

The *Gathered View*

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

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

PWS Awareness Is Everywhere!

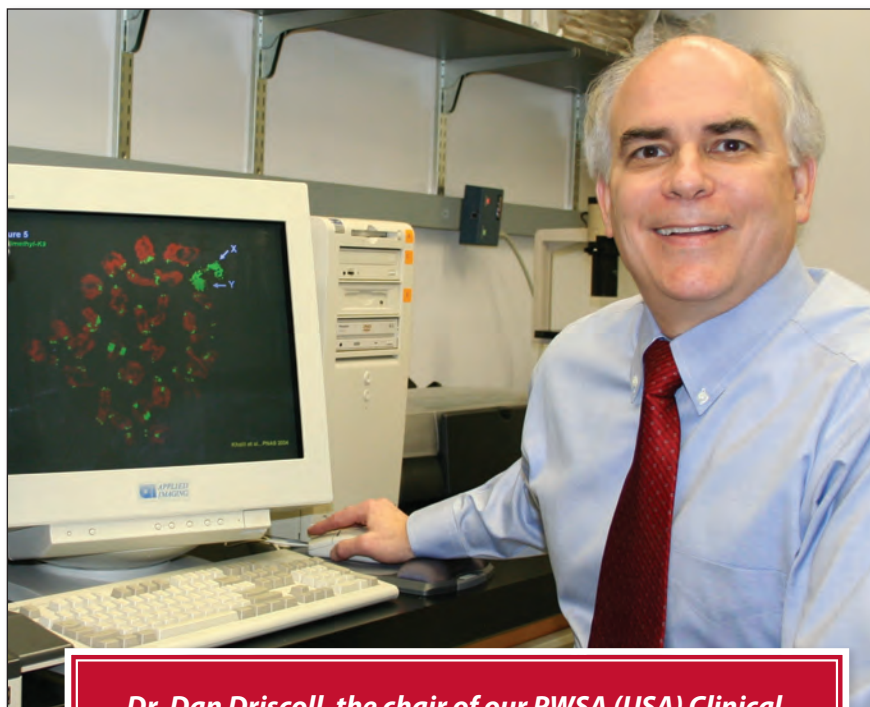
By Janalee Heinemann
PWSA (USA) Director of Research & Medical Affairs

With Awareness Month upon us, I would like to report on some of the recent exciting research awareness projects taken on by Jim Kane, our PWSA (USA) Research Advocate, and myself.

Awareness at the National Institute of Health (NIH):

In April, we met with people in the following positions to discuss our International Hyperphagia Conference, the stimulus grant options and PWS research in general, and to promote the Rare Disease Clinical Research Network (RDCRN) grant renewal. We also took some first steps to advocate and educate for PWS research at the National Institute of Diabetes & Digestive & Kidney Disease (NIDDK). All were very interested in the International Hyperphagia Day we are sponsoring.

- **Director, Center for Developmental Biology & Perinatal Medicine, Eunice Kennedy Shriver National Institute of Child Health & Human Development**
- **Chief, Intellectual & Developmental Disabilities Branch, Center for Developmental Biology & Perinatal Medicine, Eunice Kennedy Shriver National Institute of Child Health & Human Development**



Dr. Dan Driscoll, the chair of our PWSA (USA) Clinical Advisory Board, gave an hour-long presentation on PWS to well over 1,000 attendees at the American College of Medical Genetics.

- **Health Scientist Administrator, Intellectual & Developmental Disabilities Branch, Center for Developmental Biology & Perinatal Medicine, Eunice Kennedy Shriver National Institute of Child Health & Human Development, NIH, HHS**

- **Director, Obesity & Eating Disorders Program, Division of Digestive Diseases & Nutrition**

Coalition for Patient Advocacy Group (CPAG) meeting:

I chaired the CPAG meeting in Bethesda and attended the Rare Disease Clinical Research Network (RDCRN) Steering Committee meeting. Among other NIH

participants, at both meetings I spent time with:

- **Director, Office of Rare Disease Research (formerly ORD, now ORDR)**
- **Director, Extramural Research Program, ORDR, NIH**
- **Senior Health Scientist Administrator, ORDR, NIH**

Awareness, continued on page 4

In this Issue

Conference Heroes	4
Listening Therapy	7
Spring Cleaning	8

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USA PRADER-WILLI SYNDROME ASSOCIATION

*Still hungry
for a cure.*

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

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

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

Acting Executive Director's View

Dear PWSA (USA) Members and Friends:

It is now my privilege to serve as the Acting Executive Director of PWSA. This was an unexpected job change for me but I felt when called upon - because I love this organization and our mission so much - I had to step up to help us work together through this time of transition. I have experience in leadership of non-profits so, although it is not a job I sought, I am grateful my background allowed me to step in quickly.

As a PWSA crisis counselor for close to two years I know how essential it is for PWSA to be a healthy and stable organization because of the vital services we offer. I want to assure you that PWSA remains committed to providing the highest quality of service and resources to people and families living with PWS. And we are blessed with a very strong staff and volunteer team so I know I have lots of people I can count on to help in the days ahead.

As I am sure you understand, I cannot give information regarding any confidential personnel matters. However, if you have any other questions or concerns to share during this time of transition please do not hesitate to contact me. Thank you for your continued support of PWSA which makes a difference in the lives of people and families living with PWS every day.



Sincerely,

A handwritten signature in black ink, appearing to read 'Evan Farrar'.

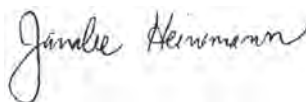
Evan Farrar
Acting Executive Director

The Board of Directors has appointed Evan Farrar, previously Crisis Intervention Counselor for PWSA (USA), to the position of Acting Executive Director of the organization. Please welcome and support Evan in his new role.

Dear PWSA (USA) members and friends,

I would like to add to Evan's letter that I enthusiastically support the decision to place Evan in the role as Acting Executive Director. I did not want to be considered for taking the position again, and over that last two years, I have had the pleasure of observing Evan's tremendous people and organizational skills. Having worked in the trenches so to speak, he also has a deep understanding of our families' strengths and needs.

We have a strong, compassionate and mature staff and an active board that consists of parents, family members and professionals who have a deep commitment to the cause of PWS. Funding is a challenge for all charitable organizations at this time due to the downturn of the economy, but we do have the funding to continue our programs and people willing to work hard to see that the quality of our services are never compromised. As many of you know, I have been involved with PWSA (USA) for 28 years, and I cannot think of a more worthwhile cause into which to put my heart and efforts. Please join me in supporting PWSA (USA).

A handwritten signature in black ink, appearing to read 'Janalee Heinemann'.

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

Production, printing and mailing of this newsletter was underwritten by CIBC Children's Miracle Day.

Awareness, continued from page 1

Steve Groft, the Director of ORDR, is on our International Hyperphagia Conference committee. All have been very helpful to CPAG members.

Medical Awareness:

In March, we had a booth at the **American College of Medical Genetics (ACMG)** in Tampa where David Wyatt, our retired crisis counselor, and I answered questions and gave out 185 full packets and several hundred other educational materials to geneticists and genetic counselors. Dr. Dan Driscoll, the chair of our PWSA (USA) Clinical Advisory Board, gave an hour-long presentation on PWS to well over 1,000 attendees.

In February, I was an advisor

to our **Canadian neighbors, the BCPWSA**, and assisted them with their first national awareness booth at the Canadian Pediatric Endocrinology Group (CPEG) scientific meeting. They have a challenging group of endocrinologists regarding growth hormone approval. Most are reluctant, and some even refuse to start children with PWS on growth hormone. We selected educational materials carefully and responded to many questions on this topic.

Due to the hard economic times, I want to assure our members that I am being very cautious with your donations. My trips to the DC area have been covered by the ORDR, and the British Columbia PWSA paid for my expenses to Canada. We selected the ACMG

meeting not only because it is an important population to educate, but because we could drive and also save shipping costs.

In our CPAG meeting we discussed the financial concerns of all non-profits in this economic climate. Most are seeing a decline in funding from major donors, foundations, and grants. Individual or small group fundraisers appear to be their (and our) salvation. To all of you who donate and go to the tremendous effort to do a fundraiser for PWSA (USA), I thank you! We could not do what we do without you.

Something I could not have said ten years ago but can say with confidence today: Prader-Willi syndrome is certainly on the right radar screens. ■

Our Conference Heroes!

By Janalee Heinemann

Director of Research & Medical Affairs

As we work on the final details of the PWSA (USA) 2009 conference, I am reminded – and always humbled – at the tremendous amount of volunteer hours and talent that go into putting on our conferences. Each year for 31 years, our conferences have been made possible because parents, relatives, friends and professionals dedicate months of their lives to work on all of the details and do everything humanly possible to keep costs down.

For the 2009 Conference, we need to give special thanks to Jim Kane and Kerry Headley. Co-chairing the International Hyperphagia conference with Jim, I am acutely aware of the daily effort he has put into this conference over the last 6-7 months. Due to his efforts, Prader-Willi syndrome is getting known throughout the National Institutes of Health (NIH) system, among obesity researchers, and within the world of other syndromes dealing with hyperphagia. Thanks to Kerry, we are assured the materials will be very professional in appearance, the presenters will be able to lean on her to work out the details of their trips and presentations, and the logistics of Scientific Conference and the Clinical Advisory Board meeting will be handled. Both Jim and Kerry are working with the hotel and pour over

the budget to assure every penny is used wisely and accounted for. Then there is Barb McManus who works on all of the details of registration, and Jim Gardner who is going over the budget and spending with a fine-tooth comb. I also cannot say enough about the time donated by our dedicated professionals who produce high caliber Scientific, Providers, Hyperphagia conferences, and our Clinical Advisory meeting. This year this includes Drs. Merlin Butler, Dan Driscoll, Ann Scheimann, Tony Goldstone, plus Jackie Mallow and Mary K. Ziccardi.

Reflecting over the last several years, we can speak with pride about the high quality of the conferences hosted in many states such as Wisconsin, New York, and Texas. Each conference has received very positive reviews, and in spite of the complexity of our conferences, especially those with a youth program, we have been able to provide a low-cost, high-quality conference without breaking the PWSA (USA) bank.

As other charitable organizations have had to learn how to rely more on volunteer efforts due to the economic downturn, we can proudly say that PWSA (USA) has had a strong volunteer foundation from the beginning. In fact, the very heart and soul of our organization is volunteerism. Bless the hundreds of volunteers who through their heroic efforts have made our conferences a success over the years!

Medical and Research View

Ask The Professionals

The following two questions were answered by Jim Loker, M.D. who is on our PWSA (USA) Clinical Advisory Board and the father of 14-year-old Anna who has PWS. Dr. Loker is Medical Director for Pediatrics and Pediatric Cardiology at Bronson Methodist Children's Hospital.

Vomiting and PWS

Q Can anyone answer for me why our children who have PWS do not vomit? I'm unsure whether it is due to a lack of gag reflex or low muscle tone, or something else. Anyone care to enlighten me why no vomit and why it is so serious if they do?

A Vomiting is actually a complex reflex involving the stomach and central nervous system. Since the vomiting center is located in the hypothalamus, it appears to be affected in PWS as are other hypothalamic activities. Reflux and rumination (food is regurgitated, rechewed, and reswallowed) do not involve the hypothalamus, so they can and often are seen in PWS. True vomiting may (but not always) be a symptom of a more serious problem than in the general population.

Heart Problems and PWS

Q I heard about a child with PWS who has severe dilated cardiomyopathy. Is this common?

A There are metabolic and mitochondrial syndromes that have both hypotonia and dilated cardiomyopathy, but it is not a common feature in PWS. Although it is not common, it is known to happen. In our PWSA (USA) review of deaths, a 17 month old girl died from dilated cardiomyopathy. The Japanese group had two infants in their 2004 study die from dilated cardiomyopathy. These are most likely due to a viral myocarditis and had nothing to do with the Prader-Willi syndrome. The hypotonia and other features of PWS will complicate care of anyone with dilated cardiomyopathy.

The most common heart failure seen in PWS is obesity related right heart failure due to pulmonary hypertension as a result of hypoventilation, obstruction, obesity, etc. Keeping your child with PWS slim is the best way to prevent heart complications. ■

Primary Ovarian Dysfunction Contributes to the Hypogonadism in Women with Prader-Willi Syndrome

A study sponsored by PWSA (USA)

Talia Eldar-Geva^{1,4}, Harry J Hirsch², Ron Rabinowitz¹, Fortu Benarroch³, Orit Rubinstein², and Varda Gross-Tsur²

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BACKGROUND: The aims of our study were to characterize the reproductive hormone profile and investigate the aetiology of hypogonadism in women with PWS. **METHODS:** Ten women, age 10, who have PWS and Body Mass Index (BMI) matched controls were included. Blood samples were drawn, and abdominal ultrasounds were performed. Anti-Mullerian hormone (AMH), inhibin B (INB), gonadotropins, sex-steroids, TSH and prolactin levels and ovarian volume and antral follicles count (AFC) in women with PWS were compared with results from controls and with the reference ranges. **RESULTS:** Compared to controls, women with PWS had lower INB and AMH levels. INB levels were exceptionally low in all women with PWS, but individual AMH levels overlapped with the

levels in the controls. Ovarian volume and AFC were all lower in the PWS group compared to the controls. Gonadotropins and sex steroids were similar in both groups. **CONCLUSIONS:** Reproductive function in women with PWS is characterized by variable AMH, markedly low INB and normal gonadotropins levels, along with small ovaries and low AFC. Our results suggest a unique follicular stage-specific insult in women with PWS. Thus, primary ovarian dysfunction is a major component of hypogonadism in PWS. ■

(Janalee notes: More investigation is needed to fully assess their results and its implications for the PWS population. We are discovering more and more heterogeneity (differences) in our PWS population. They are individuals with PWS, not just PWS.)

Visit our newly improved web site for more pictures, regular updates and more...
www.pwsausa.org

Brain Mechanisms of Overeating: How do High-Calorie Foods Influence the Brain?

The PWS Research Program at Case Western Reserve University is seeking children & adults with PWS (7-40 years of age) to participate in research regarding social functioning and studies examining the brain's response to overeating. Participation involves 1-2 days of scheduled visits to the Dimitropoulos Lab on the Case campus in Cleveland, Ohio. Participation in some portions of the research can also take place in the participant's home or school (for those within driving distance of Cleveland) or at state or national PWSA conferences. Some participants may also be eligible for the functional MRI scanning portion of the research at Case.

Why should you participate in this research?

Participants receive feedback on cognitive and behavioral assessments conducted as part of the research. This information may help educational planning and vocational training. Participants receive an honorarium to help defray the costs incurred for time and travel.

By taking part you will be helping us learn more about the characteristics of PWS and autism spectrum disorders. Our research is based upon the belief that we can improve treatments when we have a better understanding of the symptoms of these disorders.

To schedule an appointment or obtain more information please contact: Dr. Anastasia Dimitropoulos, phone: 216-368-3471, email: axd116@case.edu

Current research is funded by grant RO3HD058766-01 from the NICHD and a grant from PWSA (USA).

Air Transportation Options for Research

Air transportation resources may be available for patients going to The Children's Institute or for research trips, including travel to one of the participating sites for the NIH Rare Diseases Clinical Research Network (RDCRN).

Angel Flights volunteer pilots provide flights in single-engine, four-six seat aircraft to patients at no charge. To be eligible, patients must be medically stable, ambulatory, and able to sit upright in an aircraft seat during flight. Angel Flights are for patients in financial need and who have their medical status certified by their doctors. An escort may accompany the patient, and children may be accompanied by both parents.

Flight distances are limited to 1,000 miles. Weight restrictions apply, and luggage is limited to 50 pounds. Safety is a primary

concern. Pilots will not fly in poor weather. Patients need to be flexible, have a back-up plan or be able to reschedule their appointments.

For patients who live farther than 1,000 miles, other resources may be available through **Mercy Medical Airlift (MMA)**, which manages programs and services available to patients with both common and rare diseases.

If you are interested in finding out if Angel Flights meets your air transportation needs to participate in a clinical research study, contact Marita Eddy at 301-451-9646 or meddy@mail.nih.gov

If you are flying to any of the RDCRN facilities, contact Marita.

For patients who are looking for travel help to other locations, call the National Patient Travel Center at 800-296-1217 or check www.patienttravel.org

A Credit Card to Consider

Do you love your credit card? Or would you consider using a new one?

The Prader-Willi Syndrome Association MasterCard is available for individuals and businesses, with no annual fee. Every time you use the card, you generate a contribution that helps PWSA (USA) continue its services for families affected by PWS.

You can check your balance, pay your bills, change your address, and more through a secure, state-of-the-art online banking system. And you're covered by around-the-clock fraud protection, with no liability for fraudulent charges.

Would this card help you show your support for PWSA (USA)? To learn more – with no obligation to apply – call 1-866-438-6262 toll-free and refer to Priority Code FAC234.

Or you can enroll online: Just go to www.newcardonline.com and enter Priority Code FAC234.

Listening Therapy

By Janice Agarwal, Physical Therapist

Basic Facts About Children and Vestibular and Auditory Processing

We know our children have vestibular delays. The vestibular system is the first sensory system to fully develop (by six months after conception), and it controls the sense of movement and balance. Children born with hypotonia have minimal movement in utero and have delay in development of the vestibular system. Considered to have the most important influence on the other sensory systems and on the ability to function in everyday life, directly or indirectly, the vestibular system influences nearly everything we do. It is the unifying system in our brain that modifies and coordinates information received from other systems. One of the major functions of the vestibular system is auditory processing.

We believe that many children with PWS have auditory processing issues. This does not mean that they have hearing problems that would be detected during a normal hearing exam. They hear the sounds, but do not process them correctly. I would call it a filtering problem. Sounds and the auditory system are very complex. Children may not hear all of the words or the difference in word sounds in a sentence because a TV is on. This makes it difficult to remember information or lists and contributes to decreased attention spans. Children may not be able to discern different inflections in tones or voices. Emotional states may overwhelm or influence ability to hear. Learning social sounds and tone is imperative to integration into our communities and schools.

By using auditory processing testing, audiologists (hearing specialists) and speech language pathologists may be able to determine if your child has an Auditory Processing Disorder (APD) at an early age. At an early age, however, the auditory center of the brain may not be fully developed and a child with an early diagnosis of APD may develop better skills with time. Immature brains just can't accept and process a lot of information. Once diagnosed, children with APD usually work with a speech or occupational therapist. The audiologist will also recommend that your child return for yearly follow-up evaluations.

What is Therapeutic Listening?

Therapeutic Listening is a structured program involving specially designed music that is individually selected for patients to emphasize integration of their auditory and vestibular systems. It begins in a therapy session and eventually involves carryover into the home when a child is able to tolerate the music. How a

child interacts with the environment helps a therapist to determine how to implement an appropriate Therapeutic Listening program. A child may be able to swing, play on a ball or trampoline while listening, simultaneously challenging their auditory systems and their postural organization, motor planning, and higher-level sensory integration skills. Other children may need to sit quietly to listen to avoid being overwhelmed, but the music they hear is so intimately connected with movement that children on listening programs are often compelled to move and explore the environment in new ways. With a close connection between auditory and visual function, visual processing may improve. [Eichelberger, 2002].

Potential results from Therapeutic Listening

Music stimulates the vestibular and auditory systems. As with all treatments involving the human nervous system, results will vary among individuals. The duration of a program can be two to six months or longer, depending on the child. Some changes that have been reported include:

- Increased clarity of language
- Increased ability to follow complex directions
- Increased ability to read and write
- Increased attention and awareness to sounds
- Improved emotional state and expression
- Improved transitions
- Improved social skills and interactions
- Improved posture
- Improved motor coordination
- Improved sleep patterns

We attempted a variation of a Therapeutic Listening program with our son Alex when he was 3. At the time, I was not certain that the changes I saw were directly attributable to the listening program or to all the other things that I was doing, but all of the changes were positive. Now that he is 9 and we have a summer without a lot of planned activities, part of Alex's free time will involve Therapeutic Listening.

When starting a child on any new therapies, it is always advisable to begin with an established baseline with as few stressors as possible. Music therapy can have a very powerful (elevating or depressing) effect on emotions, increase a child's stress levels, and cause bad behavior. It is important to distinguish if these changes are due to the new therapy or to pre-existing issues. If due to the therapy, adjusting the music or giving the child more time to work through the new emotions and stressors may be appropriate.

I believe there is much merit to Therapeutic Listening. Given the issues we know our children face, if signs or symptoms of auditory or vestibular

Listening, continued on page 14

Spring House Cleaning for the Person in Supported Care

By Barb Dorn

Every spring many people begin the task of spring house cleaning. Windows are washed, walls may be painted, and many items are refreshed or replaced. People who are in supported living situations also need this annual rite of spring passage. However, they require assistance and planning to prevent this from becoming a very stressful time.

Agencies that provide care to these individuals would be doing their residents a great service by developing a plan to make sure that their environment and their personal belongings are cleaned and/or replaced every year. Families can also assist. Individuals who are hoarders may need this sort of cleaning and sorting more than once a year.

"Spring house cleaning" is an overwhelming task for most of us. Many adults with PWS are hoarders and have great anxiety when they are asked to clean, sort and discard excessive items. It is important to break down this task into small more manageable steps in order to encourage cooperation and minimize anxiety. Certain staff members may be better able to provide assistance and support. The bedroom is often the biggest and most challenging cleaning area and task to undertake. There are five areas in the bedroom noted in the table below. Consider having 5 separate "cleaning dates" for cleaning the bedroom. You will encounter failure if too much is undertaken at one time. Expect emotional escalation.

General Recommendations:

1. Break down the large task of cleaning into smaller tasks.

- a. It may take 4-6 weeks to complete the task of house cleaning. It could take 5-6 "cleaning dates" to complete the full task of spring cleaning the bedroom.
- b. Limit cleaning job to 20-30 minutes – 1 or 2 times a week.

2. Provide a check list for the person to check off.

3. Provide an incentive once the job is complete.

Celebrate success.

This is a checklist that may be used or adapted in helping the person with PWS perform the task of cleaning.

The Bedroom

1. The Bed

- Mattress
 - ✓ Check its condition and age (the average life span for a mattress is 8-10 yrs).
 - ✓ Flip and rotate -- if a pillow-top, just rotate.
- Mattress Cover
 - ✓ Check its condition – wash; replace if needed.
- Sheets & Blankets
 - ✓ Check their condition – wash; replace if needed.
- Pillow & Pillow Cover
 - ✓ Check its condition – wash; replace if needed (replacement annually is recommended).
 - ✓ People often neglect washing the pillow cover on a regular basis.

2. The Closet

- Remove and review clothing items in closet – are any items too small or worn?
 - ✓ May want to suggest donating items to a local charity. This approach is often successful in utilizing the person's willingness to help others.
 - ✓ Launder any clothing items that may need this. Winter coats, hats and mittens may need to be washed at the end of the season.
- Remove and review other items in closet – determine if any items need to be tossed.
 - ✓ If this is too difficult – suggest that item(s) be donated and discard items out of sight of the person with PWS
- Dust and vacuum floor and shelves.

3. The Dresser

- Remove and review clothing items in the dresser - are any items too small or worn?
 - ✓ Once again, you may want to suggest donating items to a local charity. This approach is often successful in utilizing his/her willingness to help others.
 - ✓ Launder any clothing items that may need this. Winter sweaters or heavier items may need to be washed at the end of the season.
- Examine undergarments. Replace if needed.

4. Window and Window Coverings

- Wash windows and window coverings / Dust blinds.
- Clean windowsills and surrounding area.

5. Rugs

- Vacuum and/or wash floor coverings and throw rugs.
Suggest rearranging the furniture. This will allow you to vacuum all areas – especially under beds and behind large furniture.

Cleaning, continued on page 10

This is a checklist that may be used or adapted in helping the person with PWS the task of cleaning other areas of their home.

If other areas of the person's home must also be cleaned, it is often helpful to solicit help from the residential staff. Sharing of responsibilities assures that the individual lives in a home that remains clutter-free and where dust and germs are kept to a minimum. Staff-resident cooperation is often needed. Each individual situation should be considered.

The Bathroom

1. Shower Curtain and liner (Shower Door)

- Should be washed at least every 3-6 months
- Replace liner at least annually.
- Wash shower door with bleach solution every 2-4 weeks.

2. Windows / window coverings

- Wash windows and window coverings / Dust blinds.
- Clean window sills and surrounding area.

3. Floor coverings / Throw Rugs

- If throw rug surrounds toilet – wash weekly and replace annually. Strongly suggest not using a rug in this location due to high colonization of germs

4. Toilet lid covering

- Wash weekly and replace annually.
- Best not to use at all.

3. Windows / window coverings

- Wash windows and window coverings / Dust blinds.
- Clean windowsills and surrounding area.

4. Floor coverings / Throw Rugs

- Move refrigerator and stove – wash all floors.
- Wash or replace throw rugs.

The Living Room

1. Windows / window coverings

- Wash windows and window coverings / Dust blinds.
- Clean windowsills and surrounding area.

2. Floor coverings / Throw Rugs

- Move all furniture and vacuum.
- Wash or replace throw rugs.

NOTE: Make sure to wipe off exercise equipment with antibacterial wipes and/or cleaner. If used by a number of different individuals, this should be done between each use.

House cleaning, whether weekly, monthly or annually, is a necessary evil that we must all undertake. By planning and providing support and encouragement, the person with PWS can be successful in completing this challenge. For those who are in supported care, it is important to make sure that this task is completed annually, using careful planning. ■

The Kitchen

*****It is best if the job of spring house cleaning is left for staff. This would be a very challenging task for most adults with PWS.***

*****Best if done when person is not at home.***

1. Refrigerator

- Clean all shelves and drawers.
- Look at expiration dates on all bottled items – discard if needed.

2. Stove / Oven

- Clean stove and oven using manufacturer's guidelines.

The International View

Toshio Tsuura from Japan writes about his son, Kai:

Kai was born in April, 1994, 14-years old boy and now goes to the junior high school for handicapped students. He lives with his father, Toshio, mother, Takako, and an elder brother. He sometimes tends to behave as he wish, which might be one of symptoms of Prader-Willi Syndrome. As far as we feel, he has almost normal appetite so that we need not care how much he eats; he used to eat [i.e., "has eaten"] low-calorie Japanese food since he was infant.

He also tries to measure and control his body weight by himself, now 5 ft inches in stature and 115 lbs.

Kai likes to attend sports activities such as swimming, cycling, football, and plays basketball at Special Olympics. In addition, he enjoys mountain climbing with his family and, last year, we challenged more than 30 mountains, in some cases stayed at tents.

When he was 7 years old, he tried the first mountain and looked so hard. However, treatment with growth hormone improved his muscle tone, which encouraged him to challenge more difficult mountains such as Mts. Kita-dake (3193 m), Hodaka-dake (3190 m), or Yariga-take (3180 m).

Although his main interests for mountain climbing had been lunches at the top of mountain or hot

Kai, continued on page 11

Fundraising

"When nothing is sure, everything is possible." ~unknown

Featured Events

It's Bright in Florida

By Jodi O'Sullivan

"If all of us touched by Prader-Willi syndrome did one thing a year or every other year--WOW!!!" wrote **Ronnie Levine** after the



Fortson Photography

Josilyn with her friend Leta

5th Annual Prader-Willi Classic in Honor of Josilyn Faith Levine, this year called **The Leta Lindley Prader-Willi Classic**. The event on January 17 in Palm Beach Gardens, Florida, was named after the LPGA Tour Professional who lent her name to the cause and was organized by Josilyn Faith's Foundation which then donated \$10,000 to PWSA (USA) for research. Lindley and other fellow LPGA Tour professionals participated. Seaview AM 960, the official radio station for the event, broadcast live from the event. Ronnie, or "Bubbie" as Josi, age 6, affectionately calls her, said of planning such a large event, "Since Josi was born, I have come to realize that you do not have to do it all alone...Be prepared... some people will disappoint you, but others will amaze you." She added, "As I have said before, we do not get a day off until Josi does."

Also in the sunshine state, **Michelle Wallace**, parent of Cameron, age 6, held the **Family Fun Day for a Cure for PWS** in Jupiter on March 28. Michelle said the best part was all the people who came. Over 400 attended, helping to raise over \$20,000 net for research. "Just the fact that that



Cameron with Spidey!

many people came and everybody that came said they had such a wonderful time and that their children had such a wonderful time...that was my goal," stated Michelle, proud that her affordable, first time event generated so much funds and awareness. Festivities included characters (e.g., Mickey Mouse, Chik-fil-A cow), a DJ, face painting, pony rides, a petting zoo, silent auction, raffles, four giant inflatables, and carnival games. "I don't have 400 friends, but my friends didn't mind inviting their friends because there is such a value for what you're getting," she said. Michelle anticipates doing this every other year.

Other Events

By Rachel Elder

Dance The Night Away

On February 20 people from all over New Haven, CT joined **Reagin Curran** and her sister, **Aimee Patel** to dance the night away at the **Dinner Dance in Honor of Emily Curran**. More than 100 guests attended. "One of the best parts of the night was the video Jeannette Young put together for the event with photos and music of our kids," said Reagin. To celebrate Emily, age 2 with PWS, guests signed and wrote notes to her on a large matted picture frame. The event and raffle raised more than \$8,000. Reagin described the event as a "huge celebration with lots of dancing!"

Four Years of BINGO

For the fourth year in a row, **Anita and Kyle Perrault** hosted the annual **Jacob Bingo Fundraiser** in honor of their son Jacob, 5 with PWS. The annual event held in December raised nearly \$6,150 for research with some help from Johnson and Johnson, Kyle's employer. Anita writes, "Jacob has truly come to love this tradition as he thoroughly enjoys being the center of attention! Everyone that comes to support him and PWSA (USA) is amazed with his progress."

Thanks to everyone who participated in the **Valentine Research Fund Campaign**. It was a hearty effort to fund research!

2009 Lose-A-Thon is coming to a close. Don't forget to support your Loser!

Monkey on Your Golf Club!

Daphne's Headcovers, the original headcover company, has teamed up with LPGA touring professional Leta Lindley, and Shannon Grissom, the creator of the **Monkey Made of Sockies** character in support of the Prader-Willi Syndrome Association (USA). Each purchase of this adorable headcover--a great idea for a Father's Day gift -- will support PWS research. Thanks go to Ronnie Levine, Josi's grandmother, for helping to make this opportunity possible. Leta Lindley lent her name to the PWS Classic honoring Josilyn Levine. The two met and formed a special relationship that has compelled Lindley to help in the fight against PWS.

Orders should be made through Daphne's Headcovers directly from <http://www.headcovershop.com/praderwillisyndrome.php>, which also shows picture of the

Monkey, continued on page 11

Kai, continued from page 9

springs after finishing climbing, now he learns how wonderful they are if he achieves hard mountain climbing and proposes us candidate mountains for next challenge.

Currently, he wishes to attack Mts. Fuji (3776 m, the highest mountain in Japan as you may have already known) and Aino-dake (3189 m).

As mentioned above, he grows fine and improves muscle tone,



Kai, age 14, who has PWS (UPD), climbing in the mountains

which makes our family feel happy.

[Janalee notes: After meeting with the PWS families in Japan, I realized that food is not nearly the issue it is in most other countries due to their very low-fat, low-sugar diets, and the lack of vending machines, fast food places, etc..]

Chapter View Focus Groups for Prader-Willi Syndrome

By Barb McManus,
Director of Family Support

In April, 2008, PWSA (USA) began a proactive movement to help every family affected by PWS find support either through a local chapter or in support groups. When we learned that some parents were reluctant to attend a "support group" when they weren't feeling any need for support, the term was changed to "focus groups."

Meeting others in your area with a family member with PWS is a rewarding experience for many. We often feel alone when the diagnosis of PWS is given to our child. We want to share the good, bad and ugly with others, and what a better place than with others dealing with the same things facing you.

PWSA (USA) has active chapters in AZ, AR, CA, CO, CT, DE, MD/VA/DC, FL, GA, IL, IN, IA, KY, MO, MA, NC, NJ, NY, New England, PA, UT, WA, WI. Some of these chapters are very, very active while others have only one meeting a year. You can find contact information for your state chapter at www.pwsausa.org/links/chapter.htm

While you might live in a state with an active chapter, maybe you live at the other end of the state. You can start a focus group or get involved with one in your area. To make that happen, contact Barbara

McManus at the national office 800-926-4796 or email her at bmcmanus@pwsausa.org

Here are some people who have done just that:

Cindy Johns is willing to work on a focus group in western **Mississippi**, south **Arkansas** and also **Louisiana** where Patsy White wants to be involved.

Angel Sims lives in northern **Georgia** near the Tennessee line and wishes to start a group in that area.

Connie Speirs and Lisa Ranier are getting a group started in **Alabama**.

Jennifer Lindsey of **Mississippi**, a grandmother, wishes to get more people involved in her area.

Dawn Romine has a group in central **Ohio**.

Iowa presidents Edie and David Bogaczyk informed us they have quarterly meetings. Nina Roberto and Amy McDougall have been working with others to create 6 focus groups in **New York State**.

The first meeting in Norfolk, **Virginia**, was held on April 9th at the Children's Hospital of the King's Daughters, organized by Tina E. Vitale, MSW.

Angela Cantrell planned a meeting in Charleston, **West Virginia**, in April.

Tammie Penta's chapter in **Arizona** could set up focus groups for various age groups. Tammie asks that anyone who wants more information call her at 520-297-7025, or e-mail ppenta@comcast.net, and she notes that their new website is www.pwsaaz.com

Texas starts the journey back to becoming an active chapter again with the first meeting, organized by Jennifer Dean, in San Antonio and other meetings planned for Houston and Dallas.

North Carolina is also reviving its chapter with meetings sparked by Becky Smith and Cynthia Galyean.

Chapter View, continued on page 12

Monkey, continued from page 10

item. You must go to that page to order it to have the proceeds benefit PWSA (USA) research. You can also call 866.953.8377 and be sure to mention proceeds from the purchase are to go to PWSA (USA).

If you want "PWS" embroidered on it, call (602) 279-7457; also

make sure to mention proceeds from the purchase are to go to PWSA (USA). ■



How can you find out what is happening in your area? Call the PWSA (USA) office and ask for Barbara McManus to either begin or join a group in your area.

Chapters are busy, too! The **Pennsylvania** Chapter had a winter camp event at the Woodlands with almost 50 people attending. An IEP presentation, therapy dogs and swimming in a 90 degree indoor pool were highlights...Prader-Willi Alliance of **New York** planned its 19th Annual Conference with Professional Day to take place on

April 30 and General Conference on May 1-2...**DC/MD/VA** PWS Chapter, along with Baltimore area high school students, has on its May calendar a fundraising and social event entitled "PWS Fest 2009." The funds they raise will help sponsor the First International Conference on Hyperphagia, to take place in Baltimore June 4 and 5... **New Jersey** Chapter of PWSA plans a Meeting in May with an informative session on the NJ Division of Developmental Disabilities...

Congratulations! In August

The Prader-Willi California

Foundation celebrates its 30th year of service to its families. That's way back when genetic testing was just becoming available, before growth hormone was even considered a treatment option, and long before the Internet. PWCF began with 65 family members, \$457 in the bank account, and three board members. Today it has identified over 600 persons with PWS, has a solid savings account, an Executive Director, and 11 members on a busy, active Board of Directors. Focus groups are popping up in the state, and lots of folks are Walking for PWS this spring.

Educating Others About Your Child

In the January-February issue, we noted that individual, family, and organizational memberships have been combined into a single full membership (\$50 annual dues in the United States, \$60 international), with one vote. At that time we said "Auxiliary memberships remain \$15 domestically or \$25 internationally."

So what is an auxiliary membership?

Any current member can sponsor and pay for auxiliary members, so that they will receive the Gathered View and other information from PWSA (USA). This is one of the best methods anywhere to make sure those who care for and about your child have a regular, reliable source of information about PWS, its treatment, research, and impact on the lifestyles of those with the syndrome.

Auxiliary memberships are often given to relatives, doctors, therapists, teachers, etc. Call or e-mail the national office to sign up those important people.

What We Want You To Know About Us

By PWSA (USA) Advisory Board

For PWS Awareness Month, the Advisory Board of adults with Prader-Willi

syndrome (PWS) defined what they wanted to share with the world. The following are their thoughts and words from our Advisory Board meeting.

Prader-Willi syndrome comes in all sizes, shapes and colors.

If I am slim, it is due to a lot of effort by me, my parents, and care providers.

Don't give me food or money without my parents' or care provider's permission.

Please keep food temptations away from me.

Prader-Willi syndrome is not the true shame, it is you bustin' on me and you don't even know my name (from the PWS rap song, "My Name's not Willi!").

Talk to me directly, not the person with me. Respect me as an adult.

Please understand that my muscle strength and energy are lower than yours.

I have hopes and dreams and goals – just like you.



From the Home Front Split the Fish

By Curt Shacklett

Our son, Jon, age 40 with PWS, loves to fish. Every year in the late spring we take him to Rockbridge Trout Ranch (rockbridgemo.com) near Branson, Missouri, for a long weekend of trout fishing.

Some of the adult anglers use sophisticated fly fishing gear, but such complex paraphernalia would be too difficult for Jon. So he uses a simple zebco rod and reel with a larger-than-called-for brass hook, and a lead shot that "happens" to match his tackle for fishing for the channel catfish he pursues for the rest of the summer in Oklahoma lakes and ponds. (If it works for catfish, it must work for trout, right?)

His trout bait is dice-sized chunks of left-over trout meat provided free by the fish-cleaning men employed by the facility.

One morning last spring he was out in the stream, waist deep in the chilly water in his chest waders with his big catfish net strapped to his back. A short distance away was Katy Walker, the 20-year-old daughter with PWS of our friend from Tulsa, Gretchen Hannefield-Walker, who had joined us on this trip.

Incredibly, Jon and Katy caught the same fish at the same time. Well, sort of. One of them actually hooked the large trout, and the other one snagged a broken fishing line trailing from the fish's mouth. Together they managed to land it and immediately began disputing who had title to this whale of a fish. Fortunately, Gretchen was close by and suggested they take it to the filet men (sounds better than "fish cleaners") to weigh it. Sure enough, 4.4 pounds registered on the digital scales.



But the squabble over the ownership intensified until the filet man (whom I call Solomon II) proposed a solution. "I'll split the fish in two halves." (This is what they virtually do with all of the fish that are fileted, but to Jon and Katy it suddenly seemed profoundly fair and wise!) So they were each then empowered to boast to their friends of their morning catch of such a leviathan with rainbow colors.

Oh, did I mention that the ranch personnel raise tens of thousands of trout each year and release hundreds each morning into the stream where Jon fishes? Some are as large as 12 pounds. We returned home with

50 pounds of filets (it is called 'catch and pay for'-- not catch and release), one of which was a "shared trophy" with Katy.

Like the filet man, I think we all need the wisdom of Solomon to raise

a child with Prader-Willi syndrome. Raising Jon has certainly kept us on our toes--and many times on our knees! ■

[Ed. Note: Curt Shacklett, Oklahoma City, Oklahoma, is a previous Chairman of the Board of Directors of PWSA (USA).



I was talking on the telephone on a very windy March day to my 4- almost 5-year-old grandson, Nathan Bennett, when he said to me, "Grama, Mr. Wind has very strong muscles today!" Nathan always makes our day sunny!

~ Deborah Carpenter
Tariffville, CT



Siena Mehta, 4 1/2, from Redondo Beach, California, has beautiful, long, flowing hair. Siena shows she also has a most beautiful heart by donating 10 inches of her hair to Locks of Love. Her mother Nisha says she was so excited during her haircut and loves her new "do."

Sonny's Plea

By Nina Roberto
Richmond Hill, New York

*Don't feed me cookies
Don't feed me cake
I have Prader-Willi
For Goodness sake!!*

*Although I may be tempted
To taste, take and have
I have to be strong
For me, my mom and my dad.*

*They worry for me
And I understand why
'Cause my belly will hurt
And I don't want to cry.*

*So give me my food,
Of course just a bit
Just make sure it's from mom
Or she'll have a fit!!!*

*I want to stay healthy
Not just for today
I want to be healthy
To live, laugh, love and play.*

Isabelle Gagne, British Columbia, Canada, Grows Up and Slim With the Help of Growth Hormone



7 months



2 years plus



3 years, 6 months, with brother Maxin

Listening, continued from page 7

issues arise, Therapeutic Listening is a reasonable, low cost, potentially high yield intervention. Unfortunately, it is often difficult to find speech and occupational therapists that recognize auditory or vestibular issues. If they are recognized, Therapeutic Listening is often not covered by insurance. Even if the result of a listening program is not "dramatic," subtle improvements in auditory or vestibular may have great long-term benefit. The earlier an Auditory Processing Disorder is recognized and treated, the more likely it is that a child will be able to be integrated into our communities and schools.

~Janice is a Pediatric Neuromuscular Training (NDT) and Sensory Integration (SI) certified therapist, and mother of Alex, 9, (PWS) and Sam, 8.



PWSA (USA) is included in the Combined Federal Campaign. If you work for the Federal government and its agencies, use CFC ID No. 10088 to designate PWSA (USA) to receive donations. Questions? Call PWSA (USA) at 1-800-926-4797.

Counselors Corner

"I really love the non-medical site. I spent hours going through it and printing off materials so that I can share it with the provider as well as for my own personal use."
~Parent of a child with PWS

Non-medical crisis situations are a part of life. That is true for people with PWS as well. Crisis experts agree that the most effective crisis management strategy is prevention. At PWSA (USA) we believe this, too. So we are very proud to introduce our new crisis web pages at www.pwsausa.org (click the Non-Medical Crisis tab). This portion of our website is designed to help people and families living with PWS to prevent and respond to crisis situations. It is also a great resource for professionals working with people with PWS.

A non-medical crisis situation can be legal, behavioral, school, or placement. It can include having difficulty obtaining needed benefits such as Supplemental Security Income (SSI) or Medicaid. The site is set up so that you can easily navigate to a page for each specific crisis situation. Each page explains the type of crisis involved and then provides "Links and Resources" containing essential tools and tips to help prevent or better manage a crisis situation. When should someone use this?

When your loved one is facing a problem you are having difficulty resolving.

When you are unclear about how to appeal an insurance denial.

When you have questions about residential placement options.

When you are working with your child's school to resolve a behavioral crisis in the classroom.

When you are facing a legal or financial crisis.

When you and your family are simply feeling overwhelmed and need some tips on how to take care of yourselves.

Whenever you are facing any type of non-medical crisis situation this site should be your first stop. Our goal is to have a 24/7 Non-Medical Crisis web presence that is user friendly and helpful. So if we are missing anything, let us know by e-mailing me at efarrar@pwsausa.org

See you next time in Counselors Corner! ■

Evan Farrar, Crisis Intervention Counselor

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Contributions, continued on page 16

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Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers.



PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to www.pwsausa.org/donate

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