Mike Fleming & The Steck Family	6th Annual Charity Golf Outing
Margaret Hoese & Dorothy Morse	2nd Annual Mahjongg Tournament in Honor of Roxy Peterson
Karen Mrad & Mary Fava	Macy's "Shop for a Cause" in Honor of Joseph Dominic Frazier
Christine Mazzella	Diva 1/2 Marathon
Kerry Sexton & Robin Grey	Kerry Sexton 1st Annual Charity Tennis Tournament in Honor of Chase Grey
Cynthia Wilson & Justin Loeb	PWSA Oliva Restaurant Fundraiser in Honor of Emerson
John Boughton & April Boughton	Great Ohio Bicycle Adventure
Laura Shea & Lynnie Gambordella	Tea for a Cure Party
Clint & Karla Hurdle	2011 Annual Golf for PWSA (USA) Charity Tournament in Honor of Madison Hurdle
Kevin & Christie Bevacqua	8th Annual Jack Martin Bevacqua Dinner-Dance
Al Heinemann	*On The Move*SM Personalized Fitness Lose-A-Thon
Maureen O'Neil	An*On The Move*SM Supporting Fundraiser! Clifton IHOP PWS Donations Display Wall
PWSA IL	*On The Move*SM PWSA IL Chapter Support
Prader-Willi Florida Association & Michelle Wallace	*On The Move*SM Family Fun Day to Cure Prader-Willi Syndrome
PWSA MI	*On The Move*SM Walk for PWS
PWSA WI	*On The Move*SM PWS May Awareness Walk-A-Thon
John & Lori Lens	*On The Move*SM 2nd Annual Hunter Lens Golf Event
Navigon Financial – Josh Self, Lauren Horst & Matt Greenan	*On The Move*SM Still Hungry for a Cure 5K/10K/Fun Run
Cindy Szapacs	*On The Move*SM PJ Whelihan's Dine & Donate for PWS
PWSA IN	*On The Move*SM PWS 5K Walk/Fun Run
PWSA MN	*On The Move*SM 2011 PWSA of Minnesota Move-A-Thon
Stephanie Daale & Stacy Kramer	*On The Move*SM 5th Annual Anneke Kramer Softball Tournament & Silent Auction
PWSA GA	*On The Move*SM 7th Annual Clyde's Run in Memory of Clyde Mays
Amy Tenbrunsel	*On The Move*SM Walk and Roll for PWS
Bobbi and Dino Martello	7th Annual Softball Tournament in Honor of Madison Hurdle

**As of this printing. We make every effort to be accurate and apologize for any omissions or errors. If you notice an error, please tell us.*

PWS: Support & Research Go Hand-In-Hand

By Jennifer Bolander, Ohio

I want to remind our PWS community that it is to everyone's benefit to make sure our time, efforts, and fundraisers help *both* facets of the "support + research = progress" equation. Support for PWS families and individuals with PWS means more than funding research, and if the tide of fundraising swings more in the research direction, then support services may very well suffer.

What does this mean? **It means that, while the research projects go on and even after they finish, families and people living daily with the challenges and complexities of PWS still need assistance. This in turn means that PWS organizations which have developed quality-of-life projects and support services still need funding. Just as research projects do not happen for free, support programs also have a cost.**

Here are four examples of situations where a parent or caregiver to an individual with PWS needs assistance and support:

- Families/caregivers need support when a medical crisis arises and the ER staff at their local hospital needs immediate and focused information about how to treat an individual with PWS who is presenting with hard-to-understand symptoms.
- Families/caregivers need support when their school district staff, and/or their child's specific teacher, knows absolutely nothing about PWS. The situation can then become quite difficult for the parent trying to advocate for their child.
- Families/caregivers need support when an adult with PWS, who may be a family member or a client, is manifesting new, extremely challenging behavior patterns and/or health issues.
- Parents of a newly diagnosed child desperately need helpful and hopeful information – which is provided in the Packet of Hope – not just the overwhelmingly negative information they get on the Internet.

These are just four very basic examples of the many calls PWSA (USA) responds to daily. Thousands of families need usable information day-to-day that is provided by PWSA (USA) and the state chapters. If we do not fund these support services, the person/organization that can be called upon in any of the above situations may disappear.

The research needs to continue – along with education of the medical/educational/caregiver communities, clarification and implementation of research results, quality-of-life supports, and support for those families in crisis. Without effective support programs, research happens in a vacuum. PWSA (USA) has been working steadily and effectively for many years in all of these areas. The state chapters of PWSA (USA) have been supporting and complimenting those efforts. I hope everyone remembers this: the fact that PWS research is being funded does not make the daily challenges of PWS suddenly disappear. **PWSA (USA), and the chapters of PWSA (USA), still need the consistent support, funding, and awareness-raising efforts of all those involved in the PWS community.**

Yes, research efforts are very needed and cost money. So do support services, awareness efforts, dissemination and implementation of research results, crisis support, etc. While the research continues, and one project leads to the next, families and caregivers will continue to need assistance and support in the day-to-day living of the PWS journey. The equation "support + research = progress." In our hunger for a cure, let's not forget to fund the first part of this equation. ■

WE REMEMBER

The Sept-Oct edition of *The Gathered View* had an article of tribute for our wonderful PWSA office volunteer of ten years, **Marcia Dunn**. We are very sad to report that Marcia died on Dec.19th. Marcia was also on our Angel card this year. Ten years ago her grandson, Aiden, was diagnosed with Prader-Willi syndrome, and she was diagnosed with leukemia. In spite of the years of treatment and caring for her husband who had Alzheimer's, she volunteered every week she was not hospitalized. Marcia always had a smile on her face and a kind word to say to everyone.

Albert Einstein said, "I believe we are here to do good. It is the responsibility of every human being to aspire to do something worthwhile, to make the world a better place than the one we found." Thank you, Marcia, for making the world of Prader-Willi syndrome a better place. We will miss her dearly and remember her forever.

Marcia is wearing purple and a red hat because she was a member of the Red Hat Society, but unlike the poem says, it suited her quite well.

When I am an old woman,
I shall wear purple with a red hat
that doesn't go, and doesn't suit
me....

By Jenny Joseph

When it comes to car safety – are your children heading in the right direction?

By Todd R. Porter, MD, MSPH, CPST

Despite the significant progress in preventing unintentional motor vehicle occupant injuries and fatalities, our society still has a long way to go in shortening the gap between child passenger safety (CPS) State laws and Best Practice. "It is important to note that every transition [from rear facing to forward facing to booster seat to seat belt] is associated with some decrease in protection; therefore, parents should be encouraged to delay these transitions for as long as possible. "[*Pediatrics* 2011;127:788–793]. Muscle tone is defined by the amount of tension or resistance to movement in a muscle. Given that children with PWS have low tone, they are even more susceptible to the mechanical forces on the body during a motor vehicle crash (MVC) and therefore will benefit from delaying each transitional stage as outlined below.

Stage 1: Rear Facing

Bright Futures, The American Academy of Pediatrics, and Safe Kids recommend that children 0- 2 years of age be restrained rear facing when riding as passengers in a motor vehicle. The recommendation is based on research by Henary et al (http://www.ncbi.nlm.nih.gov/pubmed/18056317?itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum&ordinalpos=7), which showed that children 12-23 months were FIVE TIMES less likely to be killed or seriously injured when REAR FACING compared to FORWARD FACING. Even greater side impact protection was noted in the REAR FACING direction.

The rear facing direction keeps the child's entire spine in line by spreading the crash forces evenly over the entire head, neck, torso and pelvis. In the forward facing direction, the child's disproportionately large head size and low tone leads to increased forces on the weaker neck muscle, ligaments, and spinal cord.

Selection:

Infants and Toddlers may be restrained rear facing in either an Infant Carrier or Convertible Car Seat until the upper weight or height limits set by the car seat manufacturer. The best car seat is one that fits your child, fits your car, fits your family budget, and one you will use correctly every time.

Stage 2: Forward Facing

Once the child exceeds the maximum rear-facing weight and height limits of the seat set by the car seat manufacturer, he/she can be turned forward facing. Research shows that in children 1-4 years of age, forward facing seats reduce injury by 80% compared to seat belts alone.

Selection:

A child can be restrained Forward Facing in a **Convertible Car Seat, Forward Facing Harness Seat**, or a **Combination Seat with Harness**. Safety Advocates recommend keeping the child restrained in a Forward Facing Harness Seat as long as allowed by the car seat manufacturer. Maximum weight limits of the harness system range between 40-85 lbs. Parents of children with PWS who have not reached the appropriate height to safely graduate into a belt positioning booster seat should strongly consider a higher weighted harness seat. A list of higher weight harness seats is available at http://www.hmhb-mt.org/docs/BoosterAlternatives.pdf

Stage 3: Belt Positioning Booster Seats

A booster seat uses no harness. It uses the vehicle's lap AND shoulder belts only. Be sure the seat belt is properly buckled. Safety Advocates recommend that once children outgrow their forward facing harness seat as set by the car seat manufacturer, they should use a belt positioning booster seat until they can pass the 5-Step Test. This typically occurs at a height of 57 inches (4 feet 9 inches). The 5-step test can be found at http://www.safekidsdenvermetro.com/userfiles/file/5steptest.pdf . Fifty-seven inches is the average height of an 11 year-old boy and girl so most children will need to use boosters past 8 years of age. If your child with PWS has not passed the 5-step test but exceeds the maximum booster seat weight set by the manufacturer, then you should contact a child passenger safety technician trained in restraining children with special health care needs.

Why aren't seat belts good enough?

Booster seats work by positioning the lap/shoulder belt over the bony structures of the child's pelvis and shoulder and not the vulnerable abdomen and neck respectively. Research shows that premature graduation into a poorly positioned vehicle seat belt can cause head, spinal cord, and abdominal organ injuries. Children age 4-8 years restrained in BPBS are overall 45% less likely to be injured in crashes than those restrained in a vehicle seat belt, while in side impact crashes they are 68-82% less likely to sustain injuries. One Australian study showed that children less than 12 years of age were 7 times more likely to suffer spinal cord injuries when restrained in a seat belt alone compared to children 12 years and older.

Selection:

Booster seats come in backless, high back, and combination seats. While there are many different brands of booster seats – not all provide the best fit. The Insurance Institute of Highway Safety recently released a review of Better Fits to Not Recommended. Please review this site before considering your next purchase. http://www.iihs.org/research/topics/boosters/default.html

continued on page 13

Contributions

Thank you for Contributions in October and November 2011. 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.

Major Benefactors ($500 and more)

Sam P. Alterman Family Foundation Inc.
Anonymous
Thor and John Berg
Christie and Kevin Bevacqua
Suzanne Cassidy, M.D.
Dana Coit
Russell and Jane DeFauw
Disability Rights Florida
Expert Flood Examiners, LLC
GA Assoc. for PWS, Inc.
Jim and Joan Gardner
David and Judy Gordon
Richard and Sharon Greene
Tim and Carol Hearn
Janalee and Al Heinemann
Bob and Mary Hill
Hope for Children Foundation NJ, Inc.
Johns Hopkins School of Medicine
Johnson & Johnson/CitiGroup Employee Giving Program
Lori and Darrin Kerbs
Stephen and Michele Leightman
Liberty Mutual Surety
Mercy Academy
Jeff Moore
Martin Niehaus
Pfizer, Inc.
PW Alliance of NY, Inc.
PWSA of Colorado
PWSA of New England
Sandoz, Inc.
Jamie and Andy Schoenberger
Laura Shea
TEQ Instruments Corp.
Greg Cherpes, M.D.
The Little Farm
Torbert Produce, Inc.
Truist
United Way Westchester & Putnam, Inc.
University of FL Health Science Center
VFW 2179 Ladies Auxiliary
Michelle and Brian Wagner
Winthrop University Hospital
Woods Services, Inc.

Car Seats, *continued from page 12*

Stage 4: Adult Size Seat Belt

Once the child passes the 5 Step Test they are tall enough to use the vehicle lap/shoulder belt in that vehicle. It is well proven that when used correctly, seat belts reduce the risk of fatal injury to front-seat passengers by 45% and the risk of moderate-to-critical injury by 50%.

Location and Installation

Safety advocates recommend that all children 12 years and younger ride in the **back seat**. Research has shown that restraining the child in the back seat reduces the risk of injury and death by 40%. Risk reduction in injury and death was greater when a passenger airbag was present. Approximately 80-90% of car seats are improperly installed. Safety advocates strongly recommend having the child and seat inspected by a NHTSA trained Child Passenger Safety Technician. To find one in your location please go to www.seatcheck.org/ . This should be done with the transition between each Stage of car seats or purchase of a new seat. ■

PWSA (USA) is announcing a new funding grant cycle for research on Prader-Willi syndrome

Prader-Willi Syndrome Association (USA) is pleased to offer grant assistance for researchers with an interest in improving the lives of those with Prader-Willi syndrome (PWS). PWSA (USA) is seeking to fund projects for a maximum of $75,000 total for a two-year grant that is aimed at discovering and developing treatments, cures, and technologies benefiting those with Prader-Willi syndrome. Grant application deadline is March 6, 2012. For more information go to www.pwsausa.org . ■

The Prader-Willi Alliance of New York, Inc. is planning its 22nd Annual conference on April 27th & 28th, 2012 at the Best Western Hotel on 1228 Western Avenue, in Albany, New York.

This year New York State is once again facing difficult budget choices, but the needs of people with Prader-Willi syndrome (PWS) will not be decreasing along with funding. Our theme, "Working Together to Shape the Future" emphasizes the collaborative working relationships that professionals and parents need to develop to keep making progress for people affected by PWS. ■

CHUCKLE CORNER

On the night before she was to begin first grade, I sat next to my daughter Hailey's bed and began reminiscing about how far she had come from that tiny infant we had brought home six years previously. I talked about how I couldn't believe that the next day she would be starting the first grade. With tears in my eyes I looked at her and asked, "How did you get to be so big?" She looked back at me with her beautiful blue eyes and responded in a matter-of-fact tone, "A lot of shots, Mommy."

~ Kimberly Postal

Contributions
continued

Thank you for Contributions in October and November 2011. 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.

In Memory of

Catherine Armstrong
Will Dishong and Angela Shelley
Tedd Rosenfeld

Lynn Billedo
Rosanne Hutson

Serafino Centrella
Claire and Ed Beslow
James and Pamela Cammon

Alan Cox
Virginia Moore and Melanie Brown
Janice Colvin
Betty Cox
George Cox
Dennis Smith Family

Lola Downs
Laura Beddini
Lori Brannin
Allan and Frances Mac Eachern
Maureen McDonough
James and Anne McGlame
Race Brook School PTA
Mary Shaw
Joseph and Jayne Young
Lorraine Young

Mildred S. Fabio
St. Ferdinand Church
Friends of Millie Fabio
Mike and Debbie Fabio
Arctic Refrigeration Co. of Batavia, Inc.
Barbara and Joseph Wolf

Harriet Frances Girard
Joyce Mullane

Dawn Elynne Gotoh-Stevens
Rev. Michael and Judy Christian

Jay Headley
Janalee and Al Heinemann

Marjorie Henderson
Diane Dragunas
Arthur Ratka

Grace Mina Navalta
Elizabeth and Richard Randolph

Mary Neil
Betty Cox

Lois Noonan
Jeff Moore

Austin Cody Outlaw
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Christine and Robert Amos
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Will Shannon
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Isabella Stahl
Janice and Keith Stahl

Patricia Weissman
Audrey Frischer

Henry Charles Witt
Kathy and Donald Cavaliere

In Honor of (Honoree in bold)

Oliver Alden Barrett
Prudence and Tom Nelson

Nathan Bennett
Al and Deborah Carpenter

Rachel "Ray Ray" Cordosi
Mercy Academy

Brandon Dahan
Marcia Dahan

Abbi Rae Dove
Carol Wright

Aileen Fisher
LeAnn Scott

Gavin Gill
Barbara Doyle

Andrea Haller
Erich and Pauline Haller

Michael Lewis Harnden
Mary and James McCready

Madison Reilly Hurdle
Jamie and Andy Schoenberger

Maddi Kessinger
Goldman, Sachs & Co - Matching Gift Program

Alison Koerber
Chevron Humankind Matching Gift Program

Natalie Anne Kosmak
George and Rosemary Lynn Kosmak

Mackenzie Nevada Legerski
Terri Misseldine

Steve Leightman's Birthday
Anna Leightman

Mary Kathryn Logan
David Logan

Chloe Madison
Gene Hanamoto

Ramon Madrid, Jr.
Kelly and Patrick Gibbs

Gregory McCarthy
John and Florence McCarthy

Faith Morse
Christine Kalinoski
Robert and Gail Morse

Steven C. Neiger
Susan and Dennis Roubal

John "Jake" Pawulak
Susan Neal

Luke Ranieri
William and Barbara Ranieri

Judith Rivard
Judy Dobbs

Brett Rogers
Linda Steppe

Andrea's 40th Birthday
Dennis and Sharon Saacks

Katie Schuld
Valerie and Allan Schuld

Abbey Dolores Seelig
Dolores and Wendell Seelig

Serenity Sherry
Stacy Sherry

Jake Townsend
TEQ Instruments Corp.

Brian Weakly
Gary and Carolyn Weakly

Mary K Ziccardi
Dennis and Sharon Saacks

Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers.
PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to www.pwsausa.org/donate

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

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info@pwsausa.org
www.pwsausa.org

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.

Staff & Other Key Contacts

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Cindy Beles, Triage Advocate
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Evan Farrar, Crisis Counselor
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Gus Schrowang, Communications Specialist
Lin Sherman, Accounting & Systems Assistant
Michelle Torbert, Conference Chair
David Wyatt, Crisis Counselor Emeritus

Members Only: See our Web site, www.pwsausa.org, for downloadable publications, current news, current research and more. Limited to members only.
User Name: pwsamember
Password: support4u!
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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Deadlines to submit items to *The Gathered View* are: Dec. 1; Feb. 1; Apr. 1; June 1; Aug. 1; Oct. 1

October 17-20, 2012

2nd International Conference on Hyperphagia

Pennington Biomedical Research Center • Louisiana State University, Baton Rouge, LA

Sponsored by PWSA (USA) & Pennington Biomedical Research Center with support from FPWR

Join the top international scientists in the field of appetite research for a thought provoking program designed to:
• Expand your understanding of Hyperphagia • Generate points of contact and collaboration • Participate in setting the research agenda

We're hungry for a solution to obesity & appetite

ORGANIZING COMMITTEE:

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Dottie Cooper – Prader-Willi Syndrome Association (USA)

Tony Goldstone, M.A., MRCP, Ph.D. – Senior Clinical Scientist, Metabolic & Molecular Imaging Group,Imperial College London

Rashmi Gopal-Srivastava, Ph.D. – Director, Extramural Research Program, National Institutes of Health, Office of Rare Disease Research

Joan Han, M.D. – Unit on Growth and Obesity, National Institute of Child Health and Human Development, National Institutes of Health

Janalee Heinemann, M.S.W. – Director of Research and Medical Affairs-Prader-Willi Syndrome Association (USA)

Steven Heymsfield, M.D. – George A. Bray, Jr. Endowed Super Chair in Nutrition, Executive Director-Pennington Biomedical Research Center

James G. Kane, M.B.A. – Chair, Research Advocacy, Prader-Willi Syndrome Association (USA)

Ann Scheimann, M.D., M.B.A. – Assistant Professor of Pediatrics, Johns Hopkins University

Theresa Strong, Ph.D. – Professor of Medicine, University of Alabama, Birmingham

Jack Yanovski, M.D., Ph.D. – Section Chief- Unit on Growth and Obesity, National Institute of Child Health and Human Development, National Institutes of Health

For more information contact
James G. Kane
t: 1-410-321-9788

NOTE: There will also be a 26th Annual Scientific Day and a Care Providers Conference in conjunction with the Hyperphagia conference.