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

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

Registration is Underway!

32nd Annual PWSA (USA) National Conference

November 7–9, 2013
Buena Vista Palace Hotel & Spa
Walt Disney World
Orlando, Florida

Registration and additional information available at www.pwsausaconference.com

What are the dates of conference?

- Scientific Conference, Professional Providers and Chapter Leaders - Thursday, November 7, 2013
- The General Conference with programming for parents, children and young adults - Friday, November 8, 2013 and Saturday, November 9, 2013
- The Conference Gala and Dinner - Friday evening, November 8, 2013

What programming will be provided for children and adults?

- Two full days of General Conference sessions
- Two full days of programming for children birth to age six in our YIP program on Friday and Saturday, November 8 and 9
- Two full days of programming for children and young adults with PWS ages 7+ in our YAP program on Friday and Saturday, November 8 and 9
- Two full days of programming for siblings of the individual with PWS ages 7-15 on Friday and Saturday, November 8 and 9
- LIMITED ENROLLMENT: Enrollment in the YIP, YAP, and Sibling programs is LIMITED and will be filled on a first-come, first-served basis as follows:
- YIP: Limit is 5 infants (birth-1) and 55 children (ages 2-6)
- YAP: Limit is 84 individuals ages 7+
- Sibling Program: Limit is 30 siblings ages 7-15

How much will it cost?

- The room rate at the Buena Vista Palace Hotel & Spa, Lake Buena Vista, Florida, starts at just $129 a night, plus tax and resort fee. The rates are available for the three days prior to the beginning of conference and three days after conference ends if you would like to extend your stay in Orlando. A link to our discounted reservation rates will be available on the conference website.
- Room rate includes FREE Walt Disney World Transportation Buses to all Disney Parks.
- As a hotel guest and conference attendee, you can enter any Disney Park from 4:00 to close for only $59 per person.

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Conference General Sessions Include:

- Psychotropic Medications
- Wills, Trusts, & Guardianship
- Growth Hormone
- School Issues and Creating a PWS IEP
- Diet and Nutrition
- Speech Therapy
- The Adult Years – Maturing and Behaviors
- Nutrition for Infants and Young Children
- Childhood Medical and Behavioral
- Gastroparesis
- PWS Overview
- Family, Marriage, and Siblings
- Therapeutic Interventions
- Scoliosis
- Supported Living & Employment
- Scientific Overview
- Ask the Docs

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In this Issue

Volume 38, Number 4 ~ July-August 2013 ~ Our 38th Year of Publication

Growth Hormone – How Much Is Too Much?

by Janalee Heinemann, MSW
PWSA (USA) Director of Research & Medical Affairs

We know that growth hormone treatment is one of the best things that ever happened to improve the quality of life for children and adults with Prader-Willi syndrome (PWS). But, due to the enthusiasm of parents, and the lack of knowledge of some physicians ordering the growth hormone, we think it is important that you have a better understanding of the consequences of too much growth hormone (GH). In the past we have published information by Dr. Jennifer Miller on high IGF-I levels which can be a warning that the person is on too much growth hormone. Here I would like to focus on how a physician (and parents) can calculate appropriate dosage. I recently received a call from a mother who found out that her eight-year-old has been on a growth hormone dose that was probably almost double what it should have been, which in turn has created significant gigantism/acromegaly. (Too much IGF-I can cause abnormal growth of your soft tissues and skeleton creating excessive overgrowth of facial features. Gigantism is GH excess in children and acromegaly is in adults) This mom said she trusted that the physician knew the proper dosage and she did not have any concept of what would be an appropriate dose, so I'd like to give some of the guidelines from PWS experts that you can share when necessary.

From the second edition of our PWSA (USA) growth hormone booklet:

For infants with Prader-Willi syndrome, the dosing is based on body surface area. The typical starting dose is 1 mg/m2 per day. In older children, beginning doses are typically calculated based on weight alone, or ideal body weight if the child is significantly overweight. Most endocrinologists adjust doses in older children after monitoring growth velocity, weight and IGF-1 (Insulin-like Growth Factor-1) level. The largest dosage is given at the time of puberty, when children normally have their last big growth spurt. For adults, there are standardized dosing regimens for beginning GH treatments. The adult dosage then is subsequently titrated based on IGF-1 levels.

From Dr. Sue Myers, endocrinologist on our PWSA (USA) Scientific & Clinical Advisory Boards

Although the official recommended Genotropin dose for pediatric patients with PWS is 0.24 mg/kg/wk (for example, 1.5 mg daily for a 100 lb child), I would add several caveats. First, many people with PWS are very sensitive to the effects of GH. In my experience, they may need significantly less than this recommended dose to achieve IGF-1 levels in the upper half of the normal range, sometimes half as much or occasionally even less. Second, overweight children's doses should be calculated based on their ideal body weight for height.

Dr. Barbara Whitman and I did a dosing study many years ago with Drs. Allen and Carrell. We found the positive effects of GH on growth and body composition to be dose-dependent, but the side effects will likely be as well. Following IGF-1 levels at least annually is critical to avoiding overtreatment as described above.

From Dr. Moris Angulo, endocrinologist on our PWSA (USA) Clinical Advisory Board

Children with PWS seem to be a little bit more sensitive to standard doses of growth hormone (GH). The dose should be considered on ideal weight and monitor clinically features of excessive GH such as rapid growth, unusual enlargement of hands, feet and jaw as well as advanced bone age. Having at least 3 visits per year to a pediatric endocrinologist could help to identify early signs of under & over GH treatment.

From Dr. Jennifer Miller, endocrinologist on our PWSA (USA) Clinical Advisory Board

It is important for you to know that GH dosing needs to be adjusted for each individual and not only based on standardized dosing. ■

Conference, *continued from page 1*

Online hotel reservations at the negotiated discounted rate can be made now with this direct link; our discounted rate at the hotel is https://reservations.ihotelier.com/crs/g_reservation.cfm?groupID=759035&hotelID=6579. If you prefer to call and make reservations, call 1-866-397-6516 and mention **PWSA (USA) National Conference** or use the block code 1104577PW to receive the discounted conference rate.

Conference Registration Fees:

$250 per person until midnight on September 30, 2013. $275 October 1-15. Registration closes on October 15th. This fee includes breakfast and lunch on Friday and Saturday.

- YIP Infants (0-1) $125
- YIP Children (ages 2-6) $150
- YAP Participants $200
- Siblings - $150 ■

25-Hydroxyvitamin D3 Deficiency in Prader-Willi Syndrome Patients

A research study by
Jaimee L. Gribben, B.S., William B. Zipf, M.D., Rolando Lozano, M.D., and Patricia Graves, C.P.N.P., C.D.E.

Funded by Prader-Willi Syndrome Association of Ohio

The morbid obesity commonly seen in patients with Prader-Willi syndrome is treated only by enforcing strict dietary intakes, with daily caloric values of commonly less than 1000kcal/day, putting patients at risk for micro- and macro-nutrient deficiency.

This study is a retrospective review and convenient sampling survey of patients with PWS, followed by Central Ohio Pediatric Endocrinology and Diabetes Services (COPEDS) over an 18-month period of follow-up to establish vitamin D sufficiency. Using laboratory studies, we found that 28 out of 48 patients had deficient 25-hydroxyvitamin D3 blood levels of below 32ng/mL (80nmol/L), the level recommended to be sufficient by recent studies and laboratory values. Of the 33 patients that had the recommended bone density testing completed, 11 were osteoporotic, 17 were osteopenic and 5 were within normal T-scores. This group is already at high risk for osteoporosis for numerous reasons, including pituitary hormone abnormalities, sedentary lifestyle, increased bone turnover and vitamin D deficiency.

Therefore, daily supplementation of 2000 IU of vitamin D is recommended as part of the treatment regimen for Prader-Willi syndrome. These findings also may have applicability extended to other groups of cognitively impaired individuals.

More on vitamin D for PWS

With the new recommendations by AAP and clinical endocrinology for vitamin D levels, a larger population is either insufficient or deficient nowadays. Therapy is based on measurements of 25 (OH) D3 levels. Normal is 30 – 100 ng/ml. Levels less than 20 ng/ml is indicative of vitamin D3 deficiency, while levels between 20 and 30 suggest insufficiency. Vitamin D levels in obesity in general are lower than in the general population and has an inverse correlation with BMI regardless of the cause.

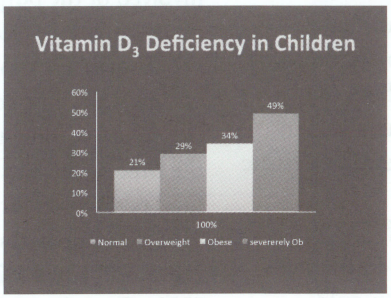
Although parents of children with PWS might want to believe that vitamin D deficiency is the cause of their child's obesity, obesity-associated vitamin D insufficiency is likely due to the decreased bioavailability of vitamin D3 not only from dietary but also cutaneous sources because of its deposition in body fat compartments; adipose tissues traps significant vitamin D from circulation. It has been shown that higher BMI leads to lower vitamin D status, providing evidence for the role of obesity as a causal risk factor for the development of vitamin D deficiency.

In children, the bone mineral density should be evaluated with Dexa scan and Z score instead of the T score used for adult population. Ideally, patients should be treated based on their levels, but I believe that vitamin D dose of 2000 IU is still safe for the teen or adult with PWS. ■

Moris Angulo, M.D.
Winthrop University Hospital

Parents of children under age 16 should check with their pediatrician or pediatric endocrinologist to get the vitamin D level tested and the recommended starting dose for their child. ■

Jennifer Miller, M.D.
University of Florida



Procedure for Tissue Donation to Support Research on Prader-Willi Syndrome, 2013

One of the ways researchers seek knowledge about the causes and possible treatments for Prader-Willi syndrome is through study of bodily tissue from individuals with the syndrome. Brain tissue, in particular, is critical to researchers who are trying to learn why PWS causes dysfunction in the hypothalamus portion of the brain. While samples of some bodily tissues can easily be obtained at the time of a scheduled surgery, brain tissue is only available after an individual's death and must be ***obtained and preserved within hours of death to be useful to researchers.*** This requires planning and a prompt decision from the individual's family as well as a major coordination of effort.

Some families will find this difficult to contemplate, in the same way that some feel they could not consider donating organs for transplant when a loved one dies.

continued on page 4

Tissue Donation, *continued from page 3*

However, other families find that such a donation gives greater meaning and purpose to the life of their loved one with PWS. When one such family tried to arrange a tissue donation at the time of their child's death, it became clear to PWS researchers and the many others who became involved that a procedure was needed to simplify the process and reduce the burden on a grieving family.

To facilitate tissue donation for PWS (USA) research purposes, the PWSA Scientific Advisory Board has established a procedure in conjunction with the Brain and Tissue Banks for Developmental Disorders centers that are funded by the National Institutes of Child Health and Human Development. These are designed specifically to register donors and to collect, preserve, and disseminate tissue for research.

The Procedure in Brief

They will pre-register individuals with PWS whose families would consider making tissue donations. In addition to brain tissue, other bodily tissue can be helpful to PWS researchers and could be obtained, with the family's or individual's permission, at the time of a planned surgery or biopsy for medical reasons.

The banks have 24-hour phone numbers that families can use to get information and counseling about tissue donation and to arrange for tissue collection in advance of a medical procedure or in the event of death of the registered family member.

Even if a family has not pre-registered, an immediate call to the nearest tissue bank may make possible a tissue donation in the event of sudden death of the loved one with PWS.

Tissue that is collected from individuals with PWS is catalogued and stored at the banks for potential research projects, and PWSA (USA)'s Scientific Advisory Board will make recommendations regarding the release of PWS tissue for specific research proposals.

Some Reassurances

Tissue donation and the death of a loved one are not easy things to consider. Many questions may come to mind, most of which can be answered by a phone call to the Brain and Tissue Bank counselors. Families should be assured that, given the sensitive nature of their task, the Brain and Tissue Banks have set as their highest priority "the emotional and physical well-being of the families and individuals" with whom they interact. Families who call for information are not pressured to register.

Time is taken to inform everyone involved of the purpose and process of tissue donation. Donor information is kept in strictest confidence. Registration is not an absolute commitment to make the donation; only the next of kin at the time of the person's death can give final permission for tissue retrieval.

NICHD Brain and Tissue Bank for Developmental Disorders (covers USA, Canada, and international)
Key Telephone Numbers
University of Maryland
655 West Baltimore Street, BRB 13-013
Baltimore, MD 21201
Project Coordinators Anthony Weldon & Deanna Wilson
1-800-847-1539 or 410-706-1755
Fax: 410-706-2128
E-mail: btbumab@umaryland.edu
Family Website: www.btbankfamily.org
Researchers Website: www.btbank.org ■

The 2013 Headley Family Scholarship to Support Young Investigators

A limited number of travel awards will be available for trainees presenting their research at the 2013 PWSA (USA) Scientific Conference via The Headley Family Scholarship. Jay Headley was the proud father of J.R. Headley who has Prader-Willi syndrome and lives in Columbus, Ohio with his mother Kerry. Jay passed away in November, 2010, after a battle with colon cancer. The Headley Family Scholarship began in 2012 as a means to support the attendance at the Scientific Conferences for young investigators.

Eligible trainees include undergraduate and graduate students and postdoctoral and clinical fellows. These awards provide young investigators whose abstracts are accepted for abstract or poster presentation with $500 in reimbursement for travel and lodging expenses. Abstract submission is mandatory for travel award eligibility; it does not, however, guarantee that the presenter will receive an award. Reimbursable expenses include conference registration fee, mileage, airfare, hotel, meals, and taxis. Award funding will be disbursed after the meeting, upon submission of travel reimbursement forms and accompanying receipts.

Eligibility Criteria

Travel awards are open to all individuals who meet the following eligibility criteria:

- Applicants must be active in research as a student or as a resident or a fellow who completed doctoral training within the last four years. Women and minorities are encouraged to apply.
- There are no citizenship or residency requirements.
- Applicants must be listed as the presenter of the abstract.

Award Determination

The Travel Award Selection Committee will award travel grants based on abstract quality, applicant statement and the letter of recommendation. Selection notifications will be sent by email to all applicants in September 2013.

Look for details on how to apply on the PWSA (USA) website under the Conference link. ■

PWSA (USA) 2013-2016 Board of Directors - Approval of 2012 Annual Membership Meeting Minutes and Election

Voting Instructions:

1. Review the candidates' statements printed on the Slate of Candidates. Read the 2012 Annual Membership Meeting Minutes.

2. Cast your vote on the Official Ballot **located on page 7.** Note any corrections necessary to the Annual Membership Meeting Minutes. Insert the ballot into the Official Ballot Envelope.

3. Print and sign your name on the Official Ballot Envelope. Affix postage. Mail it to PWSA (USA) postmarked no later than August 30, 2013.

4. If you receive *The Gathered View* only in an electronic form and were not provided with an Official Ballot Envelope, please mail your ballot to: Julie Doherty, Secretary, PWSA (USA) 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471. In the return address portion of the envelope, print your name and address and the following statement: **"I am/We are a PWSA (USA) Member in Good Standing Eligible to Vote."**

Place your signature below this statement.

Deadlines: The deadline for voting is August 30, 2013. Ballots postmarked after August 30 will not be counted.
Confidentiality: Your vote will be kept confidential. PWSA (USA) staff will verify voter eligibility and separate the Official Ballot from the Ballot Envelope before the Ballots are tallied.
Voting Criteria: Voting members must be Members in Good Standing with PWSA (USA). Membership dues must be current and paid in full or a dues waiver granted.
Member Types Eligible to Vote: Each membership type, whether individual, family or professional, is entitled to one vote.

PWSA (USA) Annual Telephonic Membership Meeting Minutes

Monday, October 29, 2012

The meeting was called to order by Vice Chairman Ken Smith at 8:02 p.m., EST.

Ken Smith advised there were no new additions to the national board of directors. John Heybach and Ken Smith were elected for another year as board chair and vice chair, respectively.

Dottie and Dale Cooper provided an overview of the national office operations. Dottie expressed the honor she and Dale have felt to spend time with our national office staff. The association is thriving, and many new initiatives are underway. The State Leaders Team was formed this year with a goal of a strong state chapter in all 50 states. The Family Support Staff is compiling a list of resources in each state. They also will have a "Train the Trainer" session in early 2013 which will enable program participants to better advocate for the person with PWS within the educational setting. Several new publications were developed this year: How a Person with PWS Thinks, What Educators Should Know, Medical Overview of PWS, and Helping Families and Professionals. Numerous additional publications are in the design and review phase.

The Second International Hyperphagia conference was held this month in Baton Rouge, as well as a State Leaders Meeting, SAB and CAB Meetings, and Professional Providers Meeting. These meetings were held at the Pennington Biomedical Research Center, which is part of the LSU medical center. We anticipate a continued relationship with this facility.

The office converted to a new IT system, and the transition is going smoothly.

Dale discussed the Angel Fund campaign. This is the one yearly fundraiser to cover operations expenses and enable us to continue all the programs and services we offer. In excess of 10,000 mailers will be sent in early November, as well as postings in the E-bulletin. These funds are critical to maintaining our ongoing operations. A new fundraising activity will debut through our state chapters that will take place year round. The funds raised will support our state chapters as well as the national office. He also noted our annual audit is complete and the state of the association is very good.

Plans for Conference 2013 are well underway. Michelle Torbert is conference chair. It will be held in November of 2013 at the Buena Vista Hotel in Orlando, same location as the 2011 conference. Begin budgeting now to attend.

Ken thanked the Coopers for all they have done for PWSA (USA) since April. They have brought many positive changes to the office. It has been an honor to work with them.

The Coopers thanked the board members for their dedication and hard work. They noted that without our host of volunteers, the organization would not be as successful as it is.

Ken also noted that the boards of PWSA (USA) and

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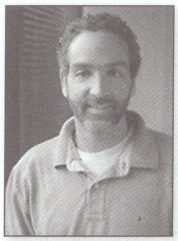
Board of Directors Nominees

Michael Alterman has been involved with PWSA (USA) since early childhood. He is fourth of the five children of Paul and Pam Alterman. Michael, along with his brother Andrew (42 with PWS) and older sister Katie Rosenberg, attended every national conference from 1989 to 2003 and served as a assistant director of the YAP program from 1998-2003. After graduation from Clemson University, Michael began his career in commercial real estate. He now runs a commercial real estate investment company called HT Group, LLC in his hometown of Atlanta, Georgia. Michael serves on many local and national non-profit boards including trustee of the Sam P. Alterman Family Foundation. But no organization or cause is dearer to his heart than PWSA (USA). Michael brings a unique perspective to the PWSA (USA) Board of Directors not only as a sibling to PWS but also as Guardian and caregiver for his brother Andrew since the passing of their father Paul in 2006. Michael lives in Atlanta, Georgia, with his wife Melissa and their two dogs Stella Blue and Gracie. ■

Sybil Cohen, from Cherry Hill, New Jersey, is a public school teacher in Sewell, New Jersey, a suburb of Philadelphia, teaching visual arts at the high school level. After earning her Bachelor of Fine Arts degree from the Tyler School of Art of Temple University, Sybil studied at the Pennsylvania Academy of the Fine Arts and, after that, received her teaching certification from Rowan University. Husband Michael Burns is also an educator and teaches American History at the college level. Her daughters, however, have been the biggest influence in Sybil's life. Her older daughter Julia, adopted from China as an infant, is now a Biology/Pre-Med major at Muhlenberg College. As a result of the adoption, Sybil joined and then served on the Board of Directors for Families with Children from China, organizing workshops and educational sessions on adoption and trans-racial adoption issues. Daughter Rose was diagnosed with PWS at the age of three. She is now 18 and will be a senior in high school next fall. Immediately after getting the diagnosis, Sybil got involved in the New Jersey Chapter of PWSA (USA), eventually becoming its president, served as a parent mentor for both the state of New Jersey and PWSA (USA), has presented at national conferences, and continually advocates for the educational entitlements of children with PWS. ■

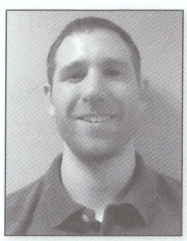


Robert Lutz says, "Ever since my daughter, Isabel, was diagnosed with PWS 13 years ago, I have been an active member of PWSA (USA). I served on the board for six years previously and only stopped when the demands of my career and family kept me from being as good a board member as I'd like to be. I remain active with both the Research Committee and the Finance Committee. I believe that PWSA (USA) serves a number of critical functions for the PWS community including (but not limited to) crisis support, educational support, advocacy with government, chapter support to enable local connections, research support and conference. My goal in serving on the board would be to help support PWSA (USA) to continue with all of its important missions serving the PWSA (USA) community.

I am a finance/strategy executive at a mid-sized pharmaceutical company. In that capacity I have developed skills in drug development, organization strategy and finance– all of which can be valuable in support of PWSA (USA). I believe as a board member I can continue to contribute to the Research and Finance Committees as well as help collaborate on the over direction and strategy of the organization." ■

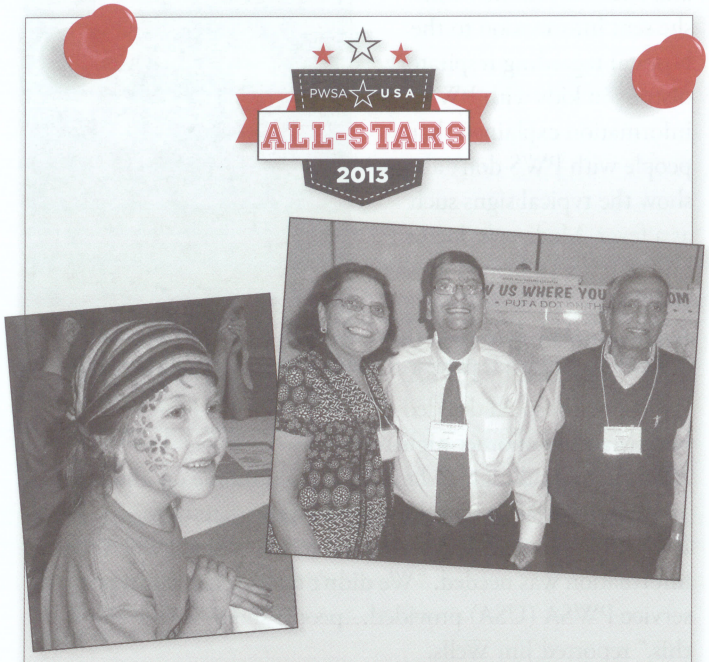
Rob Seely currently works for an architectural firm as a Senior Foodservice Designer, working with national multi-unit restaurants and retailers focusing on the client's objectives for cost, quality and timelines. He lives in Dublin, Ohio, with his wife Diane and their five children, which includes their son Reagan, 10 with PWS. Rob has served on the board of the Ohio Chapter for PWSA (USA), leading several initiatives to develop membership and raise awareness. He currently serves on the board of All God's Children, Inc., an organization that provides funding for medication, food and education for children in Africa. In addition, Rob and Diane are the founders of Reagan's Reach, a non-profit organization committed to addressing the long term residential challenges for those with PWS. He also volunteers at his son's school and for The Ronald McDonald House of Columbus, Ohio.

He says, "I look forward to the opportunity to serve on the board of PWSA (USA) and understand the responsibility to represent not only the organization but all affected by PWS. I embrace working with all of those interested in improving the lives of those living with PWS. Through a combined effort of support, research and advocacy we can provide families hope rather than fear. Together, we can work towards one goal, a better future." ■



Dr. Michael Troop, who has a daughter with PWS, Maia, age two, has been teaching in the Secondary Education Department with National Louis University for five years. He teaches a range of classes in both Secondary Education and Educational Psychology. As the Director for Urban Science, Technology, Engineering Talent Expansion Program (USTEP), he has developed a residency program that aims to support pre-service teacher development in underserved urban school districts. Dr. Troop supports teachers nationally in an effort to develop and support new and existing teachers in areas related to science differentiation, classroom management, Common Core, and Next Generation Science Standards. He brings a wealth of expertise from his work with Academy for Urban School Leadership (AUSL), where he served as an instruction coach and designed the science curriculum for pre-K through 12th grade for 24 Chicago Public Schools managed by the organization.

Dr. Troop is interested in developing high leverage practices for teachers entering high need urban schools. He is in schools regularly and conducts research on issues student teachers and educators struggle with in urban schools and develops programs to support them. ■



PWSA (USA) NATIONAL CONFERENCE

November 7-9, 2013

Walt Disney World

Buena Vista Palace Hotel and Spa

https://reservations.ihotelier.com/crs/g_reservation.cfm?groupID=759035&hotelID=6579

Orlando, Florida

Coming Soon!

PWSA (USA)'s New Website

When: around August 1, 2013

What: newly designed and improved

Thank you, Dr. Forster, for Increasing PWS Awareness in the Psychiatric Community!

Dr. Janice Forster, a child and adolescent psychiatrist and a member of the PWSA (USA) Clinical Advisory Board, reported that over 60 psychiatrists from around the country attended her lecture on Psychiatric Emergencies in PWS given on May 19th at the annual meeting of the American Psychiatric Association held in San Francisco, California. She remarked that an edited clip from Maribel's DVD really enhanced the lecture, and the topic was very well received. At least 1/3 of the audience had had contact with a person with PWS. ■

We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more good work(s) like this.

Please see our web site, www.pwsausa.org

Board of Directors, *continued from page 5*

FPWR continue to communicate at a very high level concerning areas of mutual interest.

The call was opened for questions from the members.

The meeting was adjourned at 8:30 p.m. ■

Julie L. Doherty
Secretary

OFFICIAL BALLOT

Cast your vote for the 2013-2016 Board of Directors. Vote for five (5) of the candidates listed below.

- ☐ Michael Alterman
- ☐ Sybil Cohen
- ☐ Rob Lutz
- ☐ Mike Troop
- ☐ Rob Seely

☐ Corrections to the 2012 Annual Membership Meeting Minutes: _____

_____

_____

_____

_____

_____

☐ No Corrections Necessary (if neither box is checked, we will assume you have no corrections to the minutes)

How Our Organization Helped

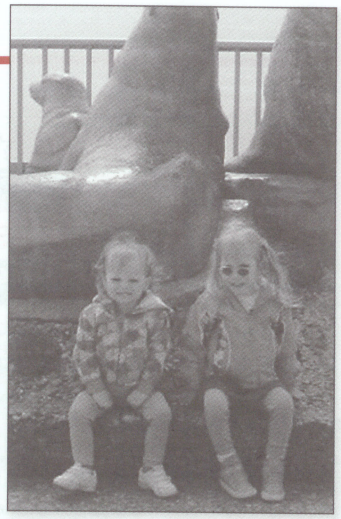
THE WELLS FAMILY

by Denise Servais

The mid-March day started out as a typical one for the Wells Family. Deanna and Jim Wells are co-leaders for the PWS chapter in Idaho. The school called to let them know that their daughter, Madison, age 4 with PWS, was sick. The school informed them that they needed to pick Madison up and take her home. "It was the second time that week that it happened," explained Jim. Apparently, Madison did not have a fever.

Jim and Deanna took Madison to her doctor who, after hearing lung sounds and noting low oxygen, recommended that the Wells take Madison to the ER for a chest X-ray. The chest X-ray showed spots, and Madison was diagnosed with pneumonia and started on antibiotics and given a breathing treatment. The Wells came prepared and gave the ER doctors a medical booklet from PWSA (USA), along with a folder filled with Madison's medical history. Given Madison's history of PWS, sleep apnea, and her current diagnosis, the doctor kept her overnight for observation.

The next day the Wells got a call from the PWSA (USA) office to discuss some unrelated issues. The Wells mentioned that Madison was in the hospital. The woman on the phone asked the Wells if they would like someone to fax some information to the hospital staff. The Wells spoke with Janalee Heinemann (PWSA (USA)'s Director of Research and Medical Affairs), and she sent information to the hospital regarding respiratory distress in kids with PWS. The information explained that people with PWS don't always show the typical signs such as a fever. Madison's doctor said that the information was very helpful in determining a treatment plan. Based on the information sent by PWSA (USA), the hospital decided to keep Madison another night. After the second night, Madison was sent home on antibiotics.



Madison on right, with sister Carly

Both the Wells and the hospital were grateful for PWSA (USA) sending information to the hospital when the information was needed. "We didn't realize that this was a service PWSA (USA) provided…people should know about this," reported Jim Wells.

Madison is back in preschool and doing well. She has a sister named Carly, age two. Madison loves school, her dog, and playing with her doll house. According to her parents, one of Madison's favorite things to do is wrap lots of beaded necklaces around her wrists and wear them as bracelets. "She looks like Punky Brewster," joked her parents, referring to a female character from the 80's sitcom. ■

CHUCKLE CORNER

When we were getting ready to go to school, I was putting on my makeup while Isabelle, age 8, attempted to get dressed on my bed nearby. She has the undressed part mastered, but is still working on the dressed part. Anyhow, as she sat there naked, she asked: "What would happen if I was naked at school?" My answer was: "You'd go to jail." Silence ensued. I was sure that was all as I watched her slip into her undies and try to maneuver her feet into her socks. We both continued to get ready in silence…and then, the next well-pondered question came… "Maman, is there food in jail?"

~Cheryl Gagne, Kelowna, BC

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

¡HOLA!

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

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

PWSA (USA): Supporting Individuals with Prader-Willi Syndrome Through RESEARCH AND BEYOND

Dale and Dottie Cooper
Interim Co-Executive Directors

The mix of research, family support, advocacy, medical and crisis counseling, education and awareness, and support of our nationwide network of chapters certainly brings about exciting times! We thought we would dedicate this issue's Executive Director's Corner to helping our readers understand our role in **supporting Research and Beyond**.

As you probably know, PWSA (USA) has funded and supported research initiatives from the time the association was formed, such as growth hormone; understanding and managing hyperphagia (uncontrollable drive to eat); the effectiveness of psychotropic medications; swallowing function; excessive daytime sleepiness; obesity and diabetes; and so much more. Just this past October PWSA (USA) hosted the 2nd International Conference on Hyperphagia which has spawned the interest of several researchers and pharmaceutical companies who are now working on and/or considering new drugs to combat hyperphagia. And now we are learning about the commonality of gastroparesis (delayed stomach emptying) -- a finding from a research grant fully funded by PWSA (USA).

But families need more than research – they need and want information on the practical applications of the findings from research and dealing with the daily challenges of PWS. That's where PWSA (USA)'s support **Beyond Research** comes in. Support also means we provide PWS medical and behavioral counseling, education advocacy, crisis counseling, information through publications, and a database of information used widely by the many researchers and professionals pursuing effective treatment of Prader-Willi syndrome.

- PWSA (USA) supports parents of newly diagnosed individuals and young children by providing age-appropriate educational information on PWS such as publications to help with feeding and nutrition, sensory integration, physical and speech therapy, behavior, and more; a parent mentor; counselors; and by connecting them with their local PWSA (USA) Chapter.
- For families of children age 6-18, PWSA (USA) provides support on education advocacy, behavior, camps, medical issues, and more.
- For parents, siblings, guardians, or professional caregivers of adults age 19 and up, PWSA (USA) is the primary source for educating the staff of supported living homes and employers on issues such as behavior, new findings of medical issues associated with aging with PWS, legal considerations, etc.

And...there is more. The number of calls coming in to PWSA (USA) and the number of lives saved is incredible. The National Office is there for families and individuals with PWS in crisis –sometimes near death and overwhelmed with the challenges. Medical emergencies are common. **PWSA (USA) is there for us**. The National Office communicates regularly with local and national medical professionals and clinics to connect them with researchers who can advise on local medical treatments. We are involved with police and emergency situations. **PWSA (USA) is there for them.** We advocate at the national level. PWSA (USA) was instrumental in getting Growth Hormone approved and accepted for all persons with PWS. PWSA (USA) assists in school IEP's and supported living ISP's. **PWSA (USA) is there for you.**

And...there is so much more. PWSA (USA) supports its chapters – helping them get stronger through local programs and services. We also provide tools and resources for chapters to fundraise and assist families with attending the PWSA (USA) bi-annual National Conference, local family support groups, chapter and membership meetings, respite for family members, a PWS clinic, legislative and education advocacy, and/or many additional and critical services.

Chapters and/or individuals can designate funds for PWSA (USA) towards a specific program (such as Research, the Crisis program, the National Conference, the new web site under design, new publications, informational webinars, medical conferences, advocacy, etc.) or leave it undesignated to be spread across the many programs as needed. Your loved ones, your needs, and the needs of our entire PWS community inspire our collective fundraising efforts. To see how you can help with a fundraiser or donation please contact Ben Karp at bkarp@pwsausa.org or Val Vance at vvance@pwsausa.org.

PWSA (USA) is the leading national provider of information and support for families, caregivers, researchers and professionals caring for someone with Prader-Willi syndrome. With our direct link to professionals who care for and provide research for persons with PWS, PWSA (USA) is your one-stop resource for authenticated answers to questions. You don't have to be in crisis to call us – **our mission is to support you**.

It is through support that we help our families promote research as well as understand, navigate, and apply research findings. And, if anyone tells you that PWSA (USA) is focused on support, tell them "YES!!! Thank you for noticing! Won't you join us?" ■

How We Talk About Prader-Willi Syndrome

by Jonathan (J.T.) Todd from his blog "Gracie Blue Eyes"

I cannot remember when we told Grace she had Prader-Willi syndrome. I'll never forget the day I found out, but I can't remember ever having a first conversation with Grace. There was never a serious sit down with a big reveal. We have never kept secret what makes Grace different.

The truth is the most serious sit downs have occurred between Joy and me. As we have had to move forward through this PWS adventure together, the big conversations and big moments have been when my wife and I sit through and talk about what our next move is to help support Grace and her needs.

When Joy called me to tell me that PWS was the diagnosis, it was in 2003 and I was busy at work. An incredible amount of pain swept through me. Yes, I thought to myself "why me?" I privately cursed at God because up to that point Grace was making great progress. It was almost as if PWS was teasing us into believing our challenges were behind us.

I remember coming home and sobbing. I remember my mother-in-law walking into the house from our backyard with a strange combination of fear, sadness and hope. I remember being so upset with my wife because she had an amazing attitude: she finally had something she could tackle. Where I found fear in the known, she was equally fearful of the unknown.

And you know what? It's OK. It is OK to feel what I felt and to ask the questions I asked in my head. It was OK to cry.

It was OK to worry. What would not have been OK was for me to stay that way. It would not have been OK for that moment to define my family or allow the diagnosis to define my daughter. It would not have been OK for us to stay paralyzed by fear and worry.

The next big moment for Joy and me was when we had to put locks on our refrigerators and cupboards. It wasn't much of a discussion but more of a realization that it was time to take that next step. It was very emotional. We had caught Grace yet again with food she should not have had. I remember how emotional Joy got. There was no waiting, no blue prints. I went to Home Depot many times. We got it done the very day we made the decision.

Throughout Grace's life we have had age appropriate discussions about PWS with her. We spoke to her about having to get growth hormone. We discussed with her why she needed some special attention at school. We talked with her about why we were locking up the food in our home. We did this in an age-appropriate way. We didn't make a big deal out of it, and neither did Grace. In fact, Grace has proven to Joy and me time and time again that she is probably the most composed of the three of us when we are faced with these large decisions.

In all the discussions, the only time I remember Grace becoming emotional was about getting her ears pierced. This was during a time in which she was skin picking. Unfortunately, the idea was already in Grace's head that her ears would be pierced, and we had to put on the brakes. She wasn't happy. But since we made that call, she has never asked about it again.

Grace doesn't know everything about PWS. She can't explain the genetics, and there are some symptoms she has not exhibited and therefore we have not yet had to cover. I used to cringe when she talked about having babies of her own someday because I don't know if that is a reality and it was not an age appropriate subject to discuss. Thankfully, her interests now are dogs and horses and not boys!

Grace and J.T.

But just in case, I do rehearse my line in the mirror for when I meet her first boyfriend: "Son, I'm not afraid to go back to prison."

When talking about PWS, the best advice I can give you is that if you are lucky enough to share your life with a significant other, you both need to be on the same sheet of music. You both have to be emotionally ready and mentally mature enough to have those serious discussions. You have to be age appropriate and honest with your child with PWS. And you have to understand that they may not get it right away. If you make a big deal of it, they will make a big deal of it.

I guess my last thought is that it is OK to cry and to feel sad. It's not OK to stay that way. Our kids need our encouragement. They need our hope and our discipline. Most of all, they need our love. ■

Guitar player J.T. wrote and recorded the song "Gracie Blue Eyes" in tribute to his daughter and to tell her how much he loves her, just as she is. He also wanted to be able to help other kids like her. The song was released to iTunes and Amazon.com and can be downloaded for 99 cents, all proceeds going to PWSA (USA). The song may also be purchased through his web site www.graciebluеeyes.com for 99 cents.

Health Concerns and the Student with Prader-Willi Syndrome - Information for School Staff

by Barb Dorn, R.N.

The student with Prader-Willi syndrome (PWS) may experience some unique health issues. It is important for school staff to be aware of these issues to ensure that the student has a safe, healthy educational experience. Health concerns along with some strategies are summarized below:

Altered Pain Threshold – Decreased Pain Sensitivity/High Pain Threshold

- Pain may be diminished or absent - even in severe injuries.
- Fatigue or irritability may be a sign of illness.
- Increased bruising & swelling is common.

Strategies

All injuries should be assessed by an adult.
Report all injuries or changes in behavior to the parent or caregiver.
Elevate and apply ice to injuries as needed.
Student may require examination by a health care professional to rule out fracture or other health problem.

Altered Temperature Regulation

- Common to see unexplained high and low temperatures.
- Little or no fever may be present with illness. Often experience low tolerance to high or low outside temperatures.

Strategies

Limit time outdoors during very warm and/or humid temperatures.
If extreme redness of the face and sweating is noted, remove to cool area; encourage cool water and/or utilize cooling measures.
In colder climates make sure student is appropriately dressed and limit exposure to cold temperatures.
If illness is suspected, notify parent.

Increased Food Drive/Food Seeking/Low Metabolism

- Because of a hypothalamic abnormality, students with PWS do not register the feeling of fullness.
- There is varying degrees of food seeking. Many sneak and/or steal food – are at great risk for choking.
- Gain weight on ½ calories of other students; require calorie restricted diet & supervision around all food.

Strategies

Receive/follow prescription from health care professional for calorie-restricted diet.
Supervise student around all food sources. Keep food out of sight.
Avoid use of food in classroom activities or as reward.
Promptly empty garbage cans that contain discarded food.
Train staff in the Heimlich maneuver.
Have plan for handling food treats and other food issues in the classroom.

Osteoporosis

- High risk due to hormone abnormalities & dietary limitations.

Strategies

At high risk for fracture – assess injuries for possible sprain/fracture. May require x-ray to rule out fracture.

Daytime Sleepiness

- Common to see in students. Often symptom of sleep apnea.
- May be result of weak chest muscles-poor air exchange.

Strategies

Physical therapy evaluation for muscle strengthening.
Get student up and moving if fatigue is noted.
May require a rest time during the school day.
Communicate problem to parent & health care provider.

Strabismus

- Often seen in younger students.
- Poor muscle tone/control in eyes.
- Glasses, patching and in some cases surgery is needed.

Strategies

Look for signs during vision screening.
Refer to eye specialist if abnormalities found.
Make sure students wears glasses and/or patches if needed.

Skin Picking

- Common problematic behavior seen in students of all ages.
- Open sores common.
- May pick at various openings of body .

Strategies

Provide diversion activities – keep hands busy.
Encourage liberal application of lotion.
Incentive program often needed to keep wound covered.
Teach self care of wound if able.
Monitor frequent trips to bathroom. Set time limits; supervise in bathroom if needed.

Behavior – Emotional Problems

- Students with PWS have problems regulating their emotions.
- Most do not handle change well.
- Some exhibit obsessive-compulsive tendencies, exaggerated emotional responses and extreme anger.
- Some take medications to assist with mood stabilization.

Strategies

Minimize changes. When they do occur – prepare if possible.
Teach ways to appropriately share feelings and emotions. Practice and reinforce these strategies frequently.
State behavior you want to see. Avoid using word "don't".
Make sure to administer medications at the appropriate times.

Severe Stomach Illness – Lack of Vomiting

- Severe stomach illness has been noted in students who have had a binge eating episode.
- Symptoms: abdominal bloating, vomiting, pain may or may not be present, general feeling of not feeling well.
- Rare for a person with PWS to vomit.

Strategies

If symptoms of stomach illness are present, notify parent. Student should be urgently evaluated by a health care professional.
Report any incidence of vomiting to the parent.
Encourage the student to share honestly if they have had a binge episode. The student should not be punished if this has occurred.

Increased Sensitivity to Medications

- More sensitive to medications that can cause sedation or sleepiness.

Strategies

Be aware of all medications that student is taking.
Report any problems to parents.

Scoliosis and Other Spine Problems

- Common to see scoliosis and other spine deformities in students w/PWS.
- Often difficult to detect if obese.
- May require bracing.

Strategies

If found, refer to orthopedic specialist.
Support and assist if brace is needed.
Adaptive measures may be needed for physical education.
Physical therapy evaluation for muscle strengthening.

Dental Problems – Dry Mouth

- Common problems:
  - thick, sticky saliva.
  - teeth grinding.
  - rumination and cavities.

Strategies

Teach and encourage good dental care and water.
Assist in referral to dentist if needed.

A Family of Strangers

Foreword by Lisa Peters, who writes about family life at www.onalifelessperfect.blogspot.com

"I found on the Internet several communities devoted to serving parents of children diagnosed with PWS. These small groups of strangers suddenly became my lifeline, and, like soldiers who serve on the battlefield together, became my family. This family has given me the precious gift of hope for my son and his happy future."

Left to right: Fred, Amber, Chris, Alberta, Denise and Fred Jr.

Amber, 33, was diagnosed with PWS when she was four. Although she is Chris's daughter, Alberta and Fred Beguhl (her grandparents) have raised her.

Now in their 70s, Alberta and Fred first met at school when they were 10, where Fred abruptly announced to his fellow classmates, "That's the girl I'm going to marry!" Married now for almost 60 years, they have raised three children and fostered several more. They have six grandchildren and 12 great-grand children.

Alberta explains that Amber learned to walk when she was three and since then she has not stopped moving. As a child, she participated first in dance classes and then in a martial arts program where she earned an orange belt. She started bowling at five and continued throughout high school, earning the highest average.

"We are so blessed with what she can do," says Alberta, recalling when Amber was a small child and begged to ride the roller coaster at an amusement park. "I can still hear her yelling RIDE, RIDE!"

Amber and her family continue their thrill-seeking adventures. This summer they rode a series of zip lines across a canyon and over the Snake River in Idaho, where according to Alberta, "Amber was the first one off all the lines." Keep in mind Alberta and Fred are in their 70s!

Alberta and Fred love to travel and exposed their daughter to this adventuresome lifestyle at a young age. They traveled in the U.S. from coast to coast with Amber in a backpack or stroller. When she got older, they visited places around the world, like Rome, Australia, Alaska, Mexico and Jamaica.

"She rode in the back of a jeep with birds flying at us, down a dusty road in Jamaica and helped paddle a raft on a back river in Cozumel," says Alberta.

They have encouraged Amber to become independent. "She has been to camp for almost 20 years, traveling 12 hours each way to get there. We try to expand her mind."

Currently, Amber continues her active lifestyle. She loves to ride horses and participates in shows where she earned ribbons this year in pole bending and barrel events. She continues to enjoy bowling. She is in an adult league where she has participated for 10 years, earning a high average of 160.

In the summer, you may find her swimming in her pool at home. She is active and adventuresome with many hobbies and interests.

She has traveled around the world and made many friends. She is a kind, loving and independent young woman with a happy life and a free spirit. She was raised by two selfless individuals who refused to let words like disability or Prader Willi syndrome alter their quest to enjoy life. ■

[Ed.Note: What better way to start—or continue—your travels with your person with PWS than a trip to the national conference in Orlando in November!]

Counselors Corner

Learning to Type

by Kate Beaver, Family Support Counselor

Working with schools and helping teachers to identify what causes our children anxiety in the school setting has been educational for our staff. We have learned that one thing the school can do to help decrease anxiety and to build long term skills is to teach children how to type and use a word processing program. Our children, who usually want to please teachers, become anxious when they are asked to practice writing or to write out spelling words or other subject matter. It seems that the children perseverate on the process of writing the words to look like they have been typed or to look like how the teacher wrote them. In doing so, our children lose sight of what they are learning and become anxious to recreate the word perfectly. Teaching typing to young children even in first grade helps lower anxiety and also gives them a long term skill. Writing will always be important, but if we can separate writing from the other learning, it's a win-win scenario. ■

Ian Goes to the Prom

Three Best Buddy seniors took Ian Adams (son of Andrea Glass) to his Junior Prom. The two young ladies shown with Ian are Foxborough High School seniors Miss Ashley Snyder and Miss Taylor Laubenstein, of Foxboro, MA. These kids were awesome and truly wanted to give him a special evening.

Reagan's Run

by Rob Seely

About six weeks ago my son's school sent home a flier about joining a running club that would be training for an upcoming 5K. I briefly looked at the flier, but the reality of my son having PWS and understanding that kids with PWS can't do things like this quickly led me to throw the paper in the trash and not give it a second thought. About an hour later, Reagan asked if I saw the flier about the running club and stated that he wanted to do it. Thinking that there was no way he understood what the club was about, I acknowledged his desire to join while explaining what he would need to do and expecting him to realize that it was not going to be "fun". But to no avail, he still wanted to participate so I agreed that he could join, all the while thinking of how I could protect him from the failure that he was going to experience, because again, kids with PWS can't participate in strenuous activities like training for 5Ks. Although over the next few weeks training went relatively well and the coaches were very supportive, I still looked for ways that I could protect him from the disappointment of not being able to run and complete a 5K. When the day of the event arrived, I had come up with the plan that I would run with him and have my wife move our car along the course of the race so when he could no longer keep going we could get in the car and minimize the disappointment of not completing the run.

As the race began, it was cold, windy and raining so I knew this would be a short run. At the one mile mark, my wife was cheering and waiting for us to join her in the car… but Reagan was not ready to quit. At mile two, my wife was cheering and giving me "the look" of what is going on…but Reagan was not ready to quit. At this point, our pace had slowed quite a bit and at times we walked but only briefly as he would soon ask to run once again. My wife called me on cell phone asking where to meet us next and I simply said…at the finish line. ■

Homecoming Queen

by Trisha Wayland

I wanted to share with everyone that my daughter, Audrie Wayland, a Junior at Chandler High School in Oklahoma, was recently elected Basketball Homecoming Queen. Audrie, who has PWS, was given this honor by her typical peers. She was nominated by two very special Junior Basketball captains. When the announcer said "And your 2013 Chandler High School Basketball Homecoming Queen IS…….AUDRIE WAYLAND!!!!!!" she put her hands over her face and started crying. The crowd went wild, and everyone stood up. I think even outside of her being chosen, one of the most memorable moments of that night was when I looked up into the stands and everyone was standing and cheering for her, even the opposing. What a testimony to the people of our community as well as the opposing town. The two Captains put on her sash and crown and gave her a kiss. What an amazing moment!

We are very fortunate that Audrie has a great support system at school, (teachers, students, cafeteria workers). She has four mainstream classes that have been modified to ensure her success. Her peers accept her and include her in as many activities as possible. They all love her and look out for her and help her when she needs it. She participates in Special Olympics and is very interested in all the high school sports teams. She loves to cheer on her friends! She attended her first Prom last weekend, had a wonderful time going to dinner with friends and dancing her booty off….literally…I had to take her to the chiropractor on Monday, because her hip was out. I told her she shook it too much, lol. ■

Story Behind the Utah Prader-Willi Association

by Frank and Judy Ipsen

We who belong to active chapters of the national PWSA (USA) know that a parent support group begins with a need– the need to associate and bond with others experiencing the same daily frustrations and uncertain future for our child's fulfillment. Each chapter has its individual story as together they learned to work hard and laugh much. Ours is a story that demonstrates what a small group with a little leadership and lots of enthusiasm can accomplish. It has been a learning process, and we have a few pointers we'd like to pass on to help those who may be struggling to form their own chapter.

We first met in 1984 as a small group of parents. Five families had met a couple of times before, but the difference was that this time we had someone who was willing to step forward in a leadership role. At the suggestion of PWSA (USA), we held a "potluck" and shared our stories. Boy, did we talk! And we laughed!

At our second meeting, we got down to work, constructing an agenda and setting goals. We outlined a plan to locate more folks with PWS in the state. We mailed information on the syndrome to physicians throughout Utah, requesting that any families with children with PWS contact our support group. We recognized that we had no professionals familiar with PWS in Utah, so we set a goal to correct that. We exhausted every resource in an effort to bring awareness to educators, physicians and state agencies who could give services to our children. PWSA (USA) was a tremendous resource. Dr. John Carey, a geneticist from the University of Utah, was eager to help as research of PWS was relatively new and making quite a stir in the medical field and particularly in the area of genetics.

Our identified folks with PWS were all young adults, so group homes became a top item on our agenda. Our eventual success with our first group home came because of our "homework." We were always conscientious of the state government policies in regards to the handicapped because this is where the funding comes from. We believed if we worked in conjunction with them to help them meet their goals, we would be more successful with our own goal. We attended state government meetings where relevant issues were being discussed, including several senate sessions. We learned the skills needed to get the attention of those who could influence or make decisions. We made ourselves known at every opportunity. We found that the "refreshment lines" were a great place to build on relationships with those who had influence. We learned that "the noisy wheel gets oiled" and that numbers are extremely important. We also learned not to underestimate our own influence. And, we learned that "NO" had another meaning – it is simply a roadblock around which to navigate.

We held meetings at least quarterly which included speakers on a variety of topics. When needed, we split up into two or three groups to discuss the needs of varied ages. We held annual summer socials and Christmas parties. In 1990 we successfully hosted the PWSA (USA) National Conference. Under new leadership, we've added fundraising local conferences and medical clinics. We continue the never-ending education of agencies that provide services for our children. As state personnel change to other positions, the new agencies do not always amend their goals to match the needs of our folks with PWS.

We keep foremost in mind that the purpose of our support group is to meet the diversified needs of our PWS families. This includes time to visit and to laugh at ourselves and our PWS experiences. You know, being a PW parent is…"trying to figure out how to lock up the apple tree" or "finding teeth marks on your artificial fruit." Janalee Heinemann gave us a great list to begin with – from there we developed our own. Laughter is a valuable survival tool! ■

[This is the first of a new series in "The Gathered View", featuring a Spotlight each issue on an individual chapter.]

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

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

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

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MEMBERS ONLY:
Access our website, www.pwsausa.org, for downloadable publications, current news, research, and more. The Members Only section is now available to everyone and the password is "pws."

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

E-mail Support Groups:
We sponsor nine groups to share information.
Go to: www.pwsausa.org/egroups

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

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

ATTENTION Federal Employees!

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

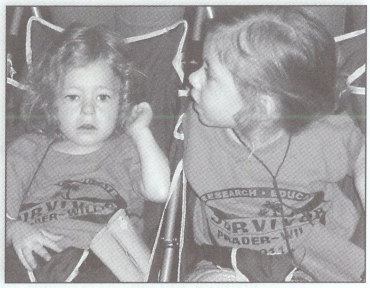
PWSA (USA) CFC ID # is 10088

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

Contributed by Clint Hurdle:

"A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles."

~Christopher Reeve
1952-2004, Actor, Director, Author and Activist



PWSA (USA) NATIONAL CONFERENCE

Registration is Underway!

Bring Your Children for YIP, YAP & Sibling Programs. PWSA (USA) has specially developed programs at the national conference for young infants (YIP) and young adults (YAP) with Prader-Willi syndrome. These programs are in place to provide care and age-appropriate activities for individuals with PWS and to enable families and loved ones to attend classes, seminars and group sessions. YIP is for children from birth to 6 years of age and their siblings who are also in that age group. YAP is for those 7+ and is loaded with activities that will appeal to each specific age group. Don't forget there is also a special program just for Siblings who are between the ages of 7-15! These programs provide opportunities for each participant to feel they are special and empowered to be all they can be! ■

Registration and additional information available at www.pwsausaconference.com

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