

The **Gathered View**

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

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

EXTREME MAKEOVER – The Family Support Program **Historical Perspective and Introducing the FAMILY SUPPORT TEAM**

By *Evan Farrar, Crisis Intervention Counselor*

Like all truly effective and useful support programs, PWSA (USA)'s collection of family support services grew over the years based on the needs of the PWS community. For example:

- When parents of newly-diagnosed children were grappling with understanding how to care for and support their child, we created the **Parent Mentoring Program** to provide parents with essential information and trained peer support.
- When parents and the medical community indicated a need for more medical information and resources, we created a **Medical Support Program** to provide medical alerts, written and video resources, and counseling support.
- When parents and professional providers expressed a growing need for a knowledgeable place to turn for crisis support and resources, we created a unique and innovative **Crisis Intervention Program** with trained counselors to assist with school, legal, behavioral, weight and other crisis situations involving people with PWS.

We are proud of this long history and grateful to the many people involved in creating and sustaining these programs. Now we begin a new chapter for PWSA (USA) family support by bringing our various family support services together into a new unified, integrated structure which will encourage collaboration and improve our effectiveness in providing consistent support for people and families living with PWS – the **PWSA (USA) FAMILY SUPPORT TEAM**. Its members are:

- **Kate Beaver, Interim Family Support Coordinator and Team Leader**
- **Janalee Heinemann, Director of Research and Medical Affairs**
- **Evan Farrar, Crisis Intervention Counselor**
- **Cindy Beles, Family Support Advocate**
- **Dottie Cooper, Interim Executive Director**

- **Nina Roberto, Family Support Counselor (Spanish)**
- **Mary Kay Aide, Resource Coordinator**

Read on to learn more from team leaders about what we are doing. We are excited to be offering this comprehensive approach for our families and are open to any questions, suggestions or feedback you may have as we move forward.

Janalee Heinemann, Director of Research & Medical Affairs, discusses: Medical Support for Families

Historically, PWSA (USA) has provided phone, email, fax and literature support for medical crises and questions. We also arrange consults when needed. There is a large gap, though, that the new Family Support Team helps to bridge – the many situations that need both medical and non-medical crisis counselors, such as behaviors and psychotropic medication questions, psychiatric admissions, suicide threats, placement needed due to morbid obesity, placement post hospitalizations, insurance denials, etc. This is a crucial area that is complex and time consuming. Putting all of our heads together weekly to discuss how we can best serve the families and provide new resources is relieving the heavy weight on our shoulders from trying to manage the situations case-by-case. Most important, though, our goal is to reduce the stress on the families who end up in a quicksand of needs with meager resources to grab onto. We are doing a much better job regarding survival with PWS and are working hard towards improving the quality of life through research, but we must keep striving to meet the urgent needs that many of our families face each day.

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Medical and Research View

Extreme Makeover, continued from page 1

Kate Beaver, Family Support Coordinator, describes how PWSA's New Family Support Program Model Improves Services for Families

PWSA is happy to report positive feedback as the organization shifts from a Crisis Counselor Model to a more comprehensive Family Support Model of services. The new model allows more comprehensive support services, consistent communication, and collaboration between medical, nonmedical and crisis service providers. The expanded Parent Mentor Program plus weekly team meetings provide more coordinated care and more consistent, ongoing peer support for our families.

This new coordinated effort will benefit our families and the organization in the following ways:

- Weekly team meetings will include family support counselors, medical and nonmedical. Increased communication will also allow for ongoing review of current programs and a forum to make service adjustments as needed.
- The new model emphasizes ongoing peer support and guidance through a stronger Parent Mentor Program, strengthening families' ability to problem solve before a situation becomes a crisis.
- Parent Mentors will have more connections with local chapters, giving our families more resources to draw from.
- PWSA (USA) will be able to service families throughout the lifespan of a person with PWS from early diagnosis throughout their stages of development and as service needs change.

Ages of child with PWS when joining PWSA (USA)

Year Joined	Infants	1-5	6-12	13-20	21-29	over 30	Total
1996	2	33	54	54	34	29	206
2001	55	43	23	23	4	12	160
2005	41	32	34	24	15	9	155
2006	113	50	51	32	13	18	277
2007	122	60	50	39	14	13	298
2008	78	55	42	33	11	18	237
2009	103	44	42	32	11	26	258
2010	100	54	34	35	12	19	254
2011	100	37	22	23	11	11	204
2012*	44	26	21	13	7	10	121

*Through May, 2012 only

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

And Cindy Beles, Family Support Advocate, tells about YouTube Videos for Parent Mentors

This summer our Family Support Team is offering monthly YouTube training videos for Parent Mentors to help equip and support their work. A link to these short videos will be emailed monthly to Parent Mentors for easy viewing. Video topics will include:

- The importance of maintaining confidentiality
- How to help a parent advocate for medical and other services
- How to be a positive mentor
- When to call national for help

And much more!

This exciting new way of providing ongoing training specifically for PWSA (USA) Parent Mentors is one of the ways we say "thanks" for their time and commitment. Together we are making a difference! ■

Participants Needed

Patrick Hall, a clinical psychology (neuropsychology emphasis) doctoral student at Wheaton College, Illinois, is conducting dissertation research to better understand how a very important mental process called executive functioning relates to the everyday behaviors of youth with Prader-Willi syndrome. Executive functioning is a set of thinking processes that play a key role in problem-solving, flexible thinking, emotional control, and self-awareness. Findings from this study may provide valuable information about how to improve the treatment and the daily functioning of affected children.

This project only requires a parent or legal guardian to fill out a few questionnaires taking approximately 30 minutes. If you are an interested parent of a child diagnosed with PWS aged 5 to 19 years old, please contact Patrick Hall at phall777@gmail.com or (630) 815-8553, and he will send you the questionnaires with a postage-paid, return-addressed envelope. Participation will be completely confidential. This investigation has been approved by the Wheaton College Institutional Review Board.

[Note: We are delighted to see that Patrick is following in the footsteps of his father, Dr. Bryan C. Hall, one of the first PWS researchers. Bryan's paper on PWS in the Journal of Pediatrics in 1972 essentially brought PWS to the attention of the U.S. pediatric and genetics community.]

The following is the announcement of the awards given to the NIH research network. The chair of our PWSA (USA) Clinical Advisory Board, Dr. Dan Driscoll, is the program coordinator of the PWS section of the Angelman, Rett and Prader-Willi syndrome consortium, and Janalee Heinemann, our Director of Research & Medical Affairs, was co-chair of the Coalition of Patient Advocacy Groups (CPAG) for seven years. To learn more go to: <http://rarediseasesnetwork.epi.usf.edu/arpwscstudies/pw-5202.htm>

**National Institutes of Health (NIH)
Rare Diseases Clinical Research Network (RDCRN)
and
Coalition of Patient Advocacy Groups (CPAG)
- Partners in Progress Awards**

On May 15th, 2012, the National Organization of Rare Diseases (NORD) during the annual Partners in Progress Celebrations honored the RDCRN team (CPAG, Scientists of RDCRN and the NIH).

“NORD salutes the scientists of RDCRN for their recognition of the importance of partnership with the patient community. We salute the patient advocates of CPAG for their dedication to advancing knowledge of rare diseases. And we honor the leadership of NIH and, in particular, the NIH Office of Rare Diseases Research, for early recognition of the importance of investigator/advocate collaboration.” ■

Volunteers Needed for Research Studies at the National Institutes of Health

Dr. Joan C. Han, a pediatric endocrinologist at the National Institutes of Health (NIH), and her colleagues reported in the July 2010 issue of *The Journal of Clinical Endocrinology & Metabolism* the results of a small pilot study of 13 patients with PWS. **They observed that patients with PWS appear to have lower blood concentrations of brain-derived neurotrophic factor (BDNF).** BDNF is a protein that is believed to play important roles in brain function and appetite, and may provide some answers to understanding the insatiable hunger of PWS and other conditions associated with hyperphagia, such as mutations in the melanocortin-4 receptor (MC4R). Dr. Han and her colleagues received

grants from the Prader-Willi Syndrome Association (USA) and the Foundation for Prader-Willi Research to conduct further studies on BDNF's role in the metabolic, cognitive, and behavioral features of PWS and MC4R mutations. **They are seeking patients of all ages (but especially age 5-17 years) who have PWS or MC4R mutations for these research studies.** Participation involves testing at the NIH Clinical Center in Bethesda, Maryland over a period of 1-2 days. Travel and housing are provided, and participants will be compensated for their time. Tests include physical exam, questionnaires, neurocognitive assessment, blood draw, urine collection, and measurements of body composition. For families unable to travel to the NIH, there is also the option of participating by mailing blood samples.

For more information, please contact Melanie Hicks at (301) 402-6762 or PWSresearch@mail.nih.gov. ■

“Hello! This is Amy.”

When you call the PWSA (USA) office, one of the friendly new voices you hear belongs to Amy Logan, who began serving as a temp Administrative Assistant in January and became permanent fulltime in May. Previously, Amy spent 15 years in healthcare administration and non-profit management in the Orlando area before moving to Sarasota with her husband and two children. One of her boys was diagnosed at age five with profound sensory neural hearing loss so Amy keenly understands in a personal way the challenges of raising a child with a significant disability. This is part of what helps Amy bring such great gifts of compassion and understanding to her work with PWSA (USA).

Her favorite part of her job is speaking with parents, family members, and professionals who call the PWSA (USA) office. She appreciates these opportunities to spread PWS awareness and connect parents and families with PWSA (USA) support services. When Amy is not working, she enjoys reading, the arts and enjoying outdoor activities with her family, including going to the beach. Amy's experience, friendly attitude, and team spirit have made her a valuable new addition to the PWSA (USA) national staff. ■



New State Leaders Team

Hello, PWSA family and friends,

We who live with (or have others who live with) the impacts of PWS know how much effort goes into daily living and all the medical appointments and follow-up. When the demands of PWS become difficult and I need re-charging, I depend on the PWSA (USA) National Office and on the support of families in my state who “understand” and can help with local resources, advocacy, listening, etc. I continue to be amazed at the energy and enthusiasm of parents who take on activities relative to forming and supporting a PWSA (USA) state chapter in addition to their family, work, and personal responsibilities. Thank goodness they do. YAY, State Leaders!!!!

That is why we are so pleased to announce the formation of a new “**State Leaders Team**”, which has as its primary purpose the goal of helping you help your state grow stronger. Members of this team are as follows:

■ **Lisa Thornton** - Team leader, President of the Utah State Chapter, and current member of the PWSA (USA) Board of Directors

■ **Julie Doherty** - CLE Yahoo Group moderator, Co-Chair of PWSA (USA) Publications Committee, and current secretary to the PWSA (USA) Board of Directors

■ **Michelle Holbrook** - Past President of the Utah State Chapter, Specialist on PWSA (USA) education support, and current member of the PWSA (USA) Board of Directors

■ **Michelle Torbert** - President of the Florida State Chapter, Chair of PWSA (USA) Fund Development Committee, current member of the PWSA (USA) Board of Directors, and chair of the 2013 PWSA (USA) National Conference

■ **Sybil Cohen** - Immediate Past President of the New Jersey State Chapter, 6-12 Yahoo Group Moderator, parent mentor through the New Jersey state advocacy network and past presenter at PWSA (USA) National Conferences

■ **Lisa Graziano** - Executive Director of the Prader-Willi California Foundation, past presenter at PWSA

(USA) National Conferences, and past member of the PWSA (USA) Board of Directors

■ **Crystal Boser** - President of the Wisconsin State Chapter, and member of the YAP team for the 2009 and 2011 PWSA (USA) National Conferences

■ **Deb Peaton** - Past President of the Florida State Chapter, and co-chair of the Welcome Reception and Gala Banquet Committee for the 2011 and 2013 PWSA (USA) National Conferences

■ **Mary Kay Aide** - Resource Support Coordinator of the National Office Team, living in Madison, WI., LPC Counselor with a Master's in Rehabilitation Counseling

Lisa Thornton, team leader, says, “The whole push from national to help each state is to start where you are and build, with all the help you need. The point is not to get overwhelmed but have the steps outlined to get to where you want to be as a state, to get to where our kids are getting the help they need. Let's all help each other!”

We are all very fortunate to have the benefit of this amazing team which has lots of experience with PWS. They are working closely with our PWSA (USA) National Office Team regarding additional initiatives to support you. Already they are hard at work behind the scenes, gathering input to plan and host the State Leaders meeting in Baton Rouge, Louisiana, in October. We look forward to seeing as many of you as possible at the International Hyperphagia and PWSA (USA) Scientific Conferences then. Make your plans now to get the best airfare, registration, and hotel rates.

Let's all give a warm welcome to Lisa, Julie, Michelle H, Michelle T, Sybil, Lisa, Crystal, Deb and Mary Kay!! ■

- Dale and Dottie Cooper



Dale and Dottie Cooper

NEW! Elementary School Power Point

Creating understanding is one of the keys to developing a more welcoming and successful classroom environment for students with PWS. Rob and Debra Lutz, parents of Isabella, created this PowerPoint to promote understanding and awareness in Isabella's elementary school classroom. In a fun and effective way this PowerPoint presentation helps classmates learn about the syndrome and what to expect when sharing a classroom with a student with PWS. This presentation helps to encourage stronger peer relationships and support for a student with PWS, and it enriches the world and understanding of all students as they learn the important lesson that every person is unique, has challenges, and needs support. We invite you to adapt and use this PowerPoint presentation for your child's classroom.

You can download this from the PWSA (USA) Web site and revise it to fit your child. It can be found under Educational Awareness Tools and also on the Home Page.

2nd International Conference on Hyperphagia October 17-20, 2012

Pennington Biomedical Research Center, Louisiana State University, Baton Rouge, Louisiana, USA



PWSA (USA) Scientific Day, Providers Conference, and State Leaders Day

Dottie Cooper, PWSA (USA) Interim Executive Director, says:

Come on down to Baton Rouge, Louisiana, October 17-20, 2012, to support International Scientists from around the world who are going to be presenting and attending the 2nd International Conference on Hyperphagia (the uncontrollable desire to eat) and PWSA (USA) Scientific Day. If scientists can find a cure or treatment for hyperphagia, the quality of life for our loved ones with PWS will be vastly improved. In addition to Research Grants, our presence will provide support and enthusiasm for doing research on this worthy cause.

You will be seriously impressed with Pennington Biomedical Research Center, internationally known for its research on obesity. We are so appreciative that they have committed to help us address the hyperphagia issue, and they are putting a lot of effort into their support of PWS research. It will be great to have a strong show of family support from around the country in the audience as observers.

There will not be a program for persons with PWS. So we encourage you to add a few days to your trip for yourself to enjoy all that Louisiana has to offer. While in Baton Rouge you may want to take advantage of the excellent Cajun restaurants, go to the top of the tallest State Capital in the country with an excellent view of the city and the Mississippi River, and/or tour Louisiana State University, the old State Capital, and our new and most interesting Louisiana Museum. You may also want to make the one-hour trip to New Orleans. The French Quarter is better and cleaner than ever, the famous WWII Museum has been getting rave reviews, and the music... and the Food...!!!! C'est Bon!!

Dale and I are from Baton Rouge, so we can attest to the great French culture. Our PWS Louisiana families are rolling out the welcome mat and October is a great time of year. Please say "YES!" to joining PWS families and researchers from around the world in Baton Rouge, Louisiana.

To register, go to www.hyperphagia.org. *Laissez Bon Temp Roulez!*

Jim Kane, Conference Chair, says: Parents Welcome!

Join the top international scientists in the fields of appetite control and obesity for an opportunity to hear the latest in research and strategy. Parents are encouraged to attend, observe and learn more about this vital aspect of PWS and expand their knowledge for more effective advocacy.

From genetics to neurology to hormones to addiction to drug studies, all the key avenues for insight will be explored. PWSA(USA) has added a few new unique elements to this conference:

- **World-renowned scientists** - PWSA and its co-sponsors have recruited a top international scientist in each of the above fields of study. They have agreed to present their ideas and relate them to the study of PWS.
- **Twenty top experts in the field of hyperphagia get involved with PWS** – Because they have never presented at a PWSA (USA) scientific conference, this conference will be an opportunity for them to develop a better

understanding of the true nature of the hyperphagia in PWS, plus encourage them to “hang a little PWS question onto each of their projects”. The increased exposure of the entire scientific world to PWS is critical to accelerating the progress in advancing the science of PWS.

- **Pennington Biomedical Research Center** – Site and a co-sponsor of the conference, Pennington has the world’s largest assembly of 80 faculty members and 600 physicians, scientists and technicians dedicated to the problems of obesity, appetite control and nutrition. Pennington’s strategy is to address nutrition from every angle--cellular, molecular, genetic and behavioral.
- **Jam-packed agenda** directed toward the scientists – The agenda is packed for three and a half days with high-level talks aimed at the scientists.

Top Ten Reasons to Attend the 2nd International Conference on Hyperphagia

- Learn the latest progress in the fight to solve the mystery of hyperphagia from 25 world-renowned scientists.
- Tour Pennington, the largest, most sophisticated facility in the world dedicated to appetite, nutrition and obesity research, and meet their top-flight scientists.
- Add to your understanding of the new role stem cell research will play in developing treatments for different aspects of human disease, including the neurology of appetite control.
- Understand the real meaning of hyperphagia and its implications in the public health menace of obesity.
- Observe a debate about the Pros and Cons of bariatric surgery, behavioral therapy and pharmacotherapy in treating

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hyperphagia, particularly in PWS.

- Hear about the connection between the hypothalamus, the brain stem and the various neurological signaling chemicals.
- Answer the question "Is PWS really the 'Window of Opportunity' to help solve the hyperphagia and obesity problems?".
- Build your understanding of the many ways genetics, including epigenetics, the SIM1 gene and gene sequencing, are at the forefront of medical research, especially appetite control and obesity.
- Enhance your understanding of addiction as a possible central force in runaway appetite.
- Hear about the 2009 Best Idea Grants, meet the grantees and hear about their progress.

New ideas will be flowing freely, so don't miss out on this unique opportunity!

The 2nd International Conference on Hyperphagia

Wednesday, Oct. 17, 5:30 p.m. until
Friday, Oct. 19, 1:30 p.m.

The PWSA (USA) Professional Providers Conference

Thursday, Oct. 18, 8:30 a.m. until
Friday, Oct. 19, 12:00 p.m.
(see page 10)

The 26th Annual PWSA (USA) Scientific Day Conference

Friday, Oct. 19, 12:00 p.m. until
Saturday, Oct. 20, 12:00 p.m.

The State Leaders Day Conference

Saturday, Oct. 20

**Register now at
www.hyperphagia.org**

**Pennington Biomedical
Research Center
Louisiana State University
Baton Rouge, Louisiana**

Headley Family Scholarship

Most of you know that in addition to her work on the General PWSA (USA) Conferences, Kerry Headley works with Dr. Merlin Butler on the PWSA (USA) Scientific Conference each year. What you might not know is that Kerry's only child has a dual diagnosis of PWS and Autism and that her husband, Jay, died in November 2010 of cancer. Kerry is now our moderator to the email support group for those who have the dual diagnosis. Kerry held a fundraiser in memory of her husband, Jay Headley, on June 1, 2012, in which she raised a total of \$6,955 for PWSA (USA)!!

Kerry says, "I'd like this money to be earmarked specifically for use as scholarship/travel reimbursement for the PWSA (USA) Scientific Day and Hyperphagia conferences under The Headley Family Scholarship. It should be considered restricted funds and used only to support the travel awards we are instituting this year for the 2nd Annual Hyperphagia Conference. My goal is to continue to raise money for this fund for many years to come so we can help our young investigators travel to and participate in our Scientific and Hyperphagia conferences."

Thank you, Kerry, for your awesome contribution to encouraging research that will benefit all our loved ones with PWS.

Below is an excerpt from the announcement published for the 2nd Annual Hyperphagia Conference announcing this scholarship fund:

Travel Awards:

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

Eligibility Criteria

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

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

Award Determination

The Travel Award Selection Committee will award travel grants based on abstract quality, applicant statement and letter of recommendation. Selection notifications will be sent by email to all applicants in September 2012.

Casting for a Cause

By Michelle M. Torbert, President,
Prader-Willi Florida Association (PWFA),
Board of Directors, PWSA(USA)



Four years ago a local Homestead businessman and friend approached me and said that he wanted to do a fishing tournament fundraiser to promote tourism to the South Florida area and wanted to know if I wanted to do it with him to raise funds for Prader-Willi syndrome. You see, he knew our daughter Leslie very well because he owns a popular Italian restaurant called The Capri and as you can imagine, it is one of Leslie's favorite places! So, in 2009 *Casting for A Cause* was born and we held our 4th annual tournament on May 6th of this year.

What is so unique about this tournament is that we run both an inshore (backcountry) and an offshore tournament simultaneously, so we are able to please both types of fishermen. The first 3 years we ran a 2-day offshore Sailfish tournament; however this year we changed it to a one-day Dolphin and other weight fish tournament. We had 19 offshore boats and 9 inshore entries and we have more boats sign up every year to fish.

The 1st place offshore boat wins \$5,000 with cash awards also for 2nd, 3rd and other weight fish categories. The inshore boats, both guided and unguided also receive trophies and cash prizes.

Rorri Peaton, a Florida resident with PWS, has fished the tournament since its inception with the exception of this year. He fishes the inshore guided division and has won several awards. The first two years, Gavin Ayers, another Florida resident with PWS fished with Rorri. They both love fishing and I know Rorri is already looking forward to next year's tournament. Our daughter Leslie, who is almost 15, likes the offshore division and fishes with her Dad and brothers. I told Dr. Dan Driscoll a few years ago that I found a "cure" for Prader-Willi syndrome, because when these guys are fishing, they don't even think about food and have actually gone over their lunch or snack time because they are having so much fun.

The last 4 years we have given over \$200,000 to both PWSA(USA) and PWFA from the proceeds of the tournament. I would love for more PWS families to participate and hope you can join us next year as we "Cast for a Cause". You can receive updates about next year's tournament at www.castingforacause.com.

This year \$85,000 was netted for PWS--\$65,000 to PWSA(USA) and \$20,000 to the Florida Chapter. Well done and many thanks! ■



Leslie Torbert



Rorri Peaton



PWS On The MoveSM Campaign Wraps Up

What a wonderful PWS Awareness Month of May, especially with the Prader-Willi syndrome *On The MoveSM* events. It's been exciting to hear how enthusiastic so many people were to be part of this campaign in support of those with PWS! **A big "thank you" goes to the event coordinators and volunteers who made these moments happen, created PWS awareness in their communities, and raised funds to advance our work.** Together, we can be a force for progress.

Planning is already beginning for 2013; many commitments have been made to host events from individuals and state organizations around the nation. Bring an *On The Move* event to your neighborhood and start planning your *On The Move* event now. Look for more information in the fall. In the meantime, you can visit <http://www.pwsausa.org/onthemove> or call PWSA (USA) at 800.926.4797 to learn more. ■

Behavior Analysis: The Short Version

By Cindy Szapacs, M.ED., Behavior Consultant, Pennsylvania

I am a behavior specialist as well as Mom to my son Daschel, age 5, who has PWS. I've outlined this "short version" of how to deal with negative behaviors which applies to *all* people, not just kids with disabilities.

Find out WHY the individual is engaging in the behavior. The four possible motivators are:

- 1) To access a preferred item/activity
- 2) To gain social attention (positive or negative - which is why people say to ignore the behavior)
- 3) To escape/avoid a demand
- 4) To gain social stimulation

If the motivator isn't obvious, keep a record for at least three days. Here is an explanation and example:

Collecting Data on Challenging Behaviors

The first step in changing challenging behaviors is learning WHY the individual demonstrates that behavior. This can be discovered by analyzing what happens immediately BEFORE and immediately AFTER the individual engages in the behavior. Fill in the following sheet for at least three days according to these directions:

1. Define the behavior of interest (BOI) in observable and measurable terms; i.e., rather than writing "tantrum," write "crying, screaming, yelling, throwing self to floor, throwing items, and/or physically resisting that lasted longer than 5 seconds."

2. Each time the individual engages in the BOI:

- a. Record the time.
- b. Record the date.
- c. Record what happened immediately before the BOI was observed = Antecedent
- d. Record exactly what the BOI looked like, including approximate length and intensity = Behavior
- e. Record what happened immediately after the BOI was observed = Consequence
- f. Record any comments you feel are important, if applicable.
- g. Remember to record only observable events. Terms like "anxious," "sad," and "nervous" are not observable behaviors. For example, rather than writing "anxious" describe what it looks like, which may be "rocking back and forth, rubbing hands together, and repeating 'all done' while looking at clock."

3. Review the data to look for trends across events. These trends will guide you in how to address the BOI.

Sample Table:

Time	
Date	
Antecedent	
Behavior	
Consequence	
Comments	

Sample Behavior Analysis

Time	10 AM
Date	7/1
Antecedent	Mom answered the phone
Behavior	Yelled, threw self on floor for about 30 seconds
Consequence	Mom hugged child
Time	5:15 PM
Date	7/1
Antecedent	Mom stopped playing with child and sat at computer
Behavior	Threw toys, cried, screamed for about 1 minute
Consequence	Mom picked up child and put on lap at computer

Analyzing the Data and Creating Corrective Strategies

Once you have an idea of *why* the behavior is occurring, you need to make the behavior ineffective and set up strategies to prevent the reoccurrence as well as create consequence strategies for when the behavior does occur, i.e., if the individual is tantruming for attention, don't give him attention; if he's tantruming for an item, don't give him the item, etc.

Prevention often involves teaching the individual a new skill. People with PWS often have poor social, communication and emotional regulation skills. Often people need to learn what to do when they are frustrated, ways to calm down, which words to use rather than behave inappropriately. This involves teaching and practicing these skills when the individual is happy, not when he is mad. Also, look at the environment and see if you can change the environment in order to change the behavior. For example,

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Organization News

Behavior, continued from page 8

if seeing a specific toy always sets him off, take that toy off the toy shelf for a while because maybe he is getting bored and can't figure out what to do next. The individual needs to learn new skills that replace the inappropriate behavior, so the newly-learned skill to replace the inappropriate behavior must have the same function as the inappropriate behavior.

Consequence does *not* equal punishment. If a behavior occurs in order to get attention (usually happens when full attention is not on him), adults *must ignore the behavior but not ignore the person*. This means do not yell or tell him to stop doing all of the inappropriate things he is doing. First, direct him, using a neutral tone of voice and avoiding eye contact, to what he *should* be doing; i.e., "hands to self" or "hands down" rather than "no hitting;" "Ask your brother to please move," rather than "Stop yelling!" Praise him if he complies. Continue to redirect him to engage in a more appropriate behavior that meets the motivation of the negative behavior. I know that for many people with PWS, simply removing them from the situation, letting them calm down on their own, and then reintroducing them to the situation is what works best for them. I know it does in my house. We don't address the behavior or talk much about it because it just draws more attention to that inappropriate behavior and he gets exactly what he wanted. Additionally, because he has some obsessive/compulsive tendencies, he just gets "stuck" on it. He then must fix what he destroyed, we move on to another activity and we *don't talk about the incident again*. This is the hardest part for the adults, because it feels counterintuitive, but it works. Delayed consequences are not effective.

4. Give the individual lots of attention when he is behaving appropriately.

When the individual is doing what he's supposed to be doing, gush over how pleased you are with their great behavior. Be careful to keep this positive. Don't say, "I like how you're not hitting." Rather, say, "You are sharing so nicely with your brother. This makes me so happy!" For every corrective/negative statement you give a person, you should give them five positive statements.

I know adults tend to want to "discipline" children and adults with PWS when they misbehave, but this doesn't teach them anything. Research supports that positive reinforcement is more effective at creating and maintaining positive behavior changes over time than is punishment. The only way to stop a behavior is to replace it with a more appropriate behavior that serves the same function as the target behavior. This isn't easy or fun, but it *is* effective. ■

Below you will find the minutes of the PWSA (USA) Annual Membership Meeting on November 12, 2011. Please review them carefully. If you have any additions or corrections, please mail them to Julie Doherty, Secretary, PWSA (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471. Be sure to sign your name. Or you may email them to info@pwsausa.org. If no additions or corrections are received by August 25, 2012, the minutes will then be approved.

PWSA (USA) ANNUAL MEMBERSHIP MEETING

Lake Buena Vista Palace Hotel, Orlando, Florida
Saturday, November 12, 2011

Board Chairman John Heybach called the meeting to order at 12:00 p.m. He welcomed all attendees. PWSA (USA) staff was asked to stand, and they were acknowledged for their service. Board members were also asked to stand.

Minutes from the September 1, 2010 annual membership meeting were approved as presented.

Interim Executive Director's Report: David Crump noted that 900 people were in attendance at conference, representing 44 states and several international visitors. He outlined the services our organization provides, the success of our grassroots fundraisers, and discussed the This is My Association campaign and the On The Move campaign. He noted that copies of the Annual Report were on the tables. He also announced the new Clint and Karla Hurdle Endowment Fund.

Finance: Steve Leightman noted that approximately \$1.6 million was raised last year! He noted that 88% of all money raised is used for programs. Membership is increasing, and our needs are increasing. We are a strong association financially with seven figures in reserve. We need to continue to raise funds to meet the needs on our wish list. This will help us to be the best we can for OUR Association.

Foundation for Prader Willi Research: Alice Viraslov, FPWR, discussed the formation of the organization and the research grants funded and money raised. She recognized their Executive Director, Keegan Johnson, and their board members in attendance. She discussed the events that occurred with PWSA (USA) and FPWR in 2008 and 2009 leading up to the joint board meeting in 2010. We all want better lives for our children. In 2011 the two organizations raised \$750,000 for the joint research plan through the One Small Step Fundraisers. She noted that while the mission statements of the two organizations may differ, we're united in improving the lives of our loved ones. John Heybach shared that it has been a pleasure working with FPWR. He believes we are on the threshold of a great change and is excited for our future.

continued on page 10

Scientific Conference: Ken Smith, Board Vice-Chair, introduced Dr. Merlin Butler to summarize this day of meetings. He discussed the genetics portion of the meeting and the two invited speakers, Dr. Tauber and Dr. Savage, as well as the five presentations. Dr. Jennifer Miller addressed the six behavior and neuropsychiatry presentations.

Meeting adjourned at 12:55 p.m.

Julie L. Doherty

PWSA (USA) Board Secretary ■

Journaling Can Help!

Put It on Paper!

By Lota Mitchell, Editor

Robert Naseef, Ph.D., psychologist, author, and father of a son with autism and mental retardation, states that researchers “have found a mountain of evidence that demonstrates that disclosing our pain when we’re suffering through a major upheaval can greatly improve our physical and mental health. Conversely, holding it in can lead to recurrent health problems.”

A few years back, a research study on people who had been laid off divided them into one group which was instructed to journal every day and a second group which had no instruction. At the end of the period, the number of members of the journaling group who had gotten jobs was statistically significantly higher than those in the non-journaling group. It was theorized that they had channeled their anger and upset onto paper while the others who hadn’t done that “leaked” some of their resentment in their interviews.

When my daughter Julie, now 42, was born with PWS, I didn’t know about journaling and email groups hadn’t happened yet. But when my son was killed in an auto crash 14 years later, I screamed my grief, fury, and despair into a steno notebook for months and months. Forget punctuation—forget grammar—forget penmanship—I just hurled my pain into that notebook. After I stopped writing in it, I carried that notebook with me for years in my briefcase.

As an Employee Assistance Professional doing short-term counseling in a business setting, I often recommended journaling to clients who were dealing with grief and other stress-related issues.

Certainly being in a PWSA (USA) email group (see page 14) can help us to express what is going on inside us, but there are times when the group isn’t available or what you are feeling is so awful that you don’t want to put it out there. Having a child with PWS is without question a “major upheaval.”

Dr. Naseef notes that “people who can open up in a group generally report that they enjoy it and learn from it. In

addition, their health notably improves—which incidentally provides the scientific basis for the rapid increase of self-help groups for all sorts of problems. But not...everyone can open up in a group, and even for those who get great benefit, the group isn’t always there at the time you may need comfort and support.”

Researcher psychologist James Pennebaker said in *Opening Up: The Healing Power of Confiding in Others*, “Writing helps us to organize and understand our thoughts and feelings. Keeping a journal that we write in with some regularity can thus be extremely helpful for our physical and emotional well-being. By translating the feelings about the events into words, we can gain perspective and understanding about ourselves and what has happened. When we confront upsetting circumstances by talking or in writing, we are often relieved to discover or rediscover that we are not alone, and this helps us gain insight.”

Writing can be done every day, or weekly, or when you feel like it. You can write an answer to a question like “what have I learned from this” or fill in the blank in a sentence like “the worst thing about my child is...” or the best thing about my child is...” Or you can simply write about your feelings at that time, no matter how bad they are; after all, this is meant for no eyes but yours.

Dr. Naseef suggests that the “important thing is to look for meaning and growth.” Whether you are seeking that or emotional release by opening up to yourself, journaling is a useful technique to deal with the considerable stresses of raising a child with PWS. ■

Annual PROVIDERS CONFERENCE

PWSA(USA) will host its annual Providers Conference concurrent with the Hyperphagia Conference in Baton Rouge, Louisiana. Beginning with an all-day session on Thursday, October 18, and continuing through the morning session on Friday, October 19, this conference addresses the many unique support issues related to Prader-Willi syndrome. There will be informative and interesting presentations on medication management, sensory integration, and optimal training curricula for caregivers supporting those with PWS. Providers will have plenty of opportunities to engage each other and contribute to group problem-solving of issues facing each of us. This conference is a “must attend” for residential providers, day program and supported employment staff and others who provide services to people with PWS. Please watch this website, the website of PWSA(USA), and *The Gathered View* for a schedule of speakers and other exciting activities of the conference!

Registration is open at www.hyperphagia.org, so don’t delay in holding your spot! ■

From The Home Front

*“Birth Announcement” and “Bullying”
Reprinted with permission from the
Prader-Willi California Foundation newsletter*

We are happy to announce the birth of our son

Ronald Eric Taylor - February 18, 1962

6 lbs., 1oz. / 24 inches long

Arcadia Methodist Hospital Arcadia, California

When Ron was born they didn't even have a name for his syndrome. I was twenty years old, the doctors came, held my hand and broke the news that most likely my child will not live more than a few weeks, and if he does he will be a vegetable, so we will be here to help you place him in a state hospital and we advise you to just walk away. You need to prepare yourself to forget you ever had this child. I said to my doctors, “I carried him for 9 months, I will stay with him to the end.”

His body soared to a grand 385 lbs and he had a heart attack at the age of 27. While he was in the hospital he decided he wanted to live in a group home that dealt with only Prader-Willi clients.

We are happy to announce the 50th birthday of

Ronald Eric Taylor- February 18, 2012

148 lbs. / 65 inches tall

Turley House, San Diego, California

We've had ups and downs, good times and bad, we've laughed, we've cried. My life with my wonderful son has never been boring. I'm so proud of all Ronald has accomplished and I know he will keep on trying. Happy birthday, dear son.

Your Mom, Lee Taylor-Elliott ■

Dealing with Bullying

A few years ago we attended a picnic at a local park with some friends from Special Olympics. While our athletes were playing on the swings, I watched from a short distance and saw three teen-aged boys making fun of our kids. As I stood there assessing the situation, I was getting angry and frustrated by their behavior. Finally, I decided to confront them. As I approached the boys, they stopped what they were doing. They could see by my angered expression that what came next was not going to be pleasant!

As I approached them, I decided to check my anger, and instead I smiled at them. I told them how fortunate they were

to be born in good health. I went on to say that our kids are the kindest people they will ever meet and it's not their fault they have a disability. I reminded these teens that our kids want what they want—to be accepted, loved and respected. The boys were taken aback. I even saw one of them with tears in his eyes as I spoke. Before we knew it, all three boys went over to our group and began pushing them on the swings. Our local paper was there that day to capture the Special Olympic event; a group shot was taken and in the back row you could see three teen boys with big smiles.

All of us learned a lesson that day. For me, it was the importance of being patient. For the boys, I hoped in my heart that it might be a life-changing event. I like to think that, for the most part, we are all good people. It was their job to be teenagers, and it was my job to be a good Dad and friend.

-Mark Ryan, father of Trevor age 22, with PWS ■

Letter from Sam Beltran, M.D. the first President of PWSA

To the Prader-Willi Syndrome Association:

The enclosed donation check to PWSA is from an old friend who makes this donation on the sixth anniversary of my marriage to my childhood sweetheart, Sylvia... She and I first met in kindergarten in Wauwatosa, Wisconsin in 1933... Sixty years later, after I was widowed for the second time, I called Sylvia...and greeted her with “After seventy-five years, isn't it time we got together?” She said yes, and we did.

Sandy and Bob Klas have now congratulated us on our wedding anniversary in this manner each year as they, too, know the life of parents with children who have developmental disabilities that complicate family life.

Our daughter Sarah celebrated her 40th birthday this year. It is of note that when the first-ever census of persons with PWS was accomplished in California by the California parents group, there were no identified persons carrying the abnormal chromosome in the age group now attained by my daughter and so many others who have benefitted from the work of the PWSA. ■

Congratulations, Logan!

-Reported by Evan Farrar, Crisis Counselor

We first began working to support Tiffany Shafer and Logan, her child with PWS, in 2007. They live in Arizona. Our first issue five years ago was to help his teacher to implement food security in Logan's classroom. Since that time we have helped along the way to work in partnership with Tiffany and Logan's school to create an appropriate learning environment for him. Today she called to let me know that this morning Logan, at his school assembly, received *3 awards for good behavior and*

continued on page 14

PWS Workshop in Cuba

By *Georgio Fornasier*,
Executive Director, International
Prader-Willi Syndrome Organisa-
tion

Three years ago a doctor from Cuba, Loisel Bello, contacted IPWSO through his brother-in-law who lives in Sweden. He needed help to confirm the clinical diagnosis of his daughter Gabriela, age 4, as this was not possible in Cuba. The methylation test confirmed that Gabriela had PWS-UPD. Loisel asked us for information and educational material in Spanish and expressed the wish to participate in a PWS Scientific Conference. We invited him to join the International PWS Conference in Taiwan in May 2010 and covered all his travel costs. The Cuban authorities and especially the Ministry of Health of his country helped him to get a passport and permission to leave Cuba. As soon as he returned home, so enthusiastic and full of information, he organised a workshop for professionals and parents, hosted by Caritas, a Catholic organisation that is very active in assisting disabled people throughout the country.

Loisel's wife, Marlen, is a psychologist specialised in teaching children with disabilities. We are lucky to have this young professional family as a reference in Cuba. They asked Caritas to help them find cases, and they found 15 patients and many doctors and professionals interested to know more about PWS.

Loisel contacted me to recruit the participation of important speakers in Spanish language from Latin America and Europe. The key speakers I contacted accepted my invitation with



At the far right is Dr. Loisel Bello; far left in front of the white column is Georgio Fornasier.

enthusiasm and covered their own travel expenses. These speakers were: Dr. Moris Angulo (El Salvador-U.S.A.), Dr. Maria Del Valle Torrado, Dr. Hugo Serdloff, Karina Abraldes (Argentina), Irune Achutegui (Spain-Italy), Dr. Fanny Cortes (Chile). They covered all important aspects of the syndrome such as genetics, endocrinology, pediatrics, psychology and psychiatrics.

Parents from other Spanish-speaking countries came to represent the IPWSO network: Luis Barrios and Mayra Urizar from Guatemala, Julia

It is amazing that three years ago there was almost no knowledge about PWS in Cuba and now we had 63 people attending the workshop.

Bonelly from Dominican Republic, Fernando Briones and Mariona from Spain and myself from Italy. All scientific speakers modified their presentations to be understandable by the parents, and priority was given to their questions and especially sharing experiences. During breaks and meals

local doctors had the opportunity to talk about scientific details with foreign speakers directly.

The 2nd Workshop on Prader-Willi Syndrome in Cuba was held from April 27-29, 2012, at the Sacerdotal House in the Capital La Habana, under the precious umbrella and organisation of Caritas Cuba. We all slept at the same house where the Conference was held and had meals at its restaurant, so we had plenty of time to stay together till late at night.

Looking at the audience, you could not distinguish who were parents and who were professionals. They all participated by heart, laughing and crying together.

It is amazing that three years ago there was almost no knowledge about PWS in Cuba and now we had 63 people attending the workshop. We were very touched meeting the oldest patient with PWS in Cuba, a 42-year-old woman who was diagnosed by Dr. Prader himself when visiting Cuba years ago. We all cried listening to the mother of Manolito, a 19-years-old boy who died some months ago. At the end she told everybody: *"Don't miss the unique and precious opportunity you had and what you learned at this fantastic meeting. Work hard and let other Cuban children with PWS live!"* ■

Contributions

Thank you for Contributions in April and May 2012. We try to be accurate in recognizing contributions above \$25, and apologize for any errors or omissions. If you notice an error, please tell us.

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WE REMEMBER

Ray Rolfs died on April 15, 2012; he would have been 46 on July 10. His sister, Jolene Amerine, sent a copy of her memorial tribute to her brother.

"Ray was such a special guy who faced many challenges since his birth.



He did not have a single malicious bone in his body. He was always thinking and acting with the innocence of a child. He was also a very strong-willed guy. He was diagnosed with Prader-Willi syndrome early in life and battled pneumonia throughout his later years. Who would have thought that he could be such a warrior? He fought through several serious bouts of it and continued to fight every day, always with the goal of another glorious meal. He was never selfish, always concerned with the happiness of others. He was so much more intelligent and inquisitive to learn than many might have given him credit for. His biggest passion besides his love for children and animals was music. It was always music. I will never forget the times we rocked out to so many records and CDs together.

"Rest in peace and God bless you, Ray. Thanks for the joy and happiness that you brought to everyone's lives. We will miss you greatly." ■

From The Home Front, continued from page 11

one reward for good citizenship! And she wanted to call us first to thank us for all of the support we've given Logan over the years. So I am sharing Logan's impressive accomplishment with you and Tiffany's heartfelt thanks to all of us for being part of making Logan's school success possible. ■

Email Support Groups

Email Support Groups can be accessed by typing:
<http://pwsausa.org/egroups/>

The Yahoo groups listed on the PWSA (USA) site are monitored by volunteers from PWSA (USA). They are active email support groups based on the ages of the individual with the syndrome or specific groups of families and others. ■

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

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 We sponsor nine groups to share information.
 Go to: www.pwsausa.org/egroups

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

**Deadlines to submit items
 to *The Gathered View* are:
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Mid-West Conference October 6 in Indianapolis

The **Prader-Willi Syndrome Mid-West Conference** will be held on October 6, 2012 at the Ruth Lilly Learning Center located at Riley Children's Hospital in Indianapolis, Indiana.

Guest speakers are Dr. Ann Scheimann – Gastrointestinal; Dr. Jennifer Miller – Endocrinology; Mary Kay Ziccardi - IEP and school related issues; and Gordon Holmes - Special Needs Estate Planning.

All guests are invited to a Meet and Greet social at 7:00 p.m. on Friday evening, October 5, at the Courtyard by Marriott Capitol, 320 North Senate Avenue, Indianapolis, IN 46204.

Conference attendees have a special room rate of \$95.00 + tax offered at the Courtyard by Marriott Capitol, with one complimentary parking pass per guest room.

To make reservations, call Marriott central reservations at 1-888-816-4091 and request a room under the "Prader-Willi Association block" or book on-line with the group code PRAPRAA using the link: <http://www.marriott.com/hotels/travel/indcd?groupCode=prapraa&app=resvlink&fromDate=10/5/12&toDate=10/6/12>

Reservation cutoff date is September 5, 2012. Due to a large convention in Indianapolis that weekend, it is advised that attendees book rooms as early as possible! ■



A young man from Texas who has PWS was in Future Farmers of America and had to raise an animal such as a rabbit or chicken. He got a hold of his father's checkbook, and his mom found out that he wrote a check for \$800. When she asked him what it was for, he said, *"I bought a cow. I told you I did not want to raise a rabbit!"*

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