

The *Gathered View*

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

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

Executive Director View

The Worth Of A Program – The Worth Of A Man

David Wyatt • April 7, 1932 – April 9, 2014

*“A kinder, more gentle person, I have never known.
Rest in peace, dear friend.”*

I realize that when you call the PWSA (USA) 800 number and ask to speak to a crisis counselor, you do not have an understanding of how this very important program evolved (unless you have been a part of our organization for many years). I would like to share with you the history and also give tribute to the man who initially made this support possible.

In 2000, David Wyatt, with a master's degree in counseling and 37 years of experience as a retired hospital chaplain and chaplain instructor, began volunteering and supporting the non-medical PWS crises. Oftentimes burdened with many of his own medical crises over the years, David worked harder than most fulltime paid employees. Many times David would be in the hospital bed with clipboard in hand, making crisis calls, and arriving to work with IV lines in his arm or chest.

Eventually, we were able to give David a small salary thanks to a heartfelt grant, funded from the Alterman Family Foundation. David remained our sole crisis counselor until mid-2006. With his soothing voice, counseling skills and true sense of compassion, he was loved by all the families he assisted.

“He was the kind of person someone meets once in a lifetime. His selflessness, love and caring showed in everything he said and did. God blessed us with his soul; I and many others will never forget him.”

“He was a great man and a very great friend to so many in our PWS community. Because of him, the lives of our children with PWS have been improved so much.”

Not only the families who he worked with, but the staff also adored him. As one staff member said, “A tremendous man who was an angel on earth and now in heaven. I am blessed to have known him & worked with him. MANY lives are better because he lived.”

We receive hundreds of calls and emails yearly from desperate parents, schoolteachers, and care providers. There is always another mother crying and another child in a serious medical, school, and/or placement crisis, etc., and the calls are often gut wrenching. But if not for PWSA (USA), who would help these families? We cannot turn our backs on these urgent needs.

We are fortunate (and unique among nonprofits) to now have two other wonderful crisis counselors, Evan and Kate, in addition to Janalee, to handle the medical crises.

To assure that we can continue to afford to keep our counselors, we are starting a designated fund in honor and memory of David.

*Yes, rest in peace, dear friend.
Ken*



Ken Smith, Executive Director

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OBITUARY

DAVID WYATT

David A. Wyatt, 82, of Siesta Key, Florida, died peacefully April 9, 2014. He was born in Amarillo, Texas, April 7, 1932. He was ordained as a Methodist minister who spent most of his career as a chaplain. After retirement, he was a volunteer crisis counselor in Sarasota for the Prader-Willi Syndrome Association (USA). David was a strong human rights advocate throughout his life.

David was the beloved father of Deborah Wyatt, M.D., of San Francisco, and her spouse Andree Hest, Pharm D., Todd Wyatt, daughter-in-law Carrie, and grandfather of Garrett and Everett Wyatt of Pleasanton, California. He was preceded in death by his four-year-old daughter, Dana. David was also the beloved adopted family member of Janalee and Al Heinemann, with whom he lived, and their children: Sarah and Chris Tenaglia, Tad and Gina Tomaseski, Tracy and Jeff White, Tina and John Kiel, and Matt Heinemann.

David was loved by many and will be remembered for his kind spirit, gentle heart, smiling face, and joy of life. Donations may go to Prader-Willi Syndrome Association (USA).



David was my friend and co-worker and will be missed. I loved his easy-going style, great patience, and sense of humor. Our families developed a close relationship with David as their Crisis Counselor. He cared, listened, and would go the extra mile for them. Although he retired a couple of years ago, many of our families continue to ask about him. He left a big impression on all of us.

~ Cindy Beles

I'm truly sorry for...all of PWSA (USA)'s families whose lives were forever changed because this incredibly kind, supportive and compassionate man came into our children's lives and ours! I had the great pleasure to speak with David about Hayden and PWS when he was born; he held my hand over the phone when I thought Hayden was not going to make it!

~ Hope and Hayden

There was no one EVER like him and there will never be again.

~ Barb McManus

All my memories of David are ones that put a smile on my face. His smile was contagious and he provided such wisdom, comfort and support for so many of us. He no doubt has a special place overhead continuing to smile down on all of us,

~ Marilyn Dumont-Driscoll, M.D.

A Special Request in Memory of David Wyatt

As most of you know by now, David was very special -- both as a person and in his role with PWSA (USA). I would like to create a collection of memories/comments from people who knew or worked with David, to give to his children and his 11-year-old twin grandsons who live in California. He did not have financial treasures to leave them so as they get older, I would like them to have the treasure of knowing who he was as a person. You may email your memories/comments to jheinemann@pwsausa.org and please include "tribute to David" in the subject line.

Thank you. ~Janalee

SPREADING THE WORD **Obesity Week 2014**

Boston, MA, Nov. 2-7, 2014

Boston Convention & Exhibition Center

As most of our members know, on the opposite years of the large PWSA (USA) conference for parents, people with the syndrome, and professionals, etc., we work on doing something creative to spread awareness and interest on the syndrome beyond our insular world of PWS. We are happy to announce that we received approval by The Obesity Society (TOS) to have a symposium on PWS at the Obesity Week conference in Boston, which will be the 38th annual scientific meeting of The Obesity Society and the second meeting in which they partner with the American Society for Metabolic and Bariatric Surgery (ASMBS). All of the events below will give us an opportunity to educate thousands of physicians, researchers, and pharmaceutical companies on the syndrome, yet also allow us to also have focused time for some of our PWS specialists and interested parties.

Prader-Willi Syndrome (USA) Agenda:

- **PWS Symposium** – Title: “Prader-Willi Syndrome: a model for understanding and treating hyperphagia and obesity”
- **PWSA (USA) Scientific Invited Dinner and Reception**

–for our Scientific and Clinical Advisory Boards and invited guests

- **PWSA (USA) Clinical Advisory Board meeting** – to focus on the medical issues of PWS
- **The Obesity Society-Pediatric Obesity Section (POS) luncheon & business meeting** – PWSA (USA) will be a key sponsor, with hundreds of attendees (clinicians, advocates, and researchers) interested in pediatric obesity.
- **PWSA (USA) Awareness Booth** – all week at the conference

We are working hard to get the donations to make all of this possible. Thank you for your fundraising efforts for PWSA (USA) **On The Move** events to help sponsor these events and all of our other important programs. If you have any connections with pharmaceutical companies or foundations that might take a particular interest in supporting our Obesity Week events, please let me know. Our momentum to spread awareness on Prader-Willi syndrome, educate professionals, and entice researchers and pharmaceutical companies to work on drugs to help the hyperphagia/hunger, has made dramatic strides over the last few years. I am more hopeful than ever that more than one new drug will be available in the near future to help our children and adults.

Janalee Heinemann, M.S.W.
Director of Research & Medical Affairs
PWSA (USA)

GI Issues in Prader-Willi Syndrome

(The following are excerpts from an excellent presentation given at a PWSA (USA) webinar: “An Overview of GI Issues in Prader-Willi Syndrome”

Presented by Ann O. Scheimann, M.D., M.B.A.

Division of Pediatric Nutrition and Gastroenterology
Johns Hopkins Children’s Center
Adjunct Faculty, Baylor College of Medicine

Common oral issues

Oromotor weakness

- Hypotonia
- Palatal abnormalities

Dental abnormalities

- Small jaw
- Small mouth with dental crowding and poor enamel

Salivary abnormalities (xerostomia /dry mouth)

- Salivary flow is only 20% of non-PWS controls
(PS Hart, *Ann NY Acad Sci* 1998)

Choking In PWS

Review of data provided by families and collected through the PWSA (USA) study of death

- 39% of families reported history of choking among the 52 families who completed questionnaires
- Choking listed as cause of death in 12/152 patients (7.9%)
- Average age 24 years (3-52 years)
- 92% of patients were male

Factors predisposing to choking

- Hyperphagia/Foraging
 - 25% of patients were food-stealing
- Viscous (sticky/gluey) saliva
- Hypotonia (weak muscle tone) of pharyngeal muscles
- Reflux

Stevenson et al., AJMG 2008

Potential Interventions

Heimlich maneuver training to:

- Adults with PWS
- Group home caregivers
- Families

Diet Modification/Supervision

- Regular meals
- Supervision during holidays
- Behavioral strategies to encourage chewing
- Increased fluid intake during meals

Constipation and Encopresis* is common problem in children with PWS

(*voluntary or involuntary fecal soiling in children who have usually already been *toilet trained*. Persons with encopresis often leak *stool* into their undergarments.)

- 10-25% of pediatric GI referrals
- soiling occurs in 1.5-7% of 7 years or older children
- Greater prevalence in boys (6:1)

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April 2014 Board Meeting Highlights

On April 11-13, 2014, the Board recently completed two-plus very productive days of meetings at the spring training camp of the Pittsburgh Pirates in Bradenton, Florida. In addition to finance, budgeting and strategic planning discussions, some of the highlights are:

National Office: We are pleased to have Ken Smith on board as our Executive Director. He is completing his move from Pennsylvania to Florida and has been working with the office staff to streamline operations. The Web site re-design has been a very large undertaking – hundreds of staff and volunteer hours have been devoted to this project, which is now entering its final stages.

■ **Obesity Week 2014:** Prader-Willi syndrome will be a topic as part of the Obesity week meetings scheduled for November 2-7, 2014, in Boston, Massachusetts. Please refer to page 3 for more info.

■ **Conference 2015:** A contract has been signed with the Buena Vista Palace Hotel (site of the 2013 conference) in Orlando, Florida, for November 4-7, 2015. The general conference will be on Friday and Saturday, November 6-7 with the Chapter Leaders conference on Thursday, November 5, 2015. Michelle Torbert and Jackie Mallow, Conference Co-Chairs, announced that the team is being formed and leaders are in place for many of the key areas. Save the date!

■ **On The Move and Grassroots Fundraising:** Thanks to the many families and state chapters who have planned and/or held their **On The Move** 2014 event in recognition of PWS National Awareness Month, this signature event continues to grow each year. Ben Karp, bkarp@pwsausa.org, can be contacted for any assistance you need with your event. Events are also being planned for the local Sarasota area, with a tennis clinic and fishing tournament to be held in September and October of this year.

■ **Chapter Relations Committee:** Since the last State Chapter Leaders meeting in November 2013, we have been working on a number of Chapter needs. Committee members will be contacting each Chapter to discuss their needs, as well as their annual membership and renewal agreement. The agreements will have new designations for Chapters: Full, Affiliate and Associate. The next Chapter Leaders meeting will be on October 11 and 12, 2014, at the Buena Vista Palace Hotel in Orlando, Florida.

■ **Research Committee:** For our upcoming research grant cycle, the committee has decided that the ongoing PWSA (USA) research focus will be on translational grants (grants that show high promise for translating basic biomedical knowledge to clinical application.) The goal is to fast-track better treatment for the syndrome. PWSA (USA) will be announcing Request for Proposals (RFPs) for grants in May, and three new grants will be awarded before the end of the year.

■ **Publications Committee:** A new book will be available soon entitled *Medical Wisdom Through The Ages*. This 150-plus-pages must-have is a collection of all medical articles printed in *The Gathered View* over the past 39 years. Any obsolete articles were omitted. This publication will be available in May and will be sold in paperback and electronic format. Watch for the e-News and Web site for availability information. ■



Shortly after David Wyatt's death on April 9, the Board met in Sarasota. Just before sunset they gathered on the beach for a balloon release in tribute to David. One side of the red balloons said, "Forever in our hearts".

¡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 niños. 20, 10 y 9. Mi hijo que tiene 10 años tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que necesitan informacion y ayuda. Les quiero dirigir a www.pwsausa.org donde vas a encontrar informacion en español. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, ninaroberto@verizon.net. ¡Hablamos pronto! ■

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

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

We are currently seeking candidates for the 2015-2018 Board of Directors and volunteers for Committee service. We have specific needs for talented individuals in the areas of:

- Finance
- Fund development
- Graphic design
- Public relations/marketing

Board and committee membership is open to family members and interested professionals.

Please contact us if you or someone you know possesses the qualities necessary to be an effective Board of Director:

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

What will you gain in return for your service?

- A sense of pride as you work to better the lives of all persons affected by PWS
- Input into decisions and policy-making that affects persons with PWS
- Increasing your knowledge about PWS and its treatment and management strategies
- Increasing your exposure to professionals who work with individuals with PWS

To nominate yourself or someone else, please contact Leadership Development Committee Co-Chairs Lisa Graziano or Mary K Ziccardi via the PWSA (USA) office at 800-926-4797 or 941-312-0400 or info@pwsausa.org or by fax to 941-312-0142. The deadline for nominations is June 5, 2014.

To continue to grow as a vibrant, effective organization, PWSA (USA) also needs volunteers for fundraising, advocacy, and family and research support, among other areas. If you are able to free up some time to help, please fill in our volunteer form at www.pwsausa.org/help/volunteer.asp. There is no deadline, as volunteers are always welcome.

Prader-Willi Syndrome Association (USA)
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www.pwsausa.org

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

“Challenges are what make life interesting; Overcoming them is what makes life meaningful.”

— Joshua J. Marine

contributed by Clint Hurdle

Joe's Story

On September 11, 2012, my baby cousin Siena was born. Shortly after, Siena was diagnosed with Prader-Willi Syndrome (PWS), a rare genetic disorder that occurs in only 1 of 15,000 births. PWS typically causes low muscle tone, short stature, incomplete sexual development, developmental delays, and a chronic feeling of hunger that, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive eating and life-threatening obesity.

Over the last year and a half, I have watched my cousin John and his wife Felicia devote their lives to raising Siena and making sure she lives as normal of a life as possible. Each day has been its own adventure, each one containing its own struggle, success story, and next step to helping Siena.

Currently, there is no cure for Prader-Willi syndrome. That's where you and I can help. This May, I will be running the Cox Providence Marathon to raise money for PWSA (USA). I urge you to donate, because the struggle Siena and her parents have endured in only a year and a half's time will only continue. Training for a marathon is tough, but Siena is the toughest person I know. Please make a donation and stay tuned for more updates. Tell your friends, and be sure to make #Miles4Siena go viral!

- Joe DiMuccio

Joe's Event Page:

<http://www.firstgiving.com/fundraiser/joedimuccio/miles4siena>

Create your own page for the person you love: <http://www.firstgiving.com/pwsausa/fundraisers>

The Ultimate Challenge

We hope you are as excited as us for 2014 **On The Move**! We wanted to let you know about a couple new things going on this year:

First, we have a new **On The Move** website: www.pwsaonthemove.org where we will be providing news from **On The Move** events, tips for fundraisers, stories from events, pictures, videos and more. Spread the word to everyone you know! To see your event updates, stories, videos, pictures and information on the blog, send them in to bkarp@pwsausa.org!

Second, Prader-Willi Syndrome Association (USA) is offering prizes to all fundraisers, chapter leaders and event organizers who reach certain fundraising levels:

For the **AWESOME** fundraisers who raise over \$500: you will win a Prader-Willi Syndrome "Still Hungry For A Cure" logo sunglasses!

For the **INCREDIBLE** fundraiser who makes over \$1,000 you will win a new **On The Move** logo water bottle (BPA free)!

And for the **EPIC** fundraiser who makes over \$2,000 you will win a new **On The Move** logo t-shirt!

Thank you everyone who is in support of this great cause. The families we serve greatly appreciate your help!

To start your own fundraising page today, visit our website: <http://www.firstgiving.com/pwsausa/fundraisers>

The Running of the Bears 5k

On Saturday, March 29, 2014, the second annual Running of the Bears 5K was held at Vestal High School in Vestal, New York, to benefit the Prader-Willi Syndrome Association (USA). The race was organized by students from the school's Varsity Club.

The students chose to donate the proceeds from the race to Prader-Willi research after meeting Cami, the young granddaughter of a teacher from our school who was diagnosed last year with Prader-Willi syndrome. Cami won all of our hearts with her winning smile and curious disposition. Cami's grandmother has been able to teach us about Prader-Willi syndrome and the difficulties facing Cami and her family as she grows up.

March weather in New York is unpredictable, but race day turned out to be just a bit overcast but seasonable with temperatures in the mid-30s. This year's race included over 300 participants. Runners and walkers took off from the front of the high school, covered the 3.1 mile course and returned to a rocking party featuring student singers, refreshments and prizes. Many local businesses contributed to help cover the costs of the party as well as commemorative **Running of the Bears** race t-shirts.

On race day, we were joined by two more local children with Prader-Willi syndrome along with their families. This year Ellie, age 7, even ran the race with her mom. The kids enjoyed hanging out with our high school volunteers and especially our fuzzy bear mascots.

The event was a great success in many ways. Including online donations, we raised over \$8,000 for the Prader-Willi Syndrome Association (USA); we all had a really great time; and the students and staff who organized this race learned so



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Storr Family Foundation

The Prader-Willi Syndrome Association (USA) is pleased to announce The Storr Family Foundation donated \$63,100 towards Dr. Robert D. Nicholls' research to understand the clinical basis of Prader-Willi syndrome, particularly as it attains to development of a new pig model of Prader-Willi syndrome, which will also be important in the future for therapeutic testing.

This generous contribution for research will make a difference to the families and children we serve.

Janalee Heinemann, M.S.W.
Director of Research & Medical Affairs
PWSA (USA)
Vice President, IPWSO

Sibling View

In support of all of the siblings in our community, PWSA (USA) is pleased to announce that Katherine Girdaukas, whose brother has PWS, will moderate our Sibling Support E-Group. Katherine is Family Support Coordinator of the Prader-Willi California Foundation, an Affiliate of PWSA (USA).

If you as a parent have a son or daughter with a sibling who has PWS, or if you personally have a brother or sister with PWS, here is a e-group where siblings can share their unique day-to-day experiences, their thoughts and their feelings, as well as receive support from those who TRULY understand. To join the group, please send an email to: pwsa-usa-siblings-subscribe@yahoogroups.com. Everyone who is accepted will need a Yahoo ID and Password to access the group. ■

Fundraising, continued from page 6

much about the rewards of community service and how much you get back when you give.

We're looking forward to next year's 3rd annual Running of the Bears.

Sincerely,

Sue Darpino, Race Director ■

New "On The Move" logo and merchandise:

For more information on logo items contact Pam Ferrara at pferrara@pwsausa.org or phone 941-312-0400.

Calendar of On The Move Events: <http://www.pwsaonthemove.org/#!clients/c1a4e>

Special Olympics

By Denise Servais

Through the power of sports, Special Olympics has had a positive impact on the lives of people like Logan Melton. Logan, age 12, is from Surprise, Arizona. In October of 2013, Logan, and his friends Hannah Wilkinsen and Andrew Kuskie (all with PWS) competed in the Special Olympics regional swimming competition in Surprise.

This was Logan's first swimming competition. Logan's mom, Tiffany Shafer, explained how at first Logan wanted to take a break shortly after swim practice had begun. "His (swim) teacher didn't let him. She was very encouraging." Shafer explained how Logan began to really like practice, "He would swim back and forth...he didn't give up...He kept

wanting to go back." Shafer said she would speed walk around the pool as Logan swam to keep him motivated.

Logan participated in the breast stroke, free style, and relay race. He won two gold medals and one bronze medal. Logan plans to compete in swimming Special Olympics this fall.

Logan lives with his older sister, Shanda, and his mom



Logan Melton

and dad. Besides swimming, Logan is in Special Olympics track. He also enjoys participating in his Lego class, loves video games, and playing with his dogs.

Special Olympics has active programs in over 170 countries and a growing body of more than 4.2 million athletes with intellectual disabilities. Check in with the Special Olympics office nearest you to learn more about volunteering and local events. ■



l to r: Hannah Wilkinsen, Logan Melton and Andrew Kuskie



The Basics of a Healthy Adult Life

Developed by Famcare

Edited by Andrea Glass

An early childhood diagnosis of Prader-Willi syndrome (PWS) usually provides parents with the opportunity to learn strategies to manage potentially difficult behaviors and obesity. Despite variable intellectual and physical abilities, it must be remembered that a cognitive disability, hunger and reduced satiety remain with the person with PWS throughout their lives. The ability to make appropriate independent decisions regarding calorie intake and choices of life rarely comes about, even as the child with PWS becomes an adult. It will always remain the responsibility of their parent or caregiver to make healthy choices and maintain firm boundaries around food, money, exercise and lifestyle.

Calorie needs – Adults with PWS require about 60% of the daily recommended calorie intake for non-PWS adults, 18 kcal/inch if they need to lose weight or 20-28 kcal/inch for weight maintenance.

Restricting calories consumed requires a consistent balance of meals and snacks. This means all extra food sources need to remain inaccessible to the person with PWS. Kitchens, pantries, refrigerators, food cupboards, fruit bowls, garbage bins, shops, relatives' homes, friends' homes, neighbors' homes, work places, day programs, food courts, shops, church functions, sporting events and independent travel all provide the opportunity for "extra" calorie intake. They are constantly thinking about food and not satisfied by the amount they consume. This is a trait of PWS, not a personality trait of the person with PWS. **A consistently secure environment coupled with psychological 'food security' is essential to achieve emotional and behavioral stability.** People with PWS certainly need choice and variety in the food they eat and what they drink, but the calorie content must be determined according to their needs. The more constant the restrictions are, the better the person with PWS will adapt to the restrictions. Also, it is extremely important to maintain restrictions once they are in place. This is not only to maintain a healthy weight but also to avoid over-consumption that could lead to severe gastric health problems.

Helpful Strategies

Calorie Bargaining – Reduce the usual energy intake for a few days prior to a party or similar irregular or special event, where higher-calorie food will be consumed. This is a useful strategy that enables greater "socializing" while managing the extra calories to avoid weight gain. Offer the person the choice to attend the event and "calorie bargain" or avoid the event. He/she may choose not to go to the event so they don't have to reduce their usual intake.

Whether you practice calorie bargaining or not, remember, it is always best if calories consumed out-of-home is discussed, planned for and chosen, before the event, wherever possible.

Exercise – All people with PWS require regular effective exercise, as much as energy restriction, throughout their lives. People with PWS have more fat and less muscle. Their muscles have reduced tone and are weaker, which reduces joint stability, agility and bone strength. **Exercise is the key to weight management, cardio-respiratory fitness, muscle strength and joint stability, bone health, mental health and the prevention of diabetes.** Exercise also provides a distraction from focusing on food, develops emotional well-being, boosts self-esteem and improves behavior. Manage the daily routine to include some physical activity, ideally 30-40 minutes of aerobic type exercise 5-6 days per week. Examples of exercise include: walking, swimming, cycling, dancing, rowing and similar continual exercise. When first introducing a new activity or exercise, a small reward for the completion of a planned exercise can be a good incentive. A planned meal or snack can be used as a routine reward for completed exercise. Exercising before eating or waiting for one hour after eating is recommended except when the person is known to have delayed gastric emptying. Then it's best to exercise immediately after eating to assist digestion. When introducing exercise, explain that as the exercise becomes easy, the intensity will gradually be increased to make them stronger. To improve fitness, the intensity or duration of the exercise should be increased very gradually. Also remember to warm-up and cool-down. Exercising in the morning has additional benefits: increased alertness, it's done and out of the way, the person is not as tired as at the end of the day.

Activities – Incidental or purposeful activity is important. Household chores such as making the bed, hanging out washing, collecting mail and helping with domestic responsibilities not only keeps them active but may also improve their self-esteem as you entrust them with family jobs. Adults like to be needed and given responsibilities to prove their ability. Mastery and praise can work wonders! Where possible, it's even better if family members can join in the exercise so it is seen to be good for everyone, not just the person with PWS. Once exercise is a regular part of their day, less encouragement is required, as it becomes a part of their consistent routine.

Outdoor activities are a wonderful way to combine energy expenditure and the many benefits gained from being outside. Sunshine is the essential source of Vitamin D! Walking on different terrains or surfaces also increases muscle strength. Taking in the sights and sounds of nature when in parks, forests or country areas can be educational and

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International View

Adult Life, continued from page 8

stimulating to the senses and mind. Each person will naturally be inclined towards certain interests, but “expanding their horizons,” when possible and appropriate, has benefits. Encourage reading, writing, craft activities, interest in world events and different sports. Remember to be mindful of the availability of extra calories at any event attended, and discuss the management of this beforehand. Being employed in an active way takes up another opportunity to expend energy in a way that is “part of the working day” rather than an uncomfortable chore.

Dressing appropriately – Talk about “dressing for the weather”. Because people with PWS often don’t feel the temperature correctly due to their irregular thermostats, parents and caregivers need to be weather guides and to encourage the person with PWS to dress appropriately for the weather – regarding clothes and shoes. People with PWS can suffer from hypothermia and hyperthermia when not dressed accordingly for the temperature.

Pain – Due to the high pain threshold, when your person with PWS is exercising or being regularly active, be aware of any injury or pain that may cause greater problems in the future and reduce their ability to exercise. Skin picked sores on the legs or stomach may be exacerbated during exercise if they are rubbed by clothing. They may need to be covered and protected to prevent infections developing.

Exercise attire – Wearing appropriate shoes for exercise may need to be pre-negotiated. When someone with PWS is not keen to wear “joggers” and has favorite shoes, they may prevent the person from exercising safely or adequately. Appropriate exercise shoes don’t need to be expensive but do need to be supportive and protective, especially if the person has diabetes. A good shoe for exercising 1) has a flexible sole and a good arch support; 2) allows for expansion of the feet as they warm up (laces are better than Velcro straps); 3) has a good heel support.

For additional information, write to: famcare@ipwso.org. ■

Family Care (FamCare) is a project of IPWSO's (our international organization) designed to support families whose adult son or daughter lives at home. We know that this can sometimes be difficult and that for living arrangements to work successfully there often have to be many compromises made by parents and other family members. The support of extended family members and friends is also most valuable to the well-being of the person with PWS and his or her parents. In most of the 103 countries that are members of IPWSO, supportive living placement outside the family home is not an option. Even in the USA, our survey showed that approximately 50% of our adults with PWS still live in their family home.

Where possible, community support can also play a significant and important role. Providing an appropriate environment for someone with PWS in all areas of their life will promote good health and longevity.

FamCare is producing leaflets on topics connected with the care and management of the syndrome, compiled with help of parents so that the advice given is from other parents, as well as professionals.

GI Issues, continued from page 3

- Some genetic predisposition with family history in 28-50% and higher incidence in monozygotic (identical) twins
- Majority have functional constipation
- Constipation in adults is defined as passage of hard stools fewer than 3 times/week
- Infants pass a mean of 4 stools/day during first week
- Children pass a mean of 1.2 stools/day at 4 years of age

Management strategies for the school age child

- Nonprescription options: Flaxseed; MiraLAX; probiotics
- Continuance of medications is key!
 - Discuss progress with physician every 1-3 months for support
 - Reinforce fluids and fiber
 - Titrate (start by taking a low dose of medicine, then gradually increasing the dosage to the required level) laxatives; add lubricant, or stimulant laxative, if needed



The whole speech thing is somewhat problematic for our daughter, Isabelle. At 8 years of age, we can mostly understand what she is saying yet she tends to mix up some sounds and words. For example, the other day while I was driving she had the hiccups and kept asking me if I could hear her “hip hops”. Sometimes I will say to her: “Isabelle, you are so beautiful! Who made you?” and her response is typically: “Dog made me.” We happily shrug off the canine version of God. The other day, however, we could not ignore her word mix-ups. She was holding her school agenda and a pen and clear as a bell asked: “Mama, can you please sign my vagina?” Incidentally, we now call the school “agenda” a school “planner”.

~ Cheryl Gagne, BC

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How to Offer Support...and How to Not

A list developed by a group of parents of children with PWS

Based from postings on the Prader-Willi Syndrome Open Forum on Facebook

Do you have friends or extended family who would like to support you but just don't know what to do or what to say – and sometimes do or say the wrong thing? Here's a list you can give them.

DO:

- Say to me: would you like a cup of tea and a catch-up—and follow up on the offer!
- Bring me coffee, hang out with me, and let me vent.
- Act with love, be kind, offer assistance and encouragement.
- Offer to drop by a meal once in a while.
- When you invite us to events, please keep them as PWS friendly as possible.
- Schedule a regular day/time to come give us a break, even an hour or two every other week.
- Try to include my child or teen with PWS in events that other "regular" kids are having/doing.
- Invite my child with PWS to play dates.
- Ask lots of questions. I don't mind. Really.
- Help make a plan ahead of time, so we can avoid problems later on.
- Have healthy snacks or a special non-food treat for my child if you're giving out treats and snacks.
- Please don't give your child snacks in front of my child unless my child has something acceptable to snack on also.
- Offer us some respite time if you can.
- Do give everyone plenty of hugs.
- Include me, and my family in things. We're lonely, really lonely.
- Be understanding when we aren't able to do things because it would be a recipe for disaster for my child. Accept that I know how much he/she can handle and act accordingly.

DON'T

- Offer typical parenting advice. PWS is NOT typical!
- Boast about your child's accomplishments and honors in front of me.
- Ever offer food without asking. EVER.
- Exclude the child with PWS.
- Be afraid to ask if mom/dad/siblings want to talk about life with PWS.
- Judge me for the parental decisions that I must make.
- Excuse my child's bad behavior as "typical kid behavior" if we say it isn't.
- Say "Oh, that's just typical five-year-old behavior." or attempt to diminish my concerns and feelings by comparing my child with PWS to other children.
- Say things like "he's so thin; just let him eat." We do not restrict food to be cruel, but to save their lives--Literally!
- Make us feel like the bad guy for doing what we MUST do...
- Say "s/he will have to learn not to overeat and look for food." Not going to happen.
- Ever joke around and say, "Oh, my son/daughter/I must have that! hahaha I'm always hungry, too!"
- Tell me that God picked me because he knew I would be such an amazing mom/dad.



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. ■

Florida

By Andrea Glass

The Florida chapter was officially established in May 1992 under the leadership of Sandy Stone and has remained active over the years. Michelle Torbert has been the President since 2007. Thanks to a group of PWS moms, Florida is one of the states that recognizes Prader-Willi syndrome as a disability for all benefits that are offered in the state. Families begin to receive benefits as soon as the child is diagnosed. Florida has consistently had strong chapter leaders who have kept the organization running and moving forward. The membership list consists of 300 families with children and adults into their 60s. The membership continues to grow. Social media and personal networking sends many new families into the group.

The chapter list also includes professional providers, doctors, educators and medical professionals that have requested to be added to our email list. Florida has many of the top PWS doctors in the U.S., including Dr. Dan Driscoll and Dr. Jennifer Miller in Gainesville. At Shands University in Gainesville we also have access to a nutritionist and other specialists. Dr. Miller advises the parents of newly diagnosed children who live in Florida to contact our state chapter, as well as the national association so that they can instantly get involved and benefit from all the collective resources. We rely on PWSA (USA) to help our

families with the many things our chapter does not do as well such as crisis intervention, both medically and in the school system and all the resources they have for each age group.

Florida has numerous group homes in Gainesville that house approximately 75 people with PWS. There are also smaller group homes in Clearwater, Tarpin Springs, Dunedin, Ft. Lauderdale, and Sarasota. In addition, there is an independent alternative living program in the Gainesville area.

The chapter officially meets twice a year with a Fall and a Spring meeting. The meetings start on Friday evening with a pizza get-together and family bonding time and a Board of Directors meeting. The following day is a full-day conference with speakers ranging from medical, behavioral, school resource, and legal. There is always social time. Each of the meetings ends with "THE RAFFLE" which is something the children look

forward to, especially if they win a gift card to a restaurant or grocery store! This provides a small fundraising component and extra time to socialize.

The chapter just completed an **On the Move** Walk-a-thon on April 6, 2014 at Westgate River Ranch, following the Spring conference. The event raised over \$15,000, and all participants had a wonderful day. The chapter is now in the process of planning a Fall meeting and Bowl-a-thon fundraiser in September in Gainesville.

As President, Michelle's vision for the chapter is to always be strong and active for Florida families. She envisions additional special education advocacy trainings in the future to equip parents in Florida to work effectively with schools which can often be a challenge. It is a huge challenge in the school systems to keep our children safe and engaged. Michelle also recognizes the importance of spreading awareness in the state. She thoroughly enjoys and is proud to be the President of this chapter. The chapter has a web page which is www.pwfa.org and a Facebook page for the Florida families.

Photos from recent On The Move Events



The camper with Prader-Willi syndrome (PWS) may experience some unique health issues. It is important for camp staff to be aware of these to ensure that the camper has a safe, healthy camp experience. A summary of common health concerns and some strategies are summarized below.

Health Concerns for the Camper with Prader-Willi Syndrome

By Barb Dorn, R.N.

Altered Pain Response – 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 and swelling is common
- Complaints of pain should be assessed

Strategies

All injuries need to be assessed by an adult – even when injuries do not appear to be severe.
Report all injuries or changes in behavior to the parent or caregiver.
Camper may require examination by a health care provider to rule out fracture or other health problem.
Apply ice and elevate injuries as needed.

Severe Stomach Illness – Lack of Vomiting

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

Strategies

If symptoms of stomach illness are present, notify parent.
Camper should be urgently evaluated by a health care professional.
Any incidence of vomiting should be reported to the parent.
Encourage the camper to share honestly if they have had a binge episode. If confirmed, he/she should not be punished.

Increased Food Drive/Low Metabolism

- Because of an abnormality in the hypothalamus, campers with PWS do not register the feeling of fullness and have varying degrees of food seeking
- Many will sneak and/or steal food – often putting them at great risk for choking and gastric illness (see below)
- Require calorie restricted diet with supervision around all food

Strategies

Receive/follow prescription from health care professional for calorie restricted diet.
Supervise around all food sources. Keep food out of sight.
Do not use food as a reward or in camp activities.
It may be necessary to empty garbage cans that contain discarded food.
Staff should be trained in the Heimlich maneuver.
Camp staff should serve food to assist with portion control.

Scoliosis and Other Spine Problems

- Common to see scoliosis and other spine deformities in persons w/PWS
- Many require bracing

Strategies

Support and assist if brace is needed.
Adaptive measures may be needed for some physical activities.
Encourage good posture.

Altered Temperature Regulation

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

Strategies

Make sure the camper does not overheat.
If extreme redness of the face and sweating is noted, remove to cool area; encourage cool water and/or cooling measures.
If illness is suspected, notify parent. Fever may not be present.

Behavior – Emotional Problems

- Persons with PWS have problems regulating their emotions
- Most do not handle change well
- Some exhibit obsessive-compulsive tendencies
- Exaggerated emotional responses and extreme anger may be seen
- Some take medications to assist with mood stabilization

Strategies

Minimize changes. When they do occur – foreshadow and prepare if possible.
Many benefit from a schedule put into writing.

Encourage ways to appropriately share feelings and emotions. Practice and reinforce these strategies frequently.

State behavior you want to see. Avoid using word “don’t”.

Administer medications as ordered.

Skin Picking and Sun Sensitivity

- Common problematic behavior seen in persons w/PWS of all ages. Open sores common
- May pick at various openings of body
- Sensitive to sun

Strategies

Provide diversion activities – keep hands busy.
Apply lotion.
Incentive program often needed to keep wounds covered.
Encourage/teach self care of wound.
Apply mosquito repellant routinely. Have camper wear long sleeves and pants for hiking or walks in the woods.
Monitor frequent trips to bathroom. Time limits and supervision in bathroom may be needed.
Apply sunscreen; encourage wearing hat & sunglasses.

Daytime Sleepiness

- Common to see daytime sleepiness
- May be related to sleep apnea or weak chest muscle resulting in poor air exchange

Strategies

Get camper up and moving.
Some may require a rest time.
Some use Continuous Positive Airway Pressure (CPAP) mask/machine at night.

Dental Problems – Dry Mouth

- Common problems: thick, sticky saliva, teeth grinding, rumination, cavities
- Most have aversion to water

Strategies

Make sure camper brushes and cares for teeth.
Encourage water. Most prefer flavored water – best if non-carbonated.
Assure compliance with use and care of bite guard if camper has one.





Andrew age 32, Amanda age 37 and Adam age 30: The A-team!

One Family – Three Children with PWS!

Can any of you who are struggling to raise one child with PWS even begin to imagine what it would be like to raise three with PWS? Sharon and Dennis Christman from Michigan did just that—and still managed to stay married 43 years.

Their children, Amanda, Adam and Andrew, whom they called the "A-team", now are grown and in residential placement at Oconomowoc, Wisconsin. Sharon reports that they have lost a collective total of 450+ pounds. All are high-functioning. When Sharon gave birth to each child, they knew that something was wrong, but they did not get a definite diagnosis of PWS, subtype imprinting, until 2001 in spite of much testing.

Since all the Christmans knew was PWS, Sharon particularly commends parents who are dealing both with a child with PWS plus other children and trying to give those sibs a normal life.

Their mother can now be a bit nostalgic about those early days. The birthday she refers to was March 29, and she says,

We're celebrating our last A-Team member's 2014 birthday today. I still find it hard to believe that Sis (aka A1) is now 37, A2 is 32 and my baby, A3, is 30. Gosh, where has the time gone??? When I was in the thick of it during their younger years, I thought some days would never, EVER end: meltdowns and tantrums, one appointment after another, OT and PT, Early Intervention, 2 and 1/2 hour IEP's with lots of tears, clueless family members and educators, long sleepless nights wondering if all my decisions made that day were the correct ones and praying to the good Lord for strength for the next day.

As the A-Team got a little older, their issues started to differ and their needs became more unique and often extreme.

Looking back, I know THIS family made it thru together only by the Grace of God!

And, truth be told, I would give anything to have those days back! My goodness, I miss those little blond heads rushing toward me for hugs dozens of times each day. I'd give anything to be digging out match box cars from the toilet. I want three youngsters curled up on our bed listening to me read them one story after another. I want to kneel beside each of them at bedtime to hear their prayers. I am so proud of the young adults they have become: friendly, loving and caring, fun to be with. Oh, they still have their issues, but they have made such fantastic strides toward trying very hard to handle things maturely. So...Happy Birthday, Sissy! I love and miss all of you. ■

How Often Does an Imprinting Defect Occur in PWS and in the General Population?

**By Merlin G. Butler, M.D., Ph.D. Professor of Psychiatry, Behavioral Sciences and Pediatrics
Department of Psychiatry & Behavioral Sciences
Kansas University Medical Center**

Imprinting defects occur in less than 3% of all individuals with PWS. The chance that the imprinting defect is due to a very small atypical deletion is about 20%.* If the father carries this deletion on his chromosome 15 that he receives from his mother, then there is a 50% chance of passing this imprinting defect to his offspring and causing PWS. This microdeletion seen as an imprinting center defect is much smaller than the typical deletion that is seen in the majority of individuals with the 15q11-q13 deletion, and requires special (research-based) testing to identify.

If PWS occurs in 1 in 10,000 live births, then about 400 babies with PWS are born per year in the USA (about 4,000,000 babies are born in the USA per year).

If 3% of PWS babies have an imprinting defect, then 12 babies with PWS (one per month) would have an imprinting defect in the USA.

*At a 20% chance of having an imprinting defect in PWS due to a very small microdeletion, then 2 to 3 babies with PWS per year in the USA would be born with this type of an imprinting defect. ■

Definition of Microdeletion

Typical microdeletion: Loss of a very small section from a chromosome that is not readily seen through a microscope but can be detected via high-resolution chromosome banding, molecular chromosome analysis (with FISH), or DNA analysis. Disorders caused by typical microdeletions include Angelman, DiGeorge, Prader-Willi, and Williams syndromes.

MedicineNet.com

Contributions

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submit items
to *The
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Dec. 1; Feb. 1;
Apr. 1; June 1;
Aug. 1; Oct. 1

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State Leaders Meeting

Dear State Leaders:

We are excited to announce the State Leaders meeting will be held Saturday, October 11, and Sunday, October 12, 2014 in Orlando. It will be held in conjunction with the PWSA (USA) Board meeting October 9-12.

In order to appropriately plan for this event we need to know who is planning to attend. Please respond by June 15, 2014 with the name your state leader planning to attend. In addition, we would like to know what topics you, the state leaders, want to discuss at the meeting this year. Please share your ideas when responding with your state attendee's name.

We look forward to having another amazing State Leaders Meeting! ■

Crystal L. Boser

Chapter Relations Chairperson



The Torch is Passed

By Lota Mitchell

This issue of *The Gathered View* is my final one as Editor. I have loved the work, but I am stepping down in this the autumn of my life in order to have more time to smell the roses (coffee not so much). I have been blessed thus far with good health, and there are so many roses.

When I became Editor six years ago, Sara Dwyer joined me as our talented and patient graphic designer. She has worked hard to learn about the syndrome, the organization and its people. Please welcome her as the new Editor.

I will join our two wonderful volunteers of three years now, Andrea Glass and Denise Servais, helping to support Sara. Please direct your articles, contributions to the Chuckle Corner and other info for the GV to Sara at pwsaeditor@pwsausa.org. ■

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