

The **Gathered View**

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

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

Donkey Therapy is a Big Ass-et in Germany!

By Janalee Heinemann, Director of Research and Medical Affairs

While in Germany, along with Jackie Mallow and Mary K. Ziccardi, for an international provider conference and International Prader-Willi Syndrome Organisation (IPWSO) board meeting, I was able to visit an incredible residential setting for PWS. Dr. Hubert Soyer is Executive Director of Absberger Regens Wagner, a multifaceted residential setting for PWS and other disabilities, serving 248 including 57 that have PWS.

Most with PWS are in six PWS-only homes of 6-11 in a home. Having so many in specialized community settings goes against all current USA concepts of "least restrictive environment", but to say we were impressed with Hubert's vision and implementation of these settings over the last 16 years (14 with PWS) would be an understatement. He has been able to meet the residents' unique needs, yet also integrate them into the community and the community into their residential events.

Each of the six small communities is on beautiful expansive acreage. All homes and workshops are very bright, clean and very cheery with lots of beautiful artwork done in a variety of mediums by the residents and created into large murals and collages in brilliant primary colors by what must be an incredible art therapist. Each workshop and community room had large pictures of each resident and worker in bright, unique frames. Schedules were done in very creative visuals. There were many interesting job options, including detailed assembly work using machinery, assembling toys, and working in their greenhouses or with the farm animals. For two hours of their work week they can choose a recreational activity of their choice--fishing, a Nordic walking group, swimming, needlework, pottery, etc.

Extracurricular options include ballet dancing, a very large art therapy studio, stage performance options, gymnastics, lymphatic drainage, spa therapy,



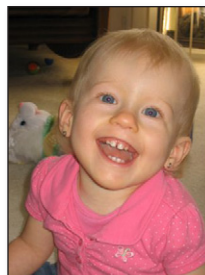
One of the donkeys therapists

sensory integration and organized sports. One of our favorites was the Asinotherapy program – which is donkey therapy. In America we encourage hippotherapy (horses) for people with PWS, but donkey therapy makes sense. Donkeys are smaller and easier to handle and pet. They like the attention, are less temperamental, and trainable. We enjoyed the irony that they are stubborn like our kids can be, and thus our kids must learn patience with them; they have to have a relationship with the donkeys to get them to do what they want. Hubert says it is also good training for the staff.

This communal setting is due to the visions of Hubert and the donation in the past of a significant amount of property by Regens Wagner, a priest and professor. Other major factors are that the government provides 90% of the funding and the amount of services would not be possible without such a large population under the same provider umbrella. Within this large setting, each person's services are impressively individualized. While we were there, they had a community summer fest on

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Maddilyn Smith



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Janalee, Mary K, Ziccardi, Dr. Hubert Soyer and Jackie Mallow in the art therapy room.

one of their properties that was attended by hundreds from the external/extended community. The Regens Wagner residents did a dance program, assisted with mass, did a show with their donkeys and sold their crafts. The community donated hogs, cakes and manual labor for the event. They also have a senior citizens day program not only for their residents, but for the external community.

The main reason for the international provider conference, initially created due to the vision and fortitude of Pam Eisen, is that each country has concepts, management and programs to share with other countries. Since Pam's death, IPWSO has created a Pam Eisen lectureship that will be awarded at every provider conference. We owe a big thank you to Dr Hubert Soyer and Norbert Hödebeck-Stuntebeck for coordinating this conference and a special thanks to Hubert for hosting us and sharing his remarkable PWS community with us. ■



Asinotherapy -- Donkey therapy used in Germany for people with PWS.

Medical and Research View

What Should Parents of a Child with PWS do about the H1N1 influenza (Swine flu)?

By Clinical Advisory Board Members Merlin Butler, M.D., Ph.D., Marilyn Dumont-Driscoll, M.D., Ph.D., Todd R. Porter, M.D., M.S.P.H.

Individuals with PWS should receive the immunization when it is available. They appear to have a normally responsive immune system and should respond appropriately to vaccinations and/or medication to combat illnesses. Most hospitals are requiring both the H1N1 swine flu and regular influenza vaccinations for all employees. It is thought to be fairly safe. Since we do not know how problematic the swine flu will be this year, we recommend that those with PWS should be vaccinated especially if there are other health issues.

While the H1N1 virus is a novel influenza virus and has garnered much media attention, we cannot risk ignoring the historical morbidity and mortality of the seasonal flu for which we already have a vaccine that is effective. To date, surveillance data on the novel H1N1 virus has shown it to be milder than the seasonal flu viruses, yet what sets it apart is that it seems to have targeted the younger population (5- 24 year olds). Time will tell if this continues to be true.

We would advise parents to focus on having the child and family vaccinated against the seasonal flu viruses. An important note is that children less than 9 years of age who are receiving the flu vaccine for the first time, or who received only one dose last year for the first time, need a booster dose four weeks after the first dose. It appears that vaccine for the novel H1N1 virus will be ready for distribution mid to late October. The current H1N1 guidelines list all children 6 months and older as a target group to receive the vaccine.

What we do not know at this time is whether everyone, given it is a novel influenza virus, will need 2 doses. Effectiveness data on this H1N1 vaccine is unknown at this time.

The symptoms of both the novel H1N1 and seasonal influenza viruses are fever, cough, sore throat, headache, chills and fatigue, and sometimes, diarrhea and vomiting. Because in PWS we cannot always use fever as an indicator of severity of illness and must also consider the possibility of central adrenal insufficiency (CAI), a parent should have their child with PWS evaluated by their primary care provider if there are concerns about their breathing, hydration, or appearance. Parents can inquire with the child's physician about the ability to perform a rapid influenza diagnostic test (RIDT). Per the Center for Disease Control, patients with illnesses compatible with novel influenza A (H1N1) virus infection but with negative RIDT results should be treated empirically based on the level of clinical suspicion, underlying medical conditions, severity of illness, and risk for complications (MMWR August 7, 2009 / 58(30);826-829). http://www.cdc.gov/h1n1flu/guidance/rapid_testing.htm

The decision to use antiviral medications (neuraminidase inhibitors tamiflu and relenza) will be determined by the physician based on results of rapid diagnostic tests and the clinical presentation and severity. Tamiflu is indicated for use in individuals over 1 years of age; however, the CDC has provided dosing guidelines for

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Medical and Research View

Dear PWSA (USA) members,

We are pleased to share with you this growth hormone consensus statement for Prader-Willi syndrome. We owe a big thanks to Dr. Dan Driscoll and the PWSA (USA) Clinical Advisory Board for taking on the difficult job of creating a consensus statement on this very important topic. To say it is a “consensus statement” means it was approved by the 15 members of this advisory board – all of whom are experts on PWS.

Because of space limitations, the dozen references at the conclusion have not been included but are available on request by calling the national office.

Janalee Heinemann, Director of Research and Medical Affairs

Growth Hormone Treatment and Prader-Willi Syndrome **PWSA (USA) Clinical Advisory Board Consensus Statement, June 2009**

Since the commercial release of recombinant human growth hormone (GH) in 1985, therapeutic use of this medication has been studied in a variety of medical conditions and genetic syndromes. Based on current medical knowledge, the Clinical Advisory Board of the Prader-Willi Syndrome Association (USA) has drafted and approved this policy statement to guide health care providers in the use of GH treatment in individuals with Prader-Willi syndrome (PWS). Currently, 60% of the individuals in the PWSA (USA) database are receiving GH therapy.

Current considerations regarding the use of GH treatment in PWS can be divided into the following categories:

- 1) GH treatment of infants/children with PWS to improve body composition abnormalities and improve linear growth
- 2) GH treatment of adults with PWS to improve body composition abnormalities and improve bone mineral density

Numerous studies indicate that GH deficiency occurs frequently in children with PWS and that treatment with GH is efficacious in improving the growth and body composition of these children¹⁻⁴.

GH should not be a substitute for appropriate nutritional intake and physical activity.

GH treatment is FDA-approved for individuals with PWS. It is well recognized that GH deficiency is a part of PWS and that provocative testing for GH deficiency is **not** indicated for children with PWS because: 1) the results can be influenced by obesity; 2) different testing protocols give widely discrepant results; 3) the diagnostic boundary for normal/abnormal GH result in response to testing is still debated; and 4) there is no ideal testing protocol.

GH Treatment of Infants and Children with PWS

Multiple studies have documented the benefits of GH therapy in individuals with PWS, including, but not limited to, improvements in lean body mass, decreased body fat, increased bone mineral density, and normalization of adult height¹⁻⁵. Further, GH treatment in infants and children with PWS has been shown to improve strength, agility, and motor development. Treatment with GH has also been shown to positively affect nitrogen balance and increase energy expenditure in individuals with PWS. Moreover, GH treatment may help preserve lean body mass during caloric restriction. There is evidence that beginning GH therapy prior to two years of age is beneficial because of the positive effects of this treatment on mental and motor development⁶⁻⁸.

The risks and benefits of GH treatment should be thoroughly discussed with the child’s parents or guardians before making a decision to treat. At the same time, it should be stressed that GH therapy is only one treatment tool for their child and should be used in conjunction with appropriate nutritional intake and physical activity. GH treatment should not be viewed as a substitute for diet and exercise.

Treatment should commence using standard dose guidelines (0.18 – 0.3 mg/kg/week) given as a daily subcutaneous injection with careful monitoring of clinical status at regular intervals. Standard GH treatment includes dose initiation and adjustment based on weight. However, there is some evidence that lean mass is a better indicator of GH requirements and, therefore, monitoring clinical growth and IGF-1 levels is helpful in determining dose adjustments. The Clinical Advisory Board recommends that the GH dose in children with PWS be adjusted on an individual basis rather than by specific criteria. Clinical monitoring should include nutritional status, height, weight, and head circumference measurements; calculation of growth velocity; bone age; physical examination; and measurement of IGF-1, glucose, insulin, and thyroid hormone levels, as well as ensuring adequate nutrition for growth and brain development. If feasible, assessment of body composition is also helpful.

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Medical and Research View

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Children with PWS have an increased risk for spinal curvature abnormalities, including scoliosis and kyphosis. In general, these findings may first become apparent or more rapidly progress during periods of rapid growth. There is no evidence that GH itself causes these abnormalities⁹. Children with PWS, whether or not they are treated with GH, should receive a careful back examination at least annually. The decision to initiate or continue GH treatment in a child with spinal curvature abnormalities should be made in consultation with an endocrinologist and an orthopedic surgeon experienced in PWS, and after full discussion with the child's parents or guardians.

Children with PWS are prone to developing obesity and its associated complications, including glucose intolerance and type 2 diabetes mellitus. GH may induce insulin insensitivity. Therefore, children with PWS and GH deficiency should be carefully monitored for signs and symptoms of glucose intolerance during GH treatment, particularly if they are massively obese (e.g., >200% of ideal body weight) or have a family history of diabetes mellitus. Routine biochemical screening tests may include fasting blood glucose, urine glucose dipstick or HbA1c. If diabetes mellitus occurs as a result of GH therapy, the GH treatment should be stopped. If treatment is restarted, the dose of GH should be substantially reduced. If glucose intolerance occurs with GH therapy it can typically be treated with an oral hypoglycemic agent, such as metformin.

Children with PWS have an increased prevalence of respiratory dysfunction, which may be related to obesity, hypotonia, or central

respiratory drive abnormalities^{3,10}. Careful history and assessment of respiratory abnormalities should be evaluated prior to and during GH therapy. Individuals with sleep apnea, either before or after beginning GH therapy, should be evaluated by a pulmonologist, otolaryngologist, and gastroenterologist to determine if:

- 1) The apnea is mild or central in origin (in which case GH is not contraindicated).
- 2) If the apnea is severe and obstructive in origin, this needs to be addressed before GH is initiated.
- 3) There are confounding pre-existing conditions, such as morbid obesity, upper respiratory tract infection, adenoid/tonsillar hypertrophy, or gastroesophageal reflux that may exacerbate sleep-disordered breathing. In addition, some groups recommend that individuals with PWS have overnight polysomnography before and ~ 6-12 weeks after beginning GH treatment¹⁰ and if there is any worsening of clinical symptoms while on GH therapy.

GH Treatment of Persons who have Achieved Final Height and Adults with PWS

Recent studies indicate that adults with PWS also benefit from GH replacement therapy, with improvements in body composition, bone mineral density, and exercise capacity^{11,12}. Treatment doses are typically started at 0.2 mg/day and increased by 0.2 mg increments as necessary to maintain IGF-1 levels within the normal range for age and sex. The prevalence of GH deficiency in adults with PWS is not well documented, but the problems surrounding provocative testing for GH deficiency are the same as described above for children. However, at this time in the U.S, insurance companies still require documentation of GH

deficiency by provocative testing in adults with PWS. ■

Help Is Here On Psychotropic Medication!

One of the most frequent pleas we get is for advice on psychotropic medication. The problem is that for PWS one size does not fit all, and although there are great medications available, without knowledge on how they impact PWS--and due caution regarding the effects on the individual person--they can do more harm than good.

We have asked our experts to write a short article that will help the psychiatrist or the health care provider who is making decisions on the drugs. We are fortunate to have terrific experts on our advisory board who donated their time to write the following two articles that are now available on our web site in both the medical and crisis section. If you do not have web access, call the office at 800-926-4797 and request a copy of the article appropriate for your circumstances.

• PSYCHIATRIC ALERT - For Psychiatrists on Prader-Willi Syndrome

By Pittsburgh Partnership- Janice L. Forster, M.D. - Child and Adolescent Psychiatrist; Linda M. Gourash, M.D. - Developmental Pediatrician (*This article is best for psychiatrists.*)

• Psychotropic Medication Tip Sheet for Patients with Prader-Willi Syndrome -- For Health Care Providers

By Elisabeth Dykens, Ph.D.; Elizabeth Roof, M.A., L.P.E, Vanderbilt University, Kennedy Center (*This article is helpful for*

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Acting Executive Director's View



Evan Farrar

In July, PWSA (USA) announced that we will not be holding a national conference in 2010. In case some members and friends of our association did not see the announcement letter from the co-chairs of our Board of Directors, we are reprinting it below. It includes the reasons behind this difficult decision. We are grateful

for the support we've received since making this announcement and look forward to continuing to work in partnership with you to serve people and families living with PWS.



Evan Farrar
Acting Executive Director

Dear PWSA (USA) Members and Friends,
IMPORTANT ANNOUNCEMENT ABOUT PWSA
(USA) 2010 CONFERENCE

We know that many of you are awaiting details regarding conference plans for 2010, so we wanted to let you know that, after careful consideration, the PWSA (USA) board has decided not to hold a conference in 2010.

REASONS FOR THE DECISION

Last fall, when we shared our plan to have a scientific conference in 2009 that was not parent focused, we also conveyed our intention to hold a full conference in 2010 with educational programming for parents and a YIP/YAP program for children and adults with PWS. We felt, as did many at the time, that by mid-2009, our economy would be stronger than it is currently, and that, although the recession might negatively affect some of our traditional revenue streams, we could overcome that challenge by aggressively pursuing new funding sources.

Unfortunately, the recession is deeper than we had anticipated and the recovery is slower. Donations to PWSA (USA) from traditional sources are down significantly, and our efforts to obtain grants from new sources have not been successful. We know that many of our families are struggling financially and do not have the funds for conference travel. Moreover, our researchers, physicians and professional providers, many of whom have seen their travel budgets drastically

reduced, tell us that they have fewer funds available for conferences. In this economic climate, we cannot in good conscience commit PWSA (USA)'s limited resources to the prospect of holding a conference in 2010.

CORE MISSION AND PRIORITIES

Like every nonprofit (and, indeed, most families) in the country, now is the time for us to focus on our mission and determine (i) how to make the best use of the dollars we have, and (ii) how to raise enough money to keep going. Toward that end, we are pursuing the following priorities:

Research. PWSA (USA) continues to sponsor important PWS research and explore new ways to promote, facilitate and fund it. For more information on current developments in research, click on the "Research" tab on our Web site.

Education.

Each day, PWSA (USA)'s [Web site](#) provides critical information to families, caregivers, researchers, scientists, educators, lawmakers, potential donors and others throughout the world. Keeping it accessible, accurate and up to date is an enormous task, but one at which we must not fail.

We have two [webinars](#) scheduled for 2009 [Ed. Note: dates to be announced]. Details will be provided in a subsequent e-mail and on our Web site.

Family Support.

In 2008, the PWSA (USA) staff handled 48% more [crisis calls](#) (medical and non-medical) than in 2007, and the numbers for early 2009 show an increase of 32% over those for 2008. As the economy worsens, the complexity of the cases seems to be increasing as well, so our crisis staff is being stretched to the limit. In addition to medical crises, the staff is handling increasing numbers of calls pertaining to residential placements (often related to behavioral crises), legal issues, psychiatric issues, Medicaid and SSI, and school/IEP issues. To help meet the challenge, PWSA (USA) has created a non-medical crisis section on the Web site.

PWSA (USA) matches parents of newly diagnosed children with [parent mentors](#) and provides new parents with a "[Package of Hope](#)" containing information about PWS.

Fund Development. Needless to say, fund development is mission critical. At a minimum, the funds we raise must cover the cost of providing the above services. If we want to do other things as well, we must raise even more.

We know the decision not to hold a conference in 2010 is disappointing for many of you. It is

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disappointing for us as well. Conferences have been an important part of our heritage, enabling us not only to educate and encourage each other, but also to come together as a community. For 34 years, though, PWSA (USA) has served the families of those affected by Prader-Willi syndrome, and we intend to continue serving those families for many years to come. With your help, we will pull through this recession together by focusing on our mission, tapping into our strong volunteer base, continuing to ensure prudent use of our financial and personnel resources, and redoubling our efforts to raise money.

CALL TO ACTION

Please consider this a call to action. Here are some ways to help in the days ahead:

Hold a fundraiser. If you are interested, please call the national office. Jodi O'Sullivan, our Director of Community Development, has how-to guides for almost any type of fundraising event you can imagine and is available to assist you along the way.

Volunteer. If you feel you have a skill set that would help with the business issues related to PWSA (USA), please call the office. We welcome your participation and expertise!

Give. Consider sending an additional gift or matching grant to support our work and encourage others to do so. Any amount will help! Every dollar you give enables us to provide essential core services such as supporting the parent of a child newly diagnosed with PWS or responding to an urgent crisis involving a person with PWS.

Our organization's strength is in our membership, families and friends who know how to face and overcome adversity and provide support in tough times. Thank you for your continued support. As you work to care for your loved one with PWS, we will continue to work for you.

Very sincerely,

Carol Hearn, Co-Chair,
PWSA (USA) Board of Directors

Ken Smith, Co-Chair,
PWSA (USA) Board of Directors



Production, printing and mailing of this newsletter was underwritten by Pfizer.

Correction regarding the May/June and July/August issues: Pfizer was also the underwriter for them.

Board Membership Update

The following PWSA (USA) Board members were elected by mail-in ballot this summer:

Dr. Gregory Cherpes	(PA)
Jackie Mallow	(WI)
James Koerber	(IN)
Lisa Thornton	(UT)
Michelle Torbert	(FL)

The following board members concluded their term of service, and we thank them for their significant contributions to the mission and work of PWSA (USA):

Dr. Linda Gourash
Mark Ryan
Mary K. Ziccardi

PWSA (USA) members can be proud of the quality of the professionals who serve on our Scientific Advisory Board and Clinical Advisory Board.

The Scientific Advisory Board (SAB) New Members

David Stevenson, M.D., received his M.D. from the University of Utah, trained in pediatrics at the University of New Mexico and clinical genetics at the University of Utah. He currently practices clinical genetics and is Assistant Professor of Pediatrics at the University of Utah. He chairs the PWSA(USA) committee to study the causes of death and mortality and morbidity issues in PWS. Because of his special research interests and clinical skills, we are pleased to have Dr. Stevenson as a new member of the SAB.

Anastasia Dimitropoulos, Ph.D., received her Ph.D. from Vanderbilt University and trained in psychology and neuroimaging at Yale University. She is currently Assistant Professor of Psychology at Case Western Reserve University. Her graduate work at Vanderbilt included studies on cognition and behavior in PWS and more recently on food-related neural circuitry using neuroimaging techniques in PWS. She has published extensively in these areas. We are pleased to have Dr. Dimitropoulos as a new member of the SAB.

We would also like to thank those individuals rotating off the PWSA(USA) SAB, including Harriette R. Mogul, M.D., M.P.H. and Phillip D. K. Lee, M.D.

The Clinical Advisory Board (CAB) New Members

The CAB is pleased to welcome Drs. Todd Porter and Marilyn Dumont-Driscoll as new members. Drs. Porter and Dumont-Driscoll bring much needed

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expertise to the CAB in the fields of general pediatrics and primary care issues.

Todd Porter, M.D., M.S.P.H., received his M.D. from the University of Virginia and pediatrics training at The Children's Hospital of Denver. Dr. Porter then completed his M.S.P.H. degree along with a second residency in Preventive Medicine. He currently practices general pediatrics in Denver, Colorado, and is working with the Colorado Chapter of PWSA (USA) to develop and fund a regional multidisciplinary PWS clinic at The Children's Hospital in Denver. He is the proud uncle of Abby Porter with PWS. Dr. Porter hopes to contribute to the CAB's efforts to focus on primary care issues in PWS.

Marilyn Dumont-Driscoll, M.D., Ph.D. is an Associate Professor of Pediatrics at the University of Florida College of Medicine in Gainesville, Florida. She is Director of the General Pediatrics Fitness Clinic at the University of Florida. She completed the Michigan State University Primary Care Faculty Development Fellowship and is a member of the Board of the Academic Pediatric Association (APA). She has reviewed for several pediatric journals and serves on the editorial board of the journal *Genetic Testing and Molecular Biomarkers*. Dr. Dumont-Driscoll is the primary care physician for several children with PWS. Her primary clinical and research interests are in general pediatrics, medical education, genetics in primary care, and the prevention and management of childhood obesity. ■

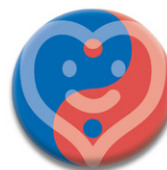
New Web Site Resource! **PWS Overview and Management - Medical Home Portal Development, Utah Medical Center.**

Once you access this Web site and go to the section called "Diagnosis and Conditions", click on the different links. Dr. Merlin Butler, chairperson of our PWSA (USA) Scientific Advisory Board, reviewed and edited this Web site, written for families and primary care physicians needing quick and accurate information.

To access this site if you receive *The Gathered View* electronically, go to:

<http://www.medicalhomeportal.org/diagnoses-and-conditions/prader-willi-syndrome/description?redirectDomain=true>

Or if you receive it by mail, go to <http://www.medicalhomeportal.org> and use the search in the top right corner for Prader-Willi ■



East Meets West

A New World for Prader-Willi Syndrome



VII International Prader-Willi Conference TAIWAN – May 21-23, 2010

Welcome to Taipei, the City of Azaleas!

Your hosts, Taiwan PWS Association, IPWSO and the Taiwan Rare Disease Foundation invite you to join us in Taipei, Taiwan for the 7th international conference for scientists, professionals, providers, caregivers, parents, and persons with PWS. Our theme, **East Meets West: A New World for PWS**, will allow us to expand the boundary of our knowledge of science and medical treatments; tools and skills for environmental and behavioral intervention; and the range of professional supports and services that are required for successful care and management of the person with PWS. <http://www.pwsa.org.tw/meeting>

SPEAKERS

International experts and specialists have been selected to provide a world view of the many aspects of genetics, endocrinology, behavioral phenomenology, and management of PWS. This conference presents an excellent opportunity for scientists, clinicians, caregivers and parents to learn from each other and to develop working relationships and partnerships that span continents. There will also be a special tribute to Pamela Eisen, past President of IPWSO.

PROGRAM

The program will follow the usual overlapping format of Scientists' Day, Parent/Professional Day, Young People's Program.

Content of the program will be available on confirmation of speakers.

VENUE

The conference will be held in the new Taipei County Hall, a venue known for its fabulous viewing platform, high above the city overlooking the rich tapestry of city life: green parks and nature reserves, many beautiful, ornate temples housing Buddhist, Taoist, and Chinese folk religion deities. You may catch a glimpse of one of the exciting festivals like the dragon boat or lantern festival. Taiwan will provide you with a wonderful opportunity to discover its beauty, visit its world famous Zoo, or walk along its many pristine beaches.

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Holidays, Halloween and PWS....

Vicki Knopf, Salem, Connecticut, mom to three with PWS, discusses Halloween.

When David, 13, was little, I dressed him up, took him around with the other kids and worried the whole time how we would handle it once the food thing kicked in. By age four, the "food thing" had kicked in full force so we traded Trick or Treat for family night where we would go for pizza and a movie or bowling, etc., and just pretend it wasn't Halloween. We have done this for the last few years successfully, and the kids really enjoy it.

Our school still lets the elementary kids celebrate Halloween with a party and a costume parade. Last year I kept Ben and Caroline home and ignored it... this year that wasn't an option, so I sent them. Ben, wearing his catchers gear from baseball, went as a baseball player, and Caroline wanted to be what else but a Princess.

The only thing left to tackle was Trick or Treat on Friday night. Friday night was also the Homecoming football game at the high school. I wasn't about to miss the game to go Trick or Treating with three kids who have PWS.

So I came up with the idea of a "Reverse Trick or Treat." David, Ben, and Caroline all love to visit and give things to people, so I went out and bought three plastic pumpkins and filled them with Halloween candy. Then I printed up a little flyer that looked like this:

Then I sent the three of them out into the crowd at the football game (I watched) and promised that if they handed out all the flyers and candy that I would save a piece of candy for each of them to eat!

They went to work handing out candy and flyers. Caroline even got \$3 given to her... she thought that was pretty cool! Husband Dave looked at me, shook his head and said, "You are either insane or a genius. Do you realize you just gave buckets of candy to kids with PWS?" I just smiled. It went off without a hitch, and they collectively handed out 60 flyers about PWS to the crowd.

They were done by halftime, then sat and ate their piece of candy and were happy as can be. So was I... no stress, no tantrums, and, most of all, no big bags of candy to contend with for weeks. Perhaps most of all there are 60 more people in this world who have heard about PWS!

Tips for Holidays

- If you will be with relatives, **carefully plan ahead of time and communicate** the importance of food control with all involved. Make sure all attending know the "rules of engagement" and agree to cooperate.

- **See that someone at all times is clearly in charge** of your child with PWS. After eating, when people are just visiting, see to it that if the food cannot all be put away, someone is responsible for guarding it. Clearly define when you are "changing guards". As Dr Linda Gourash states, "When everyone is in charge – no one is in charge."

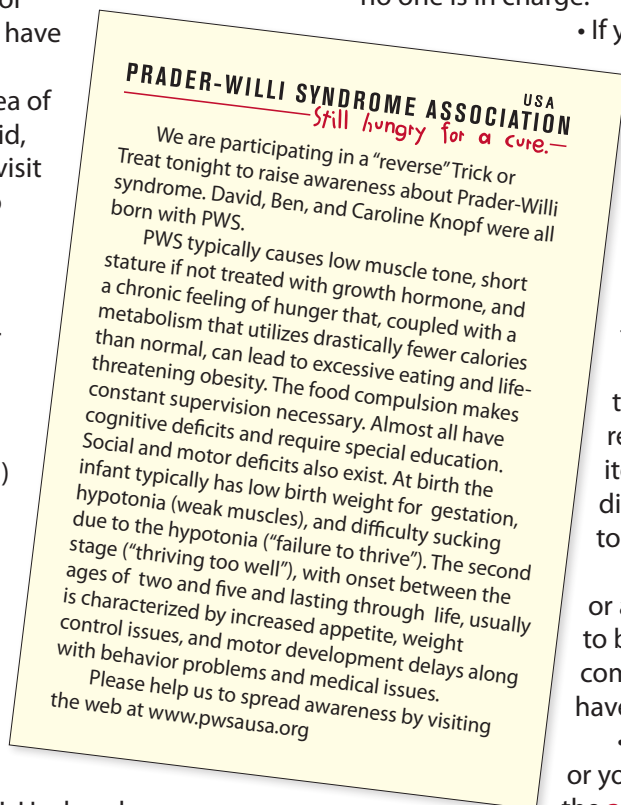
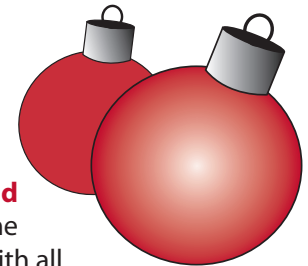
- If your child is old enough, **rehearse the "rules" before the special day** and come to a mutual agreement on what your child will be allowed to eat. You can barter, e.g., "Do you want a little extra turkey and dressing, or do you want a piece of pie as your special treat?"

- **It is okay** to request that Grandma and other relatives tuck away tempting items during your visit and to discreetly check with you prior to offering your child a treat.

- Grandpa and Grandma, or aunt and uncle, may want to bring **a special gift** toy to compensate for the food they have to deny your child.

- Go over with the hostess or your family on how to contain the **accessibility of food**. See to it that where your child is sitting

where there will not be a lot of bowls of food, rolls, or condiments nearby (many people do not consider how many calories our children can consume with the extras – sugar, butter, catsup, etc.).



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Holidays, continued from page 8

• Your child must have the **security of knowing** you will be strong in your commitment to keep them protected from food – in spite of themselves. Giving in, even once, means several battles ahead. You get tired of hearing it, but consistency is the key.

All the holidays have an extra risk factor for our older children and adults with PWS. We have had several deaths from gastric rupture and necrosis. Most of these were over the holidays or special events and due to a food binging episode that led to necrosis (deadening of the tissue) of the stomach wall and a perforation (tear) in the stomach. In most of the deaths, the person with PWS was relatively slim, so there was no great concern about weight gain. Keep in mind that a person with PWS who is slim still does not have total food control. The lack of feeling full, the high pain threshold, and a weak vomiting reflex increase the potential of filling the stomach dangerously full.

Please see that the safety and security that your child deserves is provided. ■

Flu, continued from page 2

tamiflu for infants less than 1 year of age. Relenza is approved for individuals 7 years and older and comes as a dry powder inhaler.

In summary, all children with PWS should be vaccinated for both the seasonal and novel H1N1 influenza viruses. Remember to have our PWSA (USA) Medical Alert booklet with you at all times which explains the unique medical issues of PWS. It may be ordered from our web site at www.pwsausa.org or by calling 800-926-4797. ■

Help, continued from page 4

medical staff who are not psychiatrists but are making decisions on psychotropic medications.)

ADDITIONAL RESOURCES:

• **Psychiatric Primer by Drs. Forster & Gourash** - a more detailed resource. Available at www.pwsausa.org or www.pittsburghpartnership.com.

• **A Pilot Study of Psychotropic Medications in PWS** (from *The Gathered View*) by Dykens & Roof. Available at www.pwsausa.org ■

IPWSO, continued from page 7

HOTELS

There are many hotels to cater for everyone's choice and a quick and easy rail connection straight to the Taipei County Hall.

VIDEO

<http://www.pwsa.org.tw/images/ipwso.wmv>

EXPRESSION OF INTEREST

To register your interest, receive registration papers and further information please go to:

http://www.pwsa.org.tw/meeting/index.php?option=com_contact&task=view&contact_id=1&Itemid=85

http://www.pwsa.org.tw/meeting/index.php?option=com_contact&task=view&contact_id=1&Itemid=85

TAIWAN PWS ASSOCIATION WEB SITE

<http://www.pwsa.org.tw/web> ■

Locking Resources

Following are links to places that sell keyless entry locks and other items for safety. This information was provided by a member of the 0-5 e-mail group.

Magnetic kitchen locks http://www.kidsafeinc.com/c=T3BDKKycS2WkUHtVXvo2WO5tn/product/71175/Cabinet_Locks_Magnetic_Tot_Lok_Deluxe_Starter_Set.html

Double-sided keyless entry door lock to prevent your little one from getting out of the house <http://shop.keyless-entry-locks.com/category.sc?categoryId=20>

Refrigerator lock (not for the side by side ones) http://www.marinelock.com/Refrigerator-Locks_c_1.html

Video monitoring systems http://www.avtechsolutions.com/s_baby_monitor_wireless.htm

Medic alert bracelets <http://www.laurenshope.com/category.aspx?id=128>

Fundraising Grassroots Fundraisers for PWSA (USA)

By Rachel Elder

Ethan's Shamrocks

Apollo Ridge Elementary School in Spring Church, Pennsylvania, held a fundraiser in honor of **Ethan Dean Arbuckle**, who has PWS and will celebrate his 7th birthday on September 3rd. The students raised more than \$200 for PWSA (USA). For a dollar, students purchased shamrocks on which they wrote their names. The shamrocks were then displayed at the front entrance of the school, which was covered in green by the end of the fundraiser. "The final result was a great display of caring by the students," wrote Chad Danka, student council sponsor and 5th grade teacher.

Brian Gill's Marathon

It is amazing what you can do when you set your mind to it. **Brian Gill**, dad to Gavin, who is 3 with PWS, and Kevin McElmoyle, Gavin's cousin, ran the Boston Marathon for the first time in April 2009. They trained hard for the 26.2 miles. Plus preparing physically, Brian also set out to raise funds for PWSA (USA). "Brian is loved by many in the community. So when people heard what he was doing, everyone wanted to contribute and get involved. People from his work at the Boston Police Department and BMC Court really stepped up to support him and PWS," said Karen Gill, Brian's wife. The Gills raised more than \$8,000 to support PWSA (USA). Congratulations, Brian!

The 2nd Annual Long Island Walk for PWS

Approximately 70 people arrived to walk for PWS in Long Island on May 17, 2009. **Nancy Behringer**, mother to Peter, three with PWS, and host for the walk, told us that her favorite part of the event was having all the different families meeting each other and having new families attend this year. Nancy said, "There are many families on Long Island with children with PWS, and we would like them to get together to help us make this walk bigger and better each year." There is a voice and awareness in numbers. The event raised over \$12,000.

3rd Annual Softball Tournament in Honor of Anneke Kramer

On June 20th, eight softball teams met in Iowa for the 3rd Annual Softball Tournament and Silent Auction in Honor of Anneke Kramer. Says **Stacy Kramer**, mother of Anneke, three with PWS, "We couldn't do this without the support of family." Stacy and sisters Shannon, Stephanie and Jenna have

"Sacrifice is giving something up to have something better." ~unknown

worked hard for three years to make each event a success. This year, they raised more than \$10,000 for PWSA (USA) and PWS Iowa. "Shannon, Stephanie and Jenna do a lot of the work from afar. I get the field ready and do the clean-up work," said Stacy. "My husband's family also contributes a lot, bringing donations from Rapid City, South Dakota." Blessed with gorgeous weather, the family also feels blessed to donate funds to support PWSA (USA) and build a financial base in Iowa.

Mike Kuna's Seattle-to-Portland Bicycle Classic

Mike Kuna likes a challenge. Together with nine other teammates, this father of Jack, seven with PWS, rode in the Seattle-to-Portland Bicycle Classic in July on Beach Cruiser bikes, which weigh 42 pounds and have one speed. As Mike explained in the May 2009 issue of *repertoire*, "I had done triathlon races, so biking 200+ miles did not seem like a huge challenge. But we discovered how difficult it is using cruiser bikes. This helps [convey the challenges] of living with Prader-Willi syndrome." The team rode those cruisers for 203 miles. Each year the team grows. The first year it was Mike and his brother. Then news spread, and eight fellow employees signed



Kuna's Cruisers: left to right: Mike Kuna, Matt Oein, Jeff Montague, Brady Bernhoft, Jake Barga, kneeling (Scott Kuna) Paul Benga, Max Geittmann, Everett Papulias

up to ride this year. Mike and team have donated over \$2,000 to PWSA (USA) for research, with more donations forthcoming.

The **2nd Annual Casting for a Cause Fishing Tournament** will be held March 4-7, 2010, at Homestead Bay Front Park in Homestead, Florida. For information, visit www.castingforacause.com or contact Michelle Torbert at 305-245-6484. Proceeds benefit PWSA (USA) and PWFA. Save the date! ■

Ask the Parents

This column will appear from time to time, asking parents to share their wisdom and experience. There were so many wonderful responses to this question that more will appear in subsequent issues.

Q. None of us expected to have a child with a disability or a birth defect, let alone Prader-Willi syndrome. How do you mentally approach that this has actually happened to you, that you have a child with PWS?

You cry and grieve for what has been lost. You read the lovely poem by Emily Kingsley "Welcome to Holland". You realize this hasn't happened to you—it has happened to your child and it is so unfair. You realize you've been chosen to help her/him through it. Your child works so hard to do what comes as easy as breathing to others. Routines get messed up and meltdowns occur. People stare. Well-meaning friends offer a piece of candy or a treat, not understanding the uncontrollable urge to eat—surely willpower can overcome?! Educating the educators—a constant effort. Experimenting with vitamins and medications to see what is the best solution for your child.

Our child has PWS. We occasionally let PWS have us. God blesses us daily and we must use our faith to help us through. It is not easy and never will be, for we are the parents of a child with Prader-Willi syndrome.

~ Diane Bishop (mom to 8-year-old triplets Sydney, Dustin, and Samantha, who has PWS)

God doesn't give me more than I can handle, so he must have equipped me to be the best mom for Spenser.

~ Linda Thomas (mom to Spenser, 14)

Do we ever totally fully accept that this has happened? I am not sure. When I first read the question I thought, oh we totally accepted it right away and moved on. But Elsa's second birthday just passed, and there is a little question in our minds about what she would be like if she didn't have PWS. Would she be walking, running with the older kids, talking back to me like they do? Maybe so.

As time goes on, we tend to forget about Prader-Willi. Yes, it's in her whine and sign to eat. Yes, it's in the fact she can't walk. But she is the happiest kid. Smile on her face for everyone. Would we change anything? No, never. It's rather nice to have only three kids talking back instead of four, three kids to clean up after instead of four.

With Elsa, you have to stop and smell the flowers, so to speak. Every joy in life is a big one. The

other day she was given a cookie, a rare treat. She sat on her grandpa's lap, eating it. Her eyes were closed as she ate EVERY last bite. She was in pure bliss. Every now and then she would open her eyes and smile at the cookie. If we could all enjoy something that much each day, life would be great.

We have come a long way with her, my husband and I and our children. Our other children accepted her as she is right away. She is just Elsa. But as much as on top of her care we are and how much we have gone through with just a shrug of our shoulders, we will ALWAYS have a little amount of grief for the healthy child we didn't have. So I guess we have accepted Prader-Willi but not totally 100% that it really happened.

~ Sarah Reddig (mom to Marissa, 6, Lance, 4, Gabe, 3, Elsa, 2 with PWS, and another due in Jan. 2010!!)

I am a daycare provider and care for 12 children, all various ages, all "normal" according to their parents. (Keep in mind that "normal" could mean different things to different people.) Anyway, after seeing these parents handle their "normal" children, I have come to believe that God gave this child to me because he knew that I could care for her and handle all that comes with her and that she never would have survived if he would have given her to any of them!

~ Tammy Graesser (mom to Hope, 9 with PWS by UPD)

Getting the news that our precious baby is not whole and healthy as we expected is devastating. Learning how to grieve and deal with the myriad of emotions that follow the joy of a new child and the sorrow of unfulfilled expectations is heart wrenching.

I learned very early that I was never more overwhelmed--almost to the point of panic--than when I thought of the future. It took, and continues to take, great effort to live each day with my amazing son, Cainan, and not dwell on what's in store for him. Truthfully, none of us knows what's in store for our children anyway. But it was so easy to get caught up thinking about trick-or-treating at Halloween, Thanksgiving celebrations, sleepovers at other little boys' houses, birthday parties with cake & ice cream, living with him the rest of our lives or giving him up to a group home far away--one worry led to another and another and another until I could barely breathe and I felt hopeless.

I had to force myself not to think of any of those things. Any time I started to wonder what it was going to be like "when," I would close my eyes and tell myself to stop. I've learned to live

Parents, continued on page 12

each day as it comes and celebrate each wonder and accomplishment as they come. Cainan's five, and we've made it though so many of the events I was sure would be obstacles or severely altered occasions from our family traditions--none of it has been a real problem. I've learned to be creative and we adjust, but it's all working.

Once you get past those early days of grieving and accepting the new life your child is going to have, then you can openly embrace the joy of loving the special one you've been given for just who they are. Taking one day, one moment, at a time, helped me through the grieving process because I realized I was mourning things that may or may not ever happen. There will still be times of sorrow and bitterness, but every day is a little easier.

I was also given a wonderful essay very shortly after Cainan's birth. It soon became tear stained and tattered but I still have it. I think any person who has been given the news that their child is not "normal" should get to read this beautiful essay, "Welcome to Holland". ■

~ Heather Molzer (mom to Cainan, 5)



Julie participates in a special group with the Dave Ragnacci dance studio in Scranton, where she lives in a group home. After the initial grief and the struggles with food and behavior (both now somewhat decreased), there really are lovely things in Holland!

~ Lota Mitchell
(mom to Julie, 39)



Peder just graduated from high school two weeks ago at Woods Services. Peder was class valedictorian. When asked how he got that honor, he replied, "They picked my name out of a hat!" The real chuckle, though, was when Peder said, "Mom, I have a zit on my apple core" (i.e., Adam's apple).

~Susan Lundh, Seattle, Washington

WELCOME TO HOLLAND

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome To Holland".

"Holland?!?" you say, "What do you mean "Holland"?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy" But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes that's where I was supposed to go. That's what I had planned".

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.



You Made The Difference! NIH Has Renewed Our Consortium Grant

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

I asked all of you to send a letter immediately to your legislators and the director of the National Institute of Child Health and Human Development (NICHD) to save the funding for the NIH (National Institutes of Health) Rare Disease Consortium for Angelman, Rett, and Prader-Willi syndromes. Our PWS researchers were at grave risk of losing funding for the five-year renewal. It would have been a huge setback for PWS research.

Dr. Dan Driscoll, principal investigator for the PWS consortium, states that your grassroots advocacy appeared to make the difference. NICHD has agreed to renew our consortium for the next five years. Of the ten consortia initially funded and from over 60 applications, only five were approved for the next five years – ours being one of them.

Whenever you think you are too insignificant to make a difference, remember that together we have the vision of making this a better world for our children with Prader-Willi syndrome, and together we can be powerful in action.

*Vision without action is
merely a dream.*

*Action without vision just
passes the time.*

*Vision with action can
change the world.*

- Joel Barker

The Rainbows In Our Lives

Many of you know about our petite angel of mercy, **Norma Rupe**, who has coordinated our bereavement program and study of death project for many years. Norma is 84 years old, but until recently, had the energy and enthusiasm of a young woman. Norma followed me here from St. Louis where I was the social worker for her two-year-old grandson who had cancer. Norma became my best volunteer at St. Louis Children's Hospital.

After Norma's only daughter, Pat, died in a car accident, Norma and her husband Bill moved here and she started volunteering for me at the PWSA (USA) office. With Norma's sensitivity towards grief, she has been an ideal support person in her role. Unfortunately, in April Norma's only other child, Michael, died suddenly of a heart attack, and less than two weeks later Norma was diagnosed with bladder cancer. While getting chemotherapy and radiation, Norma fell and broke her knee, then had a heart attack. In spite of all of this, she still remains our sweet Norma. Please keep her in your prayers.

Another outstanding volunteer that has continued to volunteer weekly for years is our PWS grandmother, **Marsha Dunn** -- in spite of losing her husband and undergoing years of chemotherapy treatment for leukemia. What drives a person to have the kind of dedication we see from our volunteers at the office (including those out of the office such as our board, fundraisers, and the many others who make the difference at PWSA (USA) like Norma and Marsha? I look at the qualities of each of these volunteers, and the commonalities

I have observed are that:

Each has risen above tragedy in their own lives so is not afraid of embracing others in pain.

Each has been taught that special quality of self-sacrifice and the joy of helping others.

Each has a wonderful sense of humor and a wonderful sense of compassion.

*Rainbows are
people whose lives
are bright, shining
examples for others.*

- Maya Angelou

Shine on, shine on.
The world needs more
people like you.

If anyone wants to send a card to Norma, mail it to:

Norma Rupe
4660 Ocean Boulevard
Unit L1
Siesta Key, FL 34242

Janalee ■

RESTRAINTS AND SECLUSIONS

Following is an important update on the issue on restraints and seclusions which was raised in Evan Farrar's Executive Director View in the July-August GV. Here is the link so people can read the letter if they wish.

<http://www.ed.gov/policy/elsec/guid/secletter/090731.html> ■

Down in The Dumps With Dysthymia

- for parents (and siblings) coping with PWS

By Lota Mitchell, Editor, The Gathered View

Everyone has rotten days now and then when the world seems upside-down, nothing goes right, and they feel depressed. The good old blues go away in a day or so. However, perhaps 10% of the population feels even more blue because they are suffering from clinical depression, which has much more serious symptoms, doesn't disappear, and often requires psychotherapy and/or medication.

Another level of depression much less familiar is dysthymia. According to the Diagnostic and Statistical Manual of Mental Disorders IV, "The essential feature of Dysthymic Disorder is a chronically depressed mood that occurs for most of the day more days than not for *at least two years*." A diagnosis of a Major Depressive Episode requires a minimum period of only *two weeks*, but more symptoms are required and they must be occurring every day, especially the "depressed mood and/or loss of interest or pleasure in nearly all activities."

For a diagnosis of dysthymia, at least two additional symptoms must be present when the mood is depressed: poor appetite or overeating, trouble sleeping or sleeping too much, lack of energy or fatigue, low self-esteem, difficulty with concentration or making decisions, and feelings of hopelessness. Often self-criticism and little interest in anything makes individuals feel uninteresting, inadequate and even incapable, regardless of how well they are functioning.

People with dysthymia are in

between clinical depression and normal mood. Often they have felt sad and down in the dumps for so long that it seems "normal", and they may conclude "That's just the way I am."

Children and adolescents with dysthymia may seem irritable and cranky rather than depressed, and the required time period is *one year* instead of two. Often they have low self-esteem, poor social skills, and are pessimistic; school performance may be impaired. In childhood, it seems to occur equally in boys and girls, but in adulthood women are two to three times more likely to be affected by dysthymia.

Many of the current anti-depressant drugs are being found to be effective, along with psychotherapy.

Here is one mother coping with the demands of PWS who recognized her need for help.

"Like many parents walking this journey, I am not always so positive. Last summer in particular I got to a very dark place, emotionally and mentally; I wanted to give up. I remember waking up one morning unable to move. I did not want to be a mother of a special needs child for one more day. I had lost the fight and could not take the next step in this process of recovery for our son. I have always believed in recovery... if I worked hard enough...if I gave enough, loved enough...I could fix this.

"It took everything inside me to seek the help I needed. I never wanted to ask for help in any way. I am and have always been the strong one. At the end of each day I would lie in bed thinking that there was still so more that I could do to help my son. It is never ending; my task is never done.

"I have had to make many changes in my life. I had to tell my doctor what I was feeling. I am now on medication to help with my

anxiety. I have a Home Health Aide who comes and helps with our son a few days a week. Our "team" from the Autism Center has lifted a huge weight off my shoulders--helping us come up with strategies to decrease the outbursts and tantrums that our son has daily, and teaching him to cope with life and how it affects him emotionally.

"But here's the really good news...I don't have to have all the answers!! I am feeling so differently these days...I am enjoying my life and my family!!" ■

Chapter Conferences

Chapters are becoming more active in having conferences, making it easier for people to get to them. Here's the list:

Utah's Chapter Conference was on September 4th in Salt Lake City.

Florida PWFA fall conference is September 25-26 at the Regal Sun Resort, Lake Buena Vista. For more information: www.pwfa.org.

New Jersey will present "A Workshop with Janice Agarwal" an expert Pediatric Neuromuscular and Sensory Integration Physical Therapist, November 15. Tentatively to be held in Cherry Hill with two sessions, event is free, but pre-registration is necessary. For more information: pwsa.nj@gmail.com.

Oklahoma presents its 13th Annual Chapter Conference, October 3, at the Orr Family Farm. Guest speaker is B.J. Goff. There will be supervision and many activities for individuals with PWS and siblings. For more information regarding activities and directions: www.orrfamilyfarm.com. Register by September 18 by contacting Daphne Mosley, 405-677-8089 or rdmosley@swbell.net.

New York will present its 20th Annual Conference on April 29, 30 and May 1, 2010 in Albany. A great slate of speakers is already signed up. More information will be posted on www.prader-willi.org. ■

Contributions

Thank you for Contributions in June and July 2009

We try to be accurate in recognizing contributions, and apologize for any errors or omissions. If you notice an error, please tell us.

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



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www.pwsausa.org

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

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User Name: pwsamember
Password: sarasota8588

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

The Gathered View (ISSN 1077-9965)

Editor, Lota Mitchell
GV Designer, Sara Dwyer

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

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Aug. 1; Oct. 1**

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