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

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

Aging in the Adult with Prader-Willi Syndrome – A Focus on Physical and Cognitive Health

By Barb Dorn, R.N., B.S.N., Verona, Wisconsin and Lizabeth Moser, M.S.W., L.C.S.W., Oconomowoc, Wisconsin

(This is the first in a series of three articles about aging in adults with PWS.)

As adults with Prader-Willi syndrome (PWS) grow older, we are learning more about some of the common health issues many are facing. Researchers are starting to investigate the aging process in persons with PWS. It can be challenging to distinguish between health concerns that are inherent to PWS versus concerns that we all face as we age. Family history is also contributory to many health concerns and must also be considered.



Jeff, 48

This article will highlight some of the more common physical and cognitive health issues being identified by researchers as well as professionals who are working with this aging population. According to Eiholzer and Lee (2006), some of the main medical problems being reported in adults with PWS include physical disability (resulting in mobility issues), respiratory insufficiency, osteoporosis and scoliosis. The major cause of overall death in adults with PWS was respiratory insufficiency triggered by acute or chronic lung infections – not cardiopulmonary disease as originally hypothesized.

During the 2010 International Prader-Willi Syndrome Organization conference in Taiwan, researchers from The Netherlands shared findings from their study of 102 adults with PWS ages 18-66 years. Sinnema, Maaskant, et al. reported a majority (56%) were obese. In addition, the following health conditions were common: leg edema (56%), erysipelas - an acute streptococcal infection of the skin (38%), constipation (38%), diabetes mellitus (17%), osteoporosis (16%), pneumonia (14%) and hypertension (9%). There was also a high incidence of psychiatric episodes.



Kate, 43

According to Rena Mills, R.N., Health Services Coordinator for Prader-Willi Homes of Oconomowoc (PWHO), which provides residential services to over 80 adults with PWS, premature aging seems to be a concern. By the time their residents are 40, many have medical problems like those who are 60. Mills also identified many of the same health problems as mentioned above – osteoporosis/osteopenia, constipation, intestinal blockages, pneumonia, diabetes, cellulitis, low sodium levels and high/low blood pressures.

Changes in cognitive function are also being examined to determine if the early onset of dementia may be an additional concern for adults with PWS.

Studies have shown that adults with Down syndrome (DS) are more likely to develop Alzheimer-type dementia than their peers without DS (Silverman, Zigman, Krinsky-McHale & Schupf, 2008). Still other research suggests the prevalence of dementia in adults with intellectual disabilities



Dallas, 43

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(ID) who do not have DS is higher than the general population (Strydom, Chan, Fenton, et al., 2010). What does this mean for aging adults with PWS?

In March 2009 the *State of Science on Dementia in older adults with Intellectual Disabilities* reported, "aging and cognitive functioning has been studied in so few of the ID syndromes other than DS." Sinnema and her research team from The Netherlands contributed to this critically-needed knowledge base with their 2010 case study of a 58-year-old woman with PWS. The resulting assessment scores supported the presence of dementia.



Jean,48

PWHO currently supports 27 (33%) individuals with PWS in their 40s and 2 (2%) in their 50s; one woman was diagnosed with dementia at age 54. An assessment procedure was developed to measure cognitive changes as they age, so the possible onset of dementia can be detected and early treatment implemented. This data will also be a future resource for understanding how aging influences the cognitive process in PWS.

Knowing what physical and mental health issues are common allows us to initiate preventive measures and plan appropriately for future care needs. The second article in this series will focus on five of the most common health issues being seen in aging adults with PWS along with strategies to prevent and/or minimize their effects. The third will focus on dementia research, assessment and treatment. This collaborative series will provide insight into how aging affects adults with PWS and the approaches to help to ensure they can remain healthy, productive members of their communities. ■

Medical and Research View

Ask the Professionals

Q: Are miscarriages more common in moms who have a child with PWS?

A: One in five recognized pregnancies spontaneously abort and about 50% are due to a chromosome abnormality, most commonly an aneuploidy or chromosome number problem in the embryo or fetus with triploidy accounting for 10% of those chromosome abnormal cases. Each miscarriage increases the likelihood of another miscarriage and with two miscarriages the risk for a third miscarriage is close to 40% and 50% when having three miscarriages leading to a fourth. In summary, miscarriages are common and once a miscarriage history is established there is increased risk of additional miscarriages. Their OB doctor can explain this, or if they want additional information and workup, a genetic evaluation may be warranted.

Merlin G. Butler, M.D., Ph.D., F.F.A.C.M.G.
Chair, PWSA Scientific Advisory Board; Kansas University Medical Center

A: I agree with Merlin's comments. Also, it is well documented that people who have had a problem are much more likely than those who have not to respond to surveys or questions and to remember adverse events. In order to see if this is really an association, it would be necessary to do this prospectively—or at least have a comparison group, such as people who have had a child with an abnormality that is not due to a chromosome problem, but perhaps a single gene defect. However, it is certainly worth keeping our ears open for an increased risk of miscarriage.

Suzanne Cassidy, M.D.
PWSA Scientific Advisory Board; University of California

Q: Several women have reported that they had polyhydramnios while pregnant with their child who has Prader-Willi syndrome. Is this to be expected?

A: Fetuses swallow the amniotic fluid, and if hypotonic and swallowing problems are present in the fetus (as in the infant with PWS), then the fluid may accumulate. So I suspect there would be some risk for polyhydramnios in PWS pregnancies. The fetuses and placentas with maternal disomy 15 originating from a trisomy 15 conceptus may cause placental dysfunction which could potentially contribute.

Merlin Butler, M.D.

Q: Can Risperidone cause hypothermia in PWS?

A: Possibly. Risperidone is one of the second-generation antipsychotics (SGAs). Use of SGAs or so-called atypical antipsychotics is becoming more frequent because they have fewer side effects than the first generation agents, and they have mood stabilization effects as well. However, hypothermia induced by atypical antipsychotics is a rare adverse effect that may present with mild to severe symptoms. One recent study suggests that antipsychotics that block serotonin-2 receptors (5-HT2) more than dopamine-2 receptors (D2) might have a higher risk of hypothermia. Most of the newly developed "atypical" neuroleptic drugs belong to this group. Therefore, special attention for hypothermia is warranted during the use of "atypical" neuroleptics such as Risperdal and Geodon. Finally, it should also be noted that episodes of hypothermia in persons with PWS have been reported in the absence of any medications, and this condition requires prompt medical evaluation.

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Ask the Professionals, *continued from page 2*

Janice Forster, M.D.
Pittsburgh Partnership
PWSA Clinical Advisory Board

Q: How is a child's dose of GH determined?

A: For infants, the dosing is based on body surface area (1 mg/m2/day is the typical starting dose), whereas older children's doses are typically calculated based on weight alone or ideal body weight if the child is significantly overweight. For adults, there are standardized dosing regimens for beginning adult growth hormone, and the dose is then subsequently titrated based on IGF-1 levels. For children, most endocrinologists adjust the dose by monitoring growth velocity, weight, and IGF-1 level and using a combination of this information to decide when doses need adjusting.

Jennifer Miller, M.D.
PWSA Clinical Advisory Board; University of Florida

Salivary Flow and Oral Abnormalities in Prader-Willi Syndrome

By *Ronnaug Saeves[1], Hilde Nordgarden[1], Ivar Espelid[2], Kari Storhaug[1]*
[1] TAKO-centre, Lovisenberg Diakonale Hospital, Oslo, Norway; [2] Department of Pediatric Dentistry, University of Oslo, Norway.

Presented at the International Prader-Willi Syndrome Organisation 7th Scientific Conference May 20-21, 2010, Taipei, Taiwan

INTRODUCTION: Persons with Prader-Willi syndrome (PWS) have sparse, thick and sticky saliva. High caries activity, poor oral hygiene and extreme tooth wear have been described in case reports. Oral and dental problems have received little attention by researchers. The aims of the study were to examine salivary flow rate and describe oral and dental characteristics in Prader-Willi syndrome.

METHODS: Fifty-one individuals with PWS, aged 5-41 years, and an age and sex-matched control group were examined with regard to salivary flow rates, dental caries experience, gingival inflammation, enamel defects and tooth wear. Both unstimulated and chewing stimulated whole saliva as well as taste-stimulated parotid salivary flow rates were measured. The presence or history of dental caries was evaluated both clinically and on radiographs. Tooth wear was evaluated according to a 4-point scale, the Jonkoping index. An individual tooth wear index (I_A) was created on the bases of the scores of incisal or occlusal wear for each tooth.

RESULTS: The average flow rate for unstimulated saliva (UWS) was 0.12±0.10 ml min^{-1} for individuals with PWS compared with 0.32 ± 0.20 ml min^{-1} for controls ($p<0.0001$). Chewing stimulated flow rate (SWS) was 0.41±0.35 ml min^{-1} for the PWS group compared with 1.06±0.65 ml min^{-1} for the control group ($p<0.0001$). Taste-stimulated parotid saliva was not found to differ significantly between the persons with PWS and healthy controls. There was no significant difference in caries experience in the primary dentition. Caries experience in permanent teeth (persons >18 years) was higher in the control group ($p=0.04$). The median GI-index (gingival inflammation) was significantly higher in the PWS group compared with the control group ($p=0.04$). The number of surfaces affected with enamel defects was 3.5(1.0-8.8) in the study group and 4.0(0.5-7.0) in the control group ($p=0.76$). The median tooth wear index I_A was 7.5 (0-100) in the PWS group and 2.2 (0-10.7) in the control group ($p<0.0001$)

CONCLUSIONS: Low whole salivary flow and tooth wear are very common in individuals with PWS. Taste stimulation may increase salivary flow rates in this group. The oral hygiene in the studied population with PWS was generally poor but the dental caries experience was not increased. This may reflect a low sugar diet and tight follow-up regimes. ■

Fluoride In Our Water

By Dr. Thomas Hughes, DDS
Wisconsin General Dentist and Parent of Sarah w/PWS

The recommendation changed from an average of 1.2 parts per million to .7 ppm of Fluoride in the water with the maximum now being 1.2 ppm. Most local water supplies were at 1.0 parts per million of Fluoride before this. As for people who have Prader-Willi syndrome, normal drinking water with Fluoride is fine. Parents need to watch what is in bottled water because most have no Fluoride and that can lead to more decay. Because of the diminished salivary flow, people with Prader-Willi need at least the minimum of Fluoride to protect their teeth, not less. ■

For more dental care information, go to our website www.pwsausa.org, click on Medical, and go to Dental Tips and Tricks.

Genetics Research Report

Microdeletion/microduplication of proximal 15q11.2 between BP1 and BP2: a susceptibility region for neurological dysfunction including developmental and language delay

Rachel D. Burnside; Romela Pasion; Fady M. Mikhail; Andrew J. Carroll; Nathaniel H. Robin; Erin L. Youngs; Inder K. Gadi; Elizabeth Keitges; Vikram L. Jaswaney; Peter R. Papenhausen; Venkateswara R. Potluri; Hiba Risheg; Brooke Rush; Janice L. Smith; Stuart Schwartz; James H. Tepperberg; Merlin G. Butler

The proximal long arm of chromosome 15 contains imprinted genes or genes that act differently whether they are received from the mother or the father. Loss of the imprinted genes located on chromosome 15 in the 15q11-q13 region expressed only from the father causes Prader-Willi syndrome (PWS) unusually due to a deletion. This deleted region is flanked by either of two proximal breakpoints, referred to as BP1 or BP2 and a distal breakpoint (BP3). The larger PWS deletion involves breakpoints BP1 and BP3 referred to as Type I and the smaller deletion involves breakpoints BP2 and BP3 referred to as Type II. Clinical and behavioral differences have been reported in those individuals with PWS having either the Type I or the Type II deletion. The Prader-Willi syndrome chromosome 15 deletion includes about 7 to 8 million DNA base pairs of the DNA molecule which contains the genes. The distance between BP1 and BP2 is approximately 500,000 DNA base pairs and includes four different genes (*NIPA1, NIPA2, CYFIP1, GCP5*). Reports of mutations or disturbed expression or activity of these genes appear to impact on behavior and neurological function in affected individuals. Recently, reports of deletions and duplications of genetic maternal flanked by BP1 and BP2 suggest an association with speech and motor delays, behavioral problems, seizures and autism.

We studied approximately 150 subjects with small deletions or duplications of the chromosome region between BP1 and BP2 only containing the four genes. The subjects did not have PWS. These individuals were referred for specialized genetic testing including microarray analysis. Clinical data were available on the majority of these individuals with duplications and deletions of the chromosome region between BP1 and BP2 and common findings were observed. These included developmental, motor and speech delays and neurological and/or behavior issues specifically autism, hyperactivity and tantrums. Therefore, our report to be published in the journal, Human Genetics, with Dr. R. Burnside as the first author confirmed that microdeletions and microduplications of the proximal 15q11.2 region between breakpoints BP1 and BP2 may be associated with neurological dysfunction including development and language delay. The chromosome region between BP1 and BP2 appears to be a susceptibility region for autism and behavioral disturbances. ■

Explanation of Imprinting Defects

By Daniel J. Driscoll, M.D., Ph.D.

There are three main molecular classes in PWS: deletion, maternal uniparental disomy 15 (UPD) and imprinting defect. Imprinting defects only account for about 1-3% of individuals with PWS. There are 2 types of imprinting defects: epimutation and imprinting center (IC) deletions.

Epimutations account for 85% of the imprinting defects and have a very low recurrence risk (i.e., less than 1% chance of recurrence) in a family. IC deletions account for 15% of the imprinting defects. Approximately 50% of the IC deletions are *de novo* (i.e., not inherited) and they have a low recurrence risk as well. However, about 50% of the IC deletions are inherited from an unaffected carrier father. In this case the recurrence risk is 50%. Thus, it is important to determine the type of imprinting defect (epimutation vs IC deletion) an individual has and if it is a familial mutation.

Testing for an IC deletion should only be done in an experienced lab and every family should have genetic counseling so that they fully understand the risks of recurrence. Prenatal diagnosis is available, but it would also have to be done in an experienced lab and arrangements should be made before or early in pregnancy. ■

VOLUNTEER GRAPHIC ARTIST NEEDED!

Have you wondered how you can help PWSA (USA) from the comfort of your home? Do you have talent and experience in the area of graphic arts and would like to assist with updating some of our publications and brochures? If so, we have the perfect opportunity for you. To volunteer or obtain additional information, please contact Julie Doherty, Co-Chair of PWSA (USA)'s Publications Committee, at jdoherty88@yahoo.com. ■

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

Executive Director View



Evan Farrar

A new focus of the collaborative partnership between PWSA (USA) and the Foundation for Prader-Willi Research (FPWR) is to work together on advocacy issues so that the PWS community can speak with a more united voice about the concerns of the people and families we serve. I've asked Amy Porter, a unique advocacy resource for the PWS community, to share her thoughts on the importance of advocacy. A devoted aunt to a niece with PWS, she also is Chief of Staff for Congressman Ed Royce of California. She has been instrumental in promoting legislative concerns for people with PWS, including congressional authorization for designating May as PWS Awareness month. I hope that her words will inspire you to make contact with your local elected officials. If we can help, please let us know!

~Evan Farrar

As a Congressional aide in Washington (D.C.) for the last 16 years, I can assure you that constituents can and do exert influence on their members of Congress. The degree of influence varies significantly, however, and is really a function of time and effort. Why do you need to know how to be an effective advocate to Congress? Why do you care? As the aunt of a child with PWS, I can tell you that there are millions of reasons (and dollars) why you should want to get involved with your Federal government.

PWSA has been working to build and strengthen their relationship with the National Institutes of Health (NIH) and its corresponding agencies. This relationship is important as it will have a significant impact on the amount of money that will be spent to research PWS specifically. Approximately 25 million people in the U. S. are affected by an estimated 6,000 rare diseases or conditions – and the NIH does not have the resources to study them all, nor does the Federal government. They do, however, spend millions of dollars a year to fund grants that focus research on some of these diseases and conditions.

"The squeaky wheel gets the oil" definitely applies when it comes to Congress and the distribution of research grant money. Groups and individuals spend thousands of hours and millions of dollars lobbying Congress to support their program or cause. Again, there are limited resources and unlimited needs, and in the end it often comes down to awareness and personal relationships. Awareness is important because a member of Congress is not likely to support a program or initiative that he or she has never heard of or knows nothing about. Personal relationships are important because they help to connect something foreign or abstract to someone, a person. For example, before my niece was born with PWS, I had never heard of it.

In the ten years that I have worked on the Hill, someone may have come in to talk to us – but if they did, it could not have been more than once and with no follow-up. I am sure of that because I am aware of many other diseases and disorders that have been brought to my attention by persistent constituents, family, friends and co-workers. Notice two things about this statement – persistence and "relationships".

Granted, it is easier to build strong relationships with some members of Congress and harder with others. The same can be said for staff. However, even in the tougher cases, you can be effective by being persistent and making an effort.

Does calling your Congressman really make a difference? The answer is "yes" and "no." Making one phone call to advocate for more research for funding for PWS, or writing one letter, will get you entered into the database along with the thousands of other constituents who have called or written about an issue. However, if you are calling to support a specific piece of legislation or a specific funding request, your call will be added to a list of other calls in support of the same. The longer the list, the more significant your support becomes.

More important than calling or writing, however, is going to visit your Congressman. You don't have to come to Washington to do that. In fact, it's often easier to get on the schedule in their District offices. It may take you a while, but you will get in. In some cases, the office may offer you a meeting with a staff person. Take the meeting! Members of Congress are overwhelmed with responsibilities and rely heavily on staff. Don't underestimate the value of developing a relationship with a staffer.

Use that first meeting to introduce the Congressman/woman to PWS, and briefly explain to them what problems are faced by individuals and families with PWS. Share a personal story; introduce them to your child. Let them know that NIH is doing some research, as well as some private institutions. Tell them that you will keep the office informed of any legislative initiatives that come up with respect to PWS. Finally, continue to build that relationship. Many members hold "Town Meetings" or symposiums to hear from their constituents. Take the time and go. After six months has passed, call to make another appointment. Continue to write periodic letters to remind them of your continuing concern.

Finally, remember that most members of Congress truly want to know their constituents and what is important to them. Approach them as if you want to know them as well, and build a long-standing relationship with them. The more relationships that we will build, the brighter future we can offer our loved ones.

~Amy Porter

Call for Nominations for PWSA (USA) Board of Directors and Volunteers for Committee Service

The source of PWSA (USA)'s strength lies in its membership - parents, extended family members, professionals, and others committed to promoting research, education, and support for families affected by Prader-Willi syndrome.

We are currently seeking candidates for the 2011-2014 Board of Directors and volunteers for Committee service. Please contact us if you or someone you know possesses the qualities necessary to be an effective member of the Board of Directors:

- Ability to listen, analyze, think clearly and creatively, work well with people individually and in a group.
- Membership in PWSA (USA).
- Commitment to serve a 3-year term (unless nominated to fill a shorter term).
- Willingness to attend Board and committee meetings and other special events. Ask questions, take responsibility for a given assignment, support the Association as generously as your financial resources allow and assume shared responsibility for generating resources to meet Association goals, open doors in the community.
- Develop skills you don't already possess such as understand financial statements, cultivate and solicit funds, cultivate Board members and other volunteers.
- Possess honesty, sensitivity to and tolerance of different views; a friendly, responsive, and patient approach; community-building skills; personal integrity; a sense of values; concern for the Association's development; a sense of humor.

What will you gain in return for your service?

- A sense of pride as you work to better the lives of all persons affected by PWS.
- Have input into decisions and policy-making that affects persons with PWS.
- Increase your knowledge about PWS and its treatment and management strategies
- Increase your exposure to professionals who work with individuals with PWS.
- To nominate yourself or someone else, please contact Leadership Development Committee Co-Chairs Lisa Graziano or Mary K. Ziccardi via the PWSA (USA) office at 800-926-4797 or 941-312-0400 or pwsausa@pwsausa.org or by fax to 941-312-0142. **The deadline for nominations is Friday, June 10, 2011.** ■

Wedding Bells!



Many members of the Prader-Willi syndrome family with fond memories of Jeanne Hanchett, M.D., will be happy to learn of her marriage on April 17 to Dr. Phillips P. Wedemeyer, another retired and widowed Pittsburgh physician. Best wishes to them for many years of happiness!



Jeanne was for many years the Medical Manager of the PWS/Behavioral Disorders Program at The Children's Institute in Pittsburgh. Even after she retired, she continued her interest in PWS with a monthly clinic. She also served on both the PWSA (USA) Clinical and Scientific Advisory Boards and was a participant in our national conferences. Her late husband, Dr. Jim Hanchett, a nephrologist, was also active with PWS issues until his fatal heart attack in 2003. ■

CHUCKLE CORNER

When John Heybach told his son Conor, who has PWS, that he was now on the PWSA (USA) board and he was going to the board meeting, Conor said, "Well don't goof it up, this is important!"

~John Heybach

Best Practices Guidelines for Standard of Care in PWS

Edited by Janice Forster, M.D., Pittsburgh Partnership, PWSA (USA) Clinical Advisory Board
Published by Hubert Soyer, PhD and Norbert Hodebeck-Stuntebeck

As caregivers, parents, educators, and health professionals that care for a person or persons with PWS, we are fortunate to have a new groundbreaking guideline and standard of care manual. The International PWS Organization (IPWSO), with delegates from 81 member nations, has created a must-read for everyone. Inspired by the vision and memory of Pam Eisen (past IPWSO President), PWS caregivers from around the globe gathered in Germany for two conferences to create a global standard of care and best practices model.

The book includes highly technical, thorough presentations and abstracts as the basis for workgroup discussions. There were 13 workgroups that completed a Best Practices Guideline in each discipline. It was accepted that PWS cuts across so many different aspects of the biological and behavioral sciences that no one person can have all the knowledge. This is an important realization for anyone who cares for an individual with PWS! Those who face the daily challenges of giving people with PWS the opportunity to develop their full potential and live a good life now have an amazing resource.

Over 30 people contributed to the final documents, including group home administrators, educators, parents, and medical professionals. The guides were developed by each group to represent a collaboration of best practices in each aspect of caring for a person with PWS throughout their life. The workgroups developed the following guidelines for best practices:

Adult living environments. The debate over whether persons with PWS should live with only others with PWS. A recipe for a PWS group home.

Communicating with people with PWS. Strategies to deal with speech and language deficits, cognitive rigidity, and emotional dysregulation.

Neurological, psychological, and cognitive aspects of behavior. Strategies and interventions for the best possible outcomes.

Fitness, sports and motivation. Types of exercise and motivation techniques.

Training for teachers. Dealing with the typical types of behaviors seen in the classroom and the PWS learning profile. Creating a smoother day and maximum learning.

Nutrition. The "Red, Yellow, Green" system. Special problems providers face when instituting diet plans.

Crisis management. How a crisis evolves, how to manage it, and how to avoid it.

Communication between caregivers and family. Trust and honesty in the relationship is key.

Environmental structure of work. Individuals need the proper emotional and behavioral supports to be successful in a work environment.

Psychological aspects of PWS. The psychologist can play a major role in the care of persons with PWS.

Interpersonal relationships. How to facilitate the development of interpersonal relationships.

Behavior management. Specific crisis and behavior management methods. A collaboration of more than 57 participants.

Environmental structure for living. Optimal success depends on the supports in place.

Medical checklist. Individuals with PWS should have a checkup each year.

The conferences were made possible through a grant from the Alfried Krupp von Bohlen und Halbach-Stiftung. This book, dedicated to the memory of Pam Eisen, is a new "must read" for all those who care for a person(s) with PWS. Thank you to all the participants and contributors. It is truly an amazing work. ■

~ Reviewed by Andrea Glass

PWS BEST PRACTICES GUIDELINES

Created by the IPWSO Caregiver Conferences Over Two Years in the Making

Presentations, Abstracts and Guidelines representing standards of care in over 80 nations.

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Over 200 pages, this breakthrough guide is for all caregivers, parents, teachers and health care providers. Features Guidelines and Models developed for use across all environments where people are caring for individuals with PWS.

Sultan in Kazakhstan

[This letter is addressed to Giorgio Fornasier and Janalee Heinemann because of the connection with IPSWO]

Dear Friends,

My name is Kairat. I am Sultan's uncle and an older brother of Askar *[Sultan's mother]*. On Askar's request I am writing this message as a tribute to our dear Sultan.

Tuesday 2 Feb my nephew Sultan passed away at the age of 18. He had a rare Prader-Willi syndrome. His mental/emotional development had stopped somewhere at the level of 5-6 years old. We knew he would not live a long life but losing him at this time was heart breaking.

Often Sultan was difficult and very stubborn especially with regards to food. His grandmother and primary caregiver had many difficulties with him. However he was such a special child in a body of a giant. He had body of a bear but a heart of a deer. Sultan sincerely loved little children and animals. When sitting at a play ground he would start talking to children of 5-6 years of age and would be so happy if they would talk back to him. Other parents would be wary of "this huge body mass" talking to their children and would eventually take their children away. Sultan was very sweet and gentle but was lonely at times as he was not understood by many and at times by his own family.

Sultan had lived with us for 18 years and we all are grateful he has been a part of our lives. Without him our life would not be as meaningful and rich. We tried to care for Sultan with genuine support of you all as a wonderful international family helping families everywhere in the world to deal with the syndrome. There is no doubt we could have done better and Sultan would have lived longer. But we also know that Sultan had a gracious heart and he forgave us all for any inadequate care he received from us.



Sultan was a true believer in the forgiving and loving God of the Bible. He genuinely believed in the saving grace of the Lord Jesus Christ. During his last days he was probably close to 200kg. He would sometime say that when Christ returns he would be given a new slim body and would be able to run like other boys! His words were so special! He is surely with God now as he had been the most sincere believer of us all.

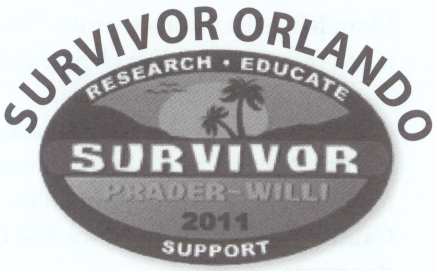
My mother has told me of his last moments before he died. The way he was getting ready to meet his end was amazing. This is having very serious impact on us. Sultan was to a serious degree both physically and mentally retarded but somehow he knew he was dying. He was so sweet asking God not to take him yet as he had not seen his newborn cousin yet (my daughter). As my mother was with him this night he asked her to call my sister (Sultan's mother) to say goodbye to her. When she came he was too weak to say anything but just gently gazed at her for 10 minutes. A little earlier he was asking my mother to forgive him for being difficult to deal with. His last words were the words of Lord's Prayer which he knew by heart. He tried to say it two times but was too weak and could not finish. He then gathered all his strength and said this prayer in full once and then another two times. He then tried to sit but instead turned on his stomach and went quiet.

What was so amazing is how serious and clear thinking Sultan was in the last hours of his life. His last words were said out loud and my mother could hear them but they were addressed only to God above. Witnessing this moment was so remarkable that it could not be described with words. It was so real and genuine. That was his big moment and Sultan was so brave to face it the way he did. As his family often we did not understand him enough. We often did not take seriously his "childlike" thoughts about his life with God.

Sultan was "unfortunate and retarded" as far as this world is concerned but he was very special and precious as far as God in Heaven is concerned. Sultan is not an angel, he is someone more special. Angels are not called children of God, but Sultan surely is a child of God. The reality of God in his death was overwhelming. I miss Sultan and want to see him. So I have to wait a little for my time to go. Until then I hope this would produce lasting fruit in our life and we would be "serious as to death" about the reality of God in this life and in eternity.

We will always treasure Sultan in our lives. ■

The Republic of Kazakhstan, an Associate Member of the International Prader-Willi Syndrome Organisation, declared its independence from Soviet Russia in 1991. It is the ninth largest nation in the world, the size of western Europe, with a 98.4% literacy rate.



The theme of PWSA (USA)'s 31st annual conference is **Survivor Orlando**. The programs for our children and young adults will be based on the popular television show with fun-filled, team-building activities. We are very pleased to announce that Clint Hurdle will be our keynote speaker! *Now, the details:*

What are the dates of conference?

Friday-Sunday, November 11-13, 2011

Scientific Conference, Professional Providers and Chapter Leaders will meet Friday, November 11.

General programming for parents, children and young adults (with and without PWS) will be provided for two full days, Saturday, November 12 and Sunday, November 13.

The Gala Dinner will be held Saturday evening, November 12. Adults: $35.00, YIP: $15.00, YAP: $20.00

NOTE: Friday, November 11, is Veteran's Day and a holiday for most students and workers.

What programming will be provided for children and adults?

Two full days of General Conference programming that includes breakout sessions on topics such as Behavior Management, Sibling Support, Diet and Nutrition, Behavioral Crisis Support, School Support and the PWS IEP, Sensory Integration, Psychotropic Medications, Scoliosis, and Aging Issues

Two full days of programming for children birth to age six in our YIP program on Saturday and Sunday

Two full days of programming for children and young adults with PWS ages 7+ in our YAP program on Saturday and Sunday

NEW

Two full days of programming for siblings of individuals with PWS ages 7-15 on Saturday and Sunday. We are excited to provide siblings an opportunity to share their challenges and feelings with others who best understand these experiences. Siblings who also have special needs should be registered for the YAP program. If you have questions about supports required for your child, please contact the office.

LIMITED ENROLLMENT: Enrollment in all 3 programs will be **CAPPED**, on a first-come, first-served basis, once conference registration begins, at the following levels:

YIP: 20 babies (birth-2), 50 children (ages 2-6)

YAP: 60 individuals ages 7+

SIBLINGS: 30 siblings ages 7-15

How much will it cost?

The room rate at the Buena Vista Palace Hotel & Spa, Lake Buena Vista, Florida, is just $119 a night, plus tax and resort fee, for a single or double room, $139 for a triple and $159 for a quad room. These rates are available for the 3 days prior to conference and 3 days after conference. www.buenavistapalace.com Mention the PWSA conference to receive our special room rate.

Conference registration is $225 per person until 9/30 and $250 after 9/30. This fee includes breakfast and lunch Saturday and Sunday. Companion registration fee, which includes the two days of meals, is $100, for those not attending the lectures.

YIP Infants (under age 2) $100

YIP Children (ages 2-6) $125

YAP Participants - $175. This fee has remained the same since 2003.

Siblings - $125

What are the advantages of staying at the conference hotel?

FREE Walt Disney World Transportation Busses to all Disney Parks

FREE Parking

FREE Wireless Internet

In-room refrigerators

As a hotel guest and conference attendee, you can enter any Disney Park from 4:00 to close for $50 per person.

Discounted base ticket and park hopper ticket options. Park tickets can be purchased in the hotel gift shop, thus eliminating the need to wait in the Will Call line at the park to retrieve tickets purchased online. This is a hassle-free and lower-cost option for obtaining park tickets! More information will be forthcoming on ticket prices and tips and tricks to a Disney vacation…

When can I register for conference?

Registration will open in late summer/early fall. Watch *The Gathered View,* our website, and our weekly E-Bulletins for exact date.

When It Matters

Perseverance is the hard work you do after you get tired of doing the hard work you already did.
~Newt Gingrich

PWSA (USA) works with people who have dreams. People who believe they can lessen burdens on those affected by PWS by holding a fundraiser for our organization. People who understand there is true meaning when they put themselves to work in pursuit of a larger goal that matters to them. The fundraiser is a means to an end. It opens up possibilities that might not otherwise be present, whether by creating awareness about PWS and thus a more understanding society or by providing dollars to fund projects directly benefiting people who need help.

To make it easier for anyone wanting to do this, PWSA (USA) launched **Prader-Willi Syndrome *On The Move,*** our first annual national awareness campaign. Chapters, groups and individuals around the country are signing up. The goal is to grow awareness and to raise funds for local initiatives as well as for the national Association. To help with this effort, PWSA (USA) has created a campaign graphic and theme, including the Prader-Willi *move character.* We are also offering event guides, fundraising websites, and campaign-branded t-shirts and water bottles. To learn more, go to www.pwsausa.org and follow the links for the National Awareness and Fundraising Campaign.

There is something magical that happens when somebody affected by PWS realizes that others care. There is splendor when we work in our communities to achieve our dreams. And there is downright pride and gratitude when we persevere for all the right reasons, despite how tired we may be or how daunting it appears, because we know it will make a difference. It's a beautiful thing to come together when it matters, and when it's about those we love who have PWS, it always does.

Please remember to thank those who are helping, like those below. We recognize their dreams, for they are ours, too.

Heartfelt thanks go to the 13 participants plus numerous donors who supported the 9th Annual **Valentine's Day Research Campaign**. Over $18,000 was raised, which will be applied directly to research projects funded by PWSA (USA).

Family and friends of parents **Anita and Kyle Perrault** gathered for their **Annual Jacob Bingo** in honor of 7-year-old **Jacob** who has PWS to raise $1,790 for research. They expect Kyle's company to double-match the $1,090 portion.

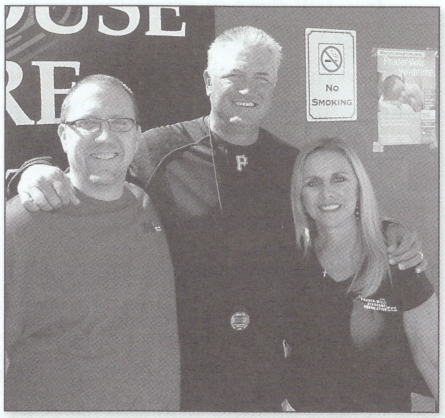
Hillarie Van Zanten from Texas wrote "Thanks so much for all that you do," when she sent in her donation of over $130 in honor of one-year-old **Emerson Parker** who has PWS after holding a **Thirty One Fundraiser** in January. "Thank *you*!"to Hillarie.

David Chirico, neighbor to the Wallace family in Florida, hosted a fundraising event in March in honor of **Cameron Wallace**, 8, who has PWS. Mom **Michelle Wallace** wrote, "He raised over $1,100." David gives extra meaning to "love thy neighbor."

Lori Guthrie of Virginia made it her **birthday wish** that others donate to PWSA (USA) through an online Cause page. She inspired over $60 in donations.

New in 2011 is **Light A Candle, Be A Light** started by **Lisa Thornton** in Utah and open to all. Participate by committing to forego a meal or two on the first Sunday of each month as a way to feel some of what our children feel. The money normally spent on food will go to PWSA (USA). To date, over $890 has been raised. Participate next month at http://www.firstgiving.com/light-a-candle.

Remember to check the PWSA (USA) events page to see what's happening near you. http://www.pwsausa.org/events/index.htm. Check out **Prader-Willi Syndrome *On The Move*** events there, too! To plan your own fundraiser, call Jodi O'Sullivan at PWSA (USA) at 800.926.4797. ■



Evan, Clint Hurdle, and Janalee enjoying the sunshine at the Pirates training camp in Bradenton, Florida

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.

My Inspiration

By Caitlin Staskiewicz, Plain City, Ohio

While on spring break, I visited the theme park *Busch Gardens* in Tampa, Florida. I saw a little boy there who reminded me a lot of my little brother Reagan. He had the same big, gapped-tooth front teeth, the buzzed, dark brown hair, and tiny arms and legs. The little boy was doing an action with his mouth, which made me think of how my little brother moves his hands back and forth as a way of helping him focus while talking. This characteristic, along with the way his family was talking both about him and with him, made me assume that he, like Reagan, had special needs.

After thinking about the assumption I had just made, I began to feel guilty about the bold conclusion I had come to about this little boy whom I didn't even know. I started to think about Reagan and how I wonder if people ever make that assumption about him. As Reagan's big sister, I want to protect him from these assumptions and to never let anyone make him feel different from other kids his age. Although Reagan may have PWS, he is no different than other kids. He has a huge imagination, he always knows how to put a smile on your face, and he has some of the world's best hugs. He does some of the same things as other kids his age, like playing tennis, listening to a ton of country music, going four wheeling, and wrestling with Daddy as much as possible.

Thinking about the amazing little boy he is made me realize how unfair it is that he has this syndrome. Then it dawned on me how selfish I've been in feeling that my disease was unfair. In April 2010, I was diagnosed with Type 1 Diabetes, and ever since then I have felt that it was unfair that I had this disease because I am active, eat healthy, and have maintained a healthy weight all my life.

Compared to my little brother, it isn't unfair, though. I was given 18 years to live a "normal life" without a care in the world, with my biggest worry being what college I would attend. Reagan wasn't as lucky as I was. At four weeks, Reagan was diagnosed with PWS. His worry, unlike mine, would be "if" he would ever be able to attend college.

> ***"Although Reagan may have PWS, he is no different than other kids."***

From that point on, his life has consisted of doctor visits, multiple therapies, daily growth hormone shots, and a strict calorie diet. My diabetes is something I have the power to control with the right diet, regular exercise, and self-injections. For Reagan it's not that easy. There is no cure to stop the hunger, or to enable his brain and fine motor skills to grow at the rate of the average child. Reagan told my mom the other day that "In Heaven, I won't be hungry anymore". It brings tears to my eyes knowing that I can't help my little brother, that the feeling of hunger will never go away, and that right now there is no cure for PWS.



Caitlin with Reagan - her inspiration

Despite all these obstacles and struggles he endures, he is as happy as can be. He plays and giggles all the time, he loves school, and he loves spending time with his family and friends. Reagan is creative, extremely talkative like his big sister, and never ceases to surprise me with how smart he is getting. Even though life with diabetes may be tough and seem unfair at times, I think of Reagan and how he never lets PWS slow him down.

So I've come to this conclusion: Reagan is my seven-year-old little brother, my best friend, and forever my inspiration. ■

How PWSA (USA) Helps Direct Care Providers

Currently, PWS serves direct care providers in the following ways:

- We have three professional providers on our Board of Directors to help us include supporting professional providers in our mission and program.
- The PWSA (USA) Professional Provider Advisory Board consists of direct care providers and other care professionals whose responsibilities include:
  - Making statements on issues of concern to direct care providers.
  - Creating resources for direct care providers.
  - Coordinating national training conferences for providers on a semi-annual basis.
  - Preparing the Provider's Corner for publication in the bi-monthly Gathered View.
  - Facilitating a Yahoo discussion group for providers to share questions and ideas.
  - Participation in international care provider conferences sponsored by the International PWS Organization.
- Regularly creating resources for providers (written and video) to help with medical and behavioral management.
- Crisis Intervention Counselors are available to consult with providers on placement problems.
- Offering a free online directory where providers can list information about their PWS specific programs for families looking for placement.
- Offering individual and agency membership to providers which includes receiving the PWSA newsletter (electronically or by mail) and other benefits.
- And by saying thank you whenever we can for the important work you are doing on behalf of people and families living with PWS! ■

To learn more about any of these support services for direct care providers please call 800-926-4797 or visit www.pwsausa.org

The Value of Specialized PWS Placement

Samantha sits at the lunch table with her friends, laughing, gossiping and talking about things that teenage girls talk about. She looks forward to after-school activities, visits home and shopping trips. Samantha is a regular girl, doing what girls do--going to school during the day and having fun with her friends after school and on the weekends. At her school Sam is a typical student; she is not an outsider, not the girl with the behaviors or mountains of challenges to overcome. She is popular and well-liked by her teachers and her friends.

Sam has PWS, but she is not "that student", or one of the students in the separate classroom, because most of her peers also have a diagnosis of PWS. Samantha came to The Latham School in November 2009 from a special needs school in New York. That school had years of experience with special needs, but had no other children with PWS and, as frequently happens, expected Sam to fit into their program because their program was not suited to meet her needs. But as many of us who have worked with, loved and cared for people with PWS know that this diagnosis is unique, and without a deep understanding of PWS a child or adult can unintentionally be placed in a setting that can jeopardize their lives.

Sam's anxiety continued to increase, and her feelings of helplessness were displayed as serious self-injury which, on at least one occasion, led to the need for emergency lifesaving surgery.

She came to Latham Centers 14 months ago with severe self-injurious behaviors. She wore a helmet, mitts on her hands and had 2:1 supervision 24/7. Upon admission Sam's helmet and mitts were removed, and her new life began. Transitions are never easy and this was no exception, but nobody gave up on Sam. Instead of Sam being asked to fit into the program, the program molded itself to fit her needs. Soon her anxiety started to decrease, and the incidents of self-harm decreased as well.

Today Sam has best friends, crushes on boys in her class and recently made high honor roll at school. In other words, Sam has a full, meaningful life that she is proud of. From an angry, scared and withdrawn girl, she has flourished into a charming, outgoing, compassionate and brave young woman with the help of her family, teachers, staff and peers who understand her and help her to use her many strengths to overcome the challenges that are inherent with PWS. ■

~Patrice Carroll, Latham Center
Cape Cod, Massachusetts

[Ed. Note: This story demonstrates the value of specialized placement for PWS. Besides Latham, there are many other good PWS-specialized schools in the USA.]

Chapter View

By Barbara McManus, Family Support

Prader-Willi Alliance of New York, Inc. (PWANY) held its 21st Annual Conference April 29-30. Themed "Changes Ahead", the focus was on providing attendees with information needed to effectively advocate for their loved ones with PWS, given the significant changes in New York resulting from tough fiscal times for the state.

Many chapters have pitched in to help support the national conference to be held in November 2011. The support enriches the possibilities for the Infant, Youth and Adult programming.

The Chapter Leaders email group has been buzzing with information about what state disability laws consider eligible for services. Acceptable characteristics vary widely from state to state. Not all persons with PWS have a low IQ, and in some states they are not eligible for services. **Massachusetts** is preparing to challenge their state laws for PWS. Go Massachusetts! What this chapter does to help the people in their state will, in the end, help others, too.

Far Northern California PWS Support Group met in April. If you are interested in future meetings in this area, call Misty Adams at 530-241-6444. For more support groups in California, visit http://www.pwcf.org/pages/sg.htm Also, the **California Prader-Willi California Foundation** announces that REGISTRATION IS NOW OPEN for PWCF's new PWS Camp at Easter Seals' Camp Harmon. July 27-Aug. 2 for ages 8-65. Call 310-372-5053 for more information.

Did you know that every state has its own email support group? Yes, there is one for every state! To sign up for your state's group, visit www.pwsausa.org/links/chapter.htm

Counselors Corner

Getting Ready for Summer



Our children with PWS will soon have the summer off from school. For parents or caregivers, this can be a very difficult time. Toward the end of the school year, plans are being made about what to do for the summer, but before it ends, there are some things to consider that could make a big difference returning to school in the fall.

One of the best ways to make a difference is to start an individualized school portfolio for your child. The school portfolio follows your child through their school years from beginning to graduation. The portfolio can include school handouts found on our website as well as yearly teacher and parent questionnaires. Before your child leaves school for the summer, have your child's current teacher fill out the questionnaire. You may be surprised by what you may find there.

The teacher's questionnaire, as well as a parent's questionnaire, is now on our website. It will help your child transition to different schools or teachers. This can also be used as a way to see how much progress your child has made from year to year. You can find the questionnaires as well as instructions on how to use a school portfolio on our website under the Education Resource link, or you can call a crisis counselor.

When summer vacation finally arrives, you may need to find and maintain meaningful activities and structure throughout the day. Of course, you may have your child in summer camp, but most are not that lucky. So what are some great strategies that are important for your child with PWS?

First you need to find some structure for your child and organize your child's day. Have a schedule of chores, tasks, or activities done at a certain times during the day. Have your child complete harder tasks first when he has more stamina and is more alert at the beginning of the day. As you structure the schedule, think about your child's routine. When chores and tasks are a part of the routine, it becomes so much easier. Make sure your child is very comfortable with the routine. Consistency, predictability, foreshadowing are also very important. Using visuals and motivators are also extremely helpful to maintain a consistent, structured routine.

If you would like more information on making a school portfolio for your child as well as tips for the summer, contact a crisis counselor.

See you next time in the Counselor's Corner. ■

~Jeremy Johnson

Contributions

Thank you for Contributions in February and March 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.

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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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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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Save the Date! Announcing the 25th Annual PWSA (USA) Scientific Day Conference

Plan to attend the 25th Annual PWSA (USA) Scientific Day Conference on **November 11, 2011** at the Buena Vista Palace at the Walt Disney World Resort in Orlando, Florida. This one-day event is where leading scientists, researchers and clinicians can share in the latest information and abstract presentations of recent research studies regarding Prader-Willi syndrome. (Parent observers will be allowed to register and attend these sessions for a nominal fee.)

The Scientific Day Conference is a wonderful opportunity to network with leading researchers and hear presentations on topics such as Genetics, Medical, Nutrition, Behavior, Social, Endocrine, and Diagnostic Criteria.

The Scientific Day is co-chaired this year by **Dr. Jennifer Miller**, M.D., Department of Pediatrics University of Florida Gainesville, Florida, and by **Dr. Merlin G. Butler**, M.D., Ph.D., Departments of Psychiatry & Behavioral Sciences and Pediatrics, University of Kansas Medical Center, Kansas City, Kansas.

We are pleased to announce that **Professor Maithé Tauber** (Hôpital des Enfants and Paul Sabatier Université, Toulouse, France) and **Dr. Cary Savage** (Director, Center for Health Behavior Neuroscience, University of Kansas Medical Center) have accepted our invitation as invited speakers at the Scientific Day Conference. Professor Tauber will be speaking on the topic of *The French Reference Centre for PWS and Pertinent Endocrine Issues in PWS* and Dr. Savage on the topic of *Functional MRI studies in Prader-Willi Syndrome and Obesity.*

Look for more information regarding conference registration, hotel registration and instructions on how to submit an abstract for review coming soon! ■

Dates to Remember

Final Abstract Submission
September 9, 2011
Scientific Day Conference
November 11, 2011

Through research, education and support, PWSA (USA) strives to improve the quality of life for all individuals living with Prader-Willi syndrome

e-Bulletin...

Reminder – stay informed and stay current with PWSA (USA)'s free weekly eBulletin.

Sign up today at www.pwsausa.org!

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