PWCF News

The Newsletter of Prader-Willi California Foundation

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

October-December, 2010 ~ Volume 21, Number 4

PWCF Announces New PWS Camp!

It is with great pleasure that PWCF announces our first camp to exclusively serve persons with Prader-Willi syndrome! PWCF is teaming up with Easter Seals to serve campers with PWS between the ages of 8 and 65 years at Camp Harmon for the week July 27 through August 2, 2011.

PWCF has been working to create a camp to exclusively serve persons with PWS over the past few years. The search for sites has been led by PWCF past Vice-President **Linda Ryan**, and this year PWCF members **Patricia and Don Carlson** joined the efforts. The trio recommended and PWCF's Board authorized their recommendation to team with Easter Seals' Camp Harmon.

Camp Harmon is located in Boulder Creek, California amidst the beautiful backdrop of the redwood forest in the Santa Cruz Mountains. The website for Camp Harmon is http://centralcal.easterseals.com/site/PageServer?pagename=CACN_PS_campharmon

Easter Seals Central California has owned and operated Camp Harmon (www.centralcal.easterseals.com) since 1963, providing high-quality residential camp programs for children and adults with disabilities. Camp Harmon features a combined lodge and dining hall, an on-site infirmary, 14 cabins with fans and bathrooms, an arts and crafts center, accessible swimming pool, a golf putting green, an athletic field and an animal farm. Campers choose from a wide variety of activities including swimming, arts and crafts, horseback riding, archery, hiking, sports and games.

The Camp is accredited by the American Camp Association and serves campers ages 8 to 65 years of age. Several of our families have sent their child to Camp Harmon over the years when it served all persons with various disabilities, and families reported that it was always a very positive experience with the exception of small weight gains. With a PWS specific camp, we will modify the programs and adjust meal and calorie counts to ensure food security, a healthy daily caloric intake, and lots of fun exercise!

The camper to counselor ratio for Camp Harmon is 3 campers per 1 counselor, and campers live in cabin groups that typically consist of six campers and two staff. The staff are all paid volunteers who are fully screened through fingerprinting and a rigorous background check. There are also two Registered Nurses on staff to distribute medication, handle medical issues and assist with self-care. PWCF representatives (Linda Ryan, Lisa Graziano, Patricia and Don Carlson) will provide PWS specific training to all camp staff. The cost to attend this week-long (six days, five nights) camp is $726 per camper; PWCF members may be able to apply for a Camp Scholarship to reduce their costs. Please note that transportation is not provided either to or from camp.

PWCF has been working hard to create a camp opportunity for our families. Easter Seals is excited to work with PWCF and PWCF is excited to work with Easter Seals because we know that Camp Harmon is a magical place where all people are treated with respect and appreciation! This new PWS exclusive camp will meet a great need for our family members by offering PWS specific programming within a safe and secure environment, reasonable costs, and on-site medical personnel to ensure a fun and safe week for campers and a week of respite for families.

Applications will be posted online and sent in the mail early in 2011. If you haven't already informed PWCF that you are interested in attending the new PWCF Camp, please contact us.

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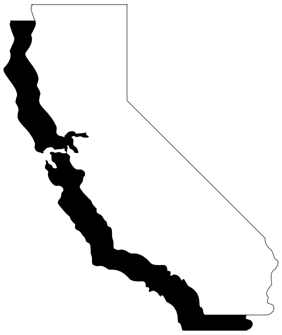

"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Wendy Young	415-924-7025	wmydmy@gmail.com
Sacramento	Diane Kavrell	530-753-5928	brandon.kavrell@cexp.com

Central California

Merced/Tulare Counties	Debbie Martinez (Teens & Adults)	559-227-0294	martinezds@gmail.com

Southern California

Los Angeles County	Lisa Graziano	310-316-8243	tlcgraz@aol.com
	Julie Casey	818-843-7321	julie.casey@att.net
Orange County	Jenn Paige Casteel	949-547-1467	marchroses@hotmail.com

Inland Region Area

San Bernardino/ Riverside County	Maria & Ken Knox	909-421-9821	teachknox@aol.com

Spanish Speaking

Mercedes Rivera (Adults with PWS)	619-822-5742	mercedes_rivera2002@yahoo.com
Maria Knox (Adolescents with PWS)	909-421-9821	teachknox@aol.com
Kilma Carillo (Infants and Children with PWS)	760-427-1100	kilmab@excite.com
Veronica Baez (Infants and Children with PWS)	760-357-8189	vbaez92@yahoo.com

On-Line Support

PWCF Online Information Sharing Group for Members. This online information sharing group is for PWCF members. To join the group, go to www.yahoogroups.com. In the search box under the heading "Join a Group" enter *PWCFmembers*. When the *PWCFmembers* group name appears, click and follow instructions to join.

PWCF Online Information Sharing Group for Professionals. This online information sharing group is for professionals working with individuals with Prader-Willi syndrome e.g., Regional Center case-workers, residential staff persons, etc. To join the group, go to www.yahoogroups.com In the search box under the heading "Join a Group" enter *PWSProfessionalsExchange*. When the *PWSProfessionalsExchange* group name appears, click and follow instructions to join.

PWSA Online eSupport Groups. **www.pwsausa.org Click Enter. Click Support.**

- for Families of Children Ages Birth-5 Years
- for Families of Children Ages 6-12 Years
- for Families of Teens
- for Families of Adults
- for Siblings
- for Spanish-Speaking Families
- for Military Families
- for PWS + Autistic Symptoms
- for Persons with PWS
- for Grandparents

International PWS Organisation

IPWSO offers information about PWS in other languages. www.ipwso.org

PWCF Member Jasmine Lee Lights State Capitol Christmas Tree at Annual Tree Lighting Ceremony

Written by Imperial Valley News

Governor Arnold Schwarzenegger and **First Lady Maria Shriver** participated in the 79th Annual State Capitol Christmas Tree Lighting Ceremony, themed *A Season of Giving*, on Tuesday, December 7. Selected to help the Governor light the tree was eight year-old **Jasmine Lee** who has Prader-Willi syndrome! The Imperial Valley News reported that, “Jasmine loves going to school at Hobart Elementary and enjoys many extracurricular activities, including piano lessons, Korean Church and community activities. Her favorite sport is tennis, followed by swimming, hiking and camping with her family.” Jasmine’s parents, **Patricia and Kang Hee Lee** who are members of Prader-Willi California Foundation, were no doubt beaming with pride as their daughter represented the more than 240,000 children and adults who are served by the Department of Developmental Services. The tree was decorated with more than 1500 ornaments handcrafted by children and adults with developmental disabilities.

“I love this time of year,” Governor Schwarzenegger reported to the Imperial Valley News. “It is the season of giving, sharing and hope. It is also a time to honor and remember our men and women in the armed forces who have sacrificed and given so much so that we may live in peace. During this holiday season, let’s all embody the spirit of these Californians and find a way to give back. I encourage everyone to help those in need, in any way you can.”

“There is no better time than the holidays to reflect and think about the ways we can help improve the lives of others,” said First Lady Maria Shriver. “Our tree lighting ceremony is a time when we come together to celebrate a season of giving and give back to families who need it most...”

RACE with Us
for Prader-Willi Syndrome

PWCF members **Chris and Jessica Patay** are searching for a few additional runners ***(all levels welcome)*** and a support crew to participate in the **Ragner Relay Los Angeles.** It is a 200-mile relay race split between 12 runners from Huntington Beach to Coronado Island, San Diego.

WHEN:	**April 2011**
WHY:	**To Raise FUNDS for PWCF and AWARENESS of Prader-Willi Syndrome**
COST:	$100 to register for the race Each runner will be encouraged to raise donations. TEAM GOAL is $50,000!!
WANTED:	**1 Female runner, 1 Male runner, 2 Drivers, and alternate runners, support crew, and more!!**
HOW:	Contact Chris and Jessica Patay for an application: patays@cox.net or call 310-489-6605

We hope that you will consider being a part of this challenging and exciting event!

Volunteer Recognition Corner

PWCF recognizes **Melissa Moss** for her work to proofread the newsletter;

Cameron Graziano for his help to mail the Membership Renewal / Dues Forms;

Carolyn Meyer, Elizabeth Greskovics, Trang Tran, Kimberly Pratto-Storr and her daughter **Naomi** for helping to prepare the General Education Meeting packets;

Aaron M. Kennedy, CFS of Stark Miller Financial Benefits Group located in Oakland, CA for reviewing PWCF’s financial records and investment portfolio.

Research Subjects Needed for PWS Research

PWS and Early-onset Morbid Obesity Natural History Study – All Persons with PWS

Researcher: Virginia Kimonis, M.D., Chief, Division of Genetics and Metabolism, UCI Med Ctr. The purpose of this study is to collect natural history information on PWS and early onset morbid (severe) obesity.

Who: Persons with a confirmed diagnosis of Prader-Willi syndrome ages birth-60 years, receiving and not receiving growth hormone.

Where: UCI Med Ctr and General Research Centers at UCI Med Ctr. and Children's Hospital, Orange County in Orange, CA.

Contact: Virginia Kimonis, M.D. at 714-456-5791 or email at vkimonis@uci.edu or Sandra Donkervoort, MS, CGC research coordinator at 949-824-0521 or email at sdonkerv@uci.edu.

New Clue for Understanding the Hunger of Prader-Willi Syndrome

In the July 2010 issue of *The Journal of Clinical Endocrinology & Metabolism*, Dr. Joan C. Han, a pediatric endocrinologist at the National Institutes of Health (NIH), and her colleagues reported 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 an important role in controlling appetite and may provide some answers to understanding the insatiable hunger of PWS and other conditions associated with hyperphagia. Dr. Han and her colleagues recently received a grant from the PWSA (USA) to conduct further studies on BDNF, and they are seeking patients with PWS (ages 0-18 years old) for this research. Participation involves providing medical information and a blood sample. For more information, please contact Dr. Han at (301) 435-7820 or hanjo@mail.nih.gov.

Resistance exercise, hormones, and metabolism in youth with Prader-Willi Syndrome (PWS)

Researchers in the Kinesiology Department at California State University Fullerton (CSUF), in collaboration with the Division of Endocrinology at the Children's Hospital of Orange County (CHOC) located in the city of Orange in CA, are investigating the hormonal and metabolic responses during exercise in children with PWS and without PWS. The purpose of this study is to better understand alterations in the endocrinology and metabolism of PWS based on the genetics and body composition particular to PWS.

We are recruiting youth with PWS between the ages 8-18 years old for a three-visit study (1.5 hours for the 1st visit to CHOC, 1 hour for a visit to CSUF, and 3 hours for a 2nd visit to CHOC). During both visits to CHOC the children will complete resistance exercises while wearing a weighted vest, in the 1st visit they will complete a health screening, and in the 2nd visit they will have their blood drawn. The visit to CSUF is for a body composition x-ray scan (DXA). Participating youth will be compensated for their time with gift certificates, and parents/caregivers for mileage and parking.

For more information or to participate in this study, please contact the research office at 657-278-3671 pwstudy@fullerton.edu, Dr. Daniela Rubin (657-278-4704) drubin@fullerton.edu, Dr. Dan Judelson (657-278-5423) djudelson@fullerton.edu. Hablamos español.

Food Tip

This food tip was submitted by Evan Postal of Newhall

Crunchies are freeze-dried fruits and vegetables. There is no added sugar, sulphur, fat or preservatives. Crunchies are created by placing frozen fruits or vegetables in a refrigerated vacuum chamber which removes up to 97% of the moisture. What's left is a product that retains virtually all of its nutrients and enzymes (unlike heat-drying), while maintaining its shape, intensifying its flavor and making it crispy and crunchy. Crunchies are a great way to get your daily recommended allowance of fruits and veggies, are wheat and gluten free, are certified Non-GMO (not genetically modified), and Kosher certified.

Veggie Crunchies come in Grilled Edamame and Wild Rice flavors and can be added to salads, baked potatoes, soups, breads, muffins, omelets, ground turkey and pastas. Fruit Crunchies come in Very Berry, Tropical Fruit and Strawberry flavors and can be added to pancakes, waffles, muffins, cookies, scones, cereals, compotes, yogurt and ice cream. For more information visit www.crunchiesfood.com

Executive Director's Column

Lisa Graziano, M.A.

Sometimes we have to look pretty hard to see how far or even *whether* we've made any progress. I have the good fortune to easily see the progress made by PWCF's Board of Directors over the last year in what boils down to five major categories of focus: Education, Advocacy, Support, Research, and Awareness. Also, I have the great personal satisfaction of seeing my own son's steady and inspiring progress. But more on that later.

Education In the area of education, PWCF continues to make available to parents and professionals many, many educational materials. There are brochures, articles, abstracts, and journal articles on myriad PWS issues available. Every *Food, Behavior & Beyond* DVD and *Understanding the Student with Prader-Willi Syndrome* DVD comes with helpful articles. Newly identified parents receive an information-packed application packet, and a *Handbook and Records Keeper* 3-ring binder is provided free to every new member.

Earlier this year PWCF was asked to speak at the annual state conference of the California Association of Superior Court Investigators to educate child custody evaluators and attorneys about the complications that PWS creates in child custody evaluations and in matters regarding legal conservatorship. This is progress.

If you have an adult child who lives in a group home or is assisted by a supported living agency, PWCF in all likelihood provided that home's staff with a PWS training provided by our Professional Residential Training Consultant. If we didn't visit your home yet and you'd like to schedule a training, please contact us. Since the inception of this program in August of 2009, we have trained hundreds of group home staff, supported living staff, vocational work site staff, and Regional Center staff throughout the state of California. The Board of Directors recently authorized expanding this educational program to also serve families who have a child or adult child living at home who are in great crisis. This is progress.

PWCF produced another stellar educational conference for families and professionals (see page 14 for the meeting overview). This year, over 25 university students volunteered to help with the Youth & Adult Program and, in so doing, became familiar with PWS. Someday, one of these volunteers may be your child's physical therapist, social worker, nurse, dentist, or psychologist and by virtue of their work at this year's meeting, they will be far more knowledgeable about the complexities of Prader-Willi syndrome. These are the seeds of future progress.

Of course it goes without saying to those of you who are experienced readers of the *PWCF News*, this information-packed quarterly newsletter helps us disseminate educational articles and important updates.

Advocacy Many families took advantage of PWCF's advocacy services throughout the year. We provided guidance, support and advocacy services to help families receive appropriate services from their Regional Center. We helped families advocate for growth hormone and other important therapies. We worked hard to help families advocate for appropriate educational supports and related services. Progress means more individuals with PWS receive appropriate services.

Support There are many avenues for support available to families and professionals. PWCF continues to maintain our 24-hour PWS related medical crisis line so if you have a PWS-related medical crisis, we can help connect your physician with a PWS expert physician somewhere in the country.

PWCF funded three PWS Clinics located in San Diego, Orange County, and Central California. If you live near one of these clinics, you're fortunate indeed! But know that there are *wonderful* private practice docs who treat patients with PWS elsewhere throughout the State.

There are, unfortunately, still too few in-person Support Groups, but there is an active group in the North Bay area and an active group in Los Angeles County. Support is available, however, on the telephone and online with PWCF's Yahoo group as well as PWSA's eSupport Groups. The Foundation's newest strategy is to assign a "seasoned" parent to mentor a newly identified new parent and guide them through the ropes that are often so difficult in the beginning years.

Earlier this year PWCF hosted our third annual PWS Family Day at The Painted Turtle as we worked toward developing a camp that will serve persons with PWS and provide some respite for their families. As wonderful as this camp is, it cannot accommodate all of our needs, and so the decision was made to create our own PWS exclusive camp. PWCF is finalizing the contract with Easter Seals' Camp Harmon to provide a week-long camp to *exclusively* serve persons with PWS ages 8-65!

Research PWCF supports both local and national research, and we encourage families to do the same. Participate in as many research opportunities as is possible and comfortable for your family. Science is making progress. Not as fast as we'd like, absolutely, but every piece of the puzzle we identify brings us closer to understanding the whole picture which is PWS, and to developing medications and treatments that effectively and safely reduce, manage, or eliminate the multiple and serious symptoms associated with Prader-Willi syndrome.

Awareness Another of PWCF's major focuses has been and continues to be to raise the public's awareness of the syndrome. Our 2010 *Walking for Prader-Willi Syndrome* events served multiple purposes: they increased public awareness through Public Service Announcements, Press Releases, and Calendar items; they brought families together in an atmosphere of fun and enjoyment; and they raised much-needed funds. The *Walk* events were expanded this year to Fresno in Central California, and in the upcoming year we are working to create another *Walk* event in the San Diego / Orange County region. We received permission from Disney and Miley Cyrus' musical team to use the song *The Climb* to promote our *Walk* events in a brand new heart-tugging DVD, now posted on our website and on YouTube. These DVDs will be sent to businesses and organizations next year to raise awareness of PWS and will also be made available to families.

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Laughter Through Tears:
Creating a Strong, Supportive, Healthy Marriage and Family
Lisa Graziano, M.A., MFT
Part IV

As we read in Parts I through III of this series, there are four key components of a healthy and strong marriage: the development of a deep friendship, a shared sense of purpose, staying connected with each other, and maintaining shared authority. It goes without saying that all children need a stable family, but children with PWS are especially in need of stability, routine and a low stress environment to help keep behavioral problems to a minimum. In Part II we reviewed the more common stressors facing the new family who is raising an infant or child with PWS and we provided a number of strategies to help manage those stressors. In Part III we reviewed some of the more common stressors that the established family faces and provided strategies to help manage those stressors.

We will now provide important information to help increase the feeling of emotional closeness and intimacy with your partner.

Strategies to Decrease Stress and Increase Marital Intimacy

When we marry, we often feel an “us against the world” feeling. Marriages that endure manage to maintain that team approach in a variety of ways.

Couples in a healthy marriage don’t always and don’t need to agree on everything. Conflict is not bad for a marriage, in fact it’s healthy. The trick is to maintain your focus on the four basic characteristics of a healthy marriage while you’re disagreeing or offering your argument: Friendship, Purpose, Connection, Cooperation.

Be Nice! Probably the most basic and yet often most difficult thing to do is to just be nice to our spouse! We may speak to our spouse in ways we wouldn’t *dream* of speaking to a friend or co-worker. Speak to your spouse as you would a friend or co-worker. Think about your spouse’s wants, needs, feelings, ideas as you would a friend’s or co-worker’s. Retrain and remind yourself that your spouse is your friend, *not* the enemy and really *is* on your same side of the family team. When having discussions, see your partner as your *friend*; it will “soften” your communication. In the beginning it can be helpful to pretend you’re being watched by an invisible person and judged on how kind you are to your spouse. Marriages often fail when one or both partners fail to experience or even care about the other’s perspective. Be conscious about your spouse’s potential thoughts and feelings in response to your words.

Create Positive Thoughts. Negative thoughts promote and sustain negative thoughts and feelings. Positive thoughts promote and sustain positive thoughts and feelings. You really *can* change your negative feelings by altering your negative thoughts to more positive statements. Force yourself to change your negative thoughts into more positive ones; it will make a *huge* difference. If at first it feels phony, that’s ok. Remind yourself that marriage is *not* 50/50. Sometimes it’s 80/20, sometimes is 30/70. Watch your negative thoughts especially at times when you’re the one doing the 80!

Depression is an inward-looking, spiraling malady; the more we feel depressed, the more drawn in to our own thoughts and feelings we become. The more we focus on our own sad thoughts and feelings, the more depressed we become. To break this cycle, work to shift your focus from your own disappointments, losses, etc. and force yourself to think and wonder about your *spouse’s* disappointments, losses, etc. Depression is also quite biochemical. It may be necessary for your health and the health of your family to seek treatment and/or medication to help relieve your level of depression if it begins to interfere with your ability to do the things you need to do on a daily basis.

Express Anger Appropriately. Be careful when expressing anger. You can’t un-ring a bell. Accusations or character assignations said in anger can linger for years and insidiously undermine intimacy. Saying “I’m sorry, I really didn’t mean it” does *not* undo the damage. Appropriate expression of anger is healthy: “Ohhhh, I’m so *angry* at you. I feel *completely* taken for granted and ignored. I have asked you at least a hundred times to pick up your hair off the bathroom floor, and you don’t do it. I don’t want to feel so *tired* all the time. I want you to pick up your hair from the floor!” NOT: “You are such an inconsiderate *&!%!”

Find the Grain of Truth in the other’s complaint or statement. It is always difficult to be “accused” of being/doing something ‘wrong’ which is why we automatically defend ourselves against such statements. Hearing “You always” or “You never” automatically sets up the need to defend oneself against what’s coming and keeps us from hearing the content of what’s being said. Finding the “grain of truth” in our spouse’s statement or accusation, acknowledging it, and then doing something about it will help. How can you find the grain of truth? First, presume there *is* a grain of truth. Second, acknowledge that part which is true. Third, if you really can’t see the grain of truth straight away, ask questions about why your spouse thinks or believes what they do and LISTEN to the response.

Eliminate the Right – Wrong Battle. Couples often get into never-ending battles because the fight assumes a Right-Wrong position: If I’m right then that proves you’re wrong. If you’re right, then that proves I’m wrong. No one wants to be wrong, so we argue our side without taking into account *anything* our partner offers. Getting out of the Right-Wrong battle will decrease hostility. How to get out of the Right-Wrong battle? Change your thinking from “That’s Wrong” to “That’s Different.” Ask open-ended questions. Why does your partner think / behave that way? What contributes to your partner’s belief? LISTEN to the response. Look for the grain of truth in the argument.

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Laughter Through Tears continued from page 6 …

High stress can develop into a competition of "My stress is greater than your stress" or "you don't understand my stress" or worse, "you don't *care* about my stress." Not only is this a Right-Wrong battle, it's also negative thinking.

Ask for what you want clearly and directly. "I" statements really *do* work. "I" statements help you get clearer on what you're wanting/needing/missing and help you ask for it without blame. Example of unclear expression of want or need: "You are so selfish. I can't believe you just watched me fold all that laundry and not once did you even offer to help." Example of a clear expression of a want or need using an "I" statement: "I'm feeling stressed tonight. I would really appreciate your help folding the laundry. If we do it together, we'll get finished faster and have time to relax/cuddle/play/make love."

Suggested Specific Techniques to Practice and Incorporate

- Create Couple Time whether it be in bed at night, or over coffee in the morning or on the weekend.
- Present a united marital front. Don't fight in front of kids; don't overrule the other parent in front of the kids; support your spouse in front of your parents or other extended family members; don't gossip about your spouse to others.
- Reminisce together about your history: your dates together, what you liked about each other, why you fell in love, your wedding, your first house, your child's birth, your hopes and dreams for the future, etc. Look at photos together.
- Remind yourself of your spouse's positive characteristics. Remind yourself why you love your spouse.
- Build in couple and family play time as often as possible.
- Share experiences / stories about the pregnancy, the stress experienced after the birth, the stress you're currently experiencing.
- Practice *really* listening to your spouse's stories. Ask questions to learn more about your spouse.
- Talk daily about each other's daily events, whether it's the big whopper events or mundane minutia. It will bring you closer together.
- Share stories about work and what the kids did today. Don't criticize. Don't offer solutions (unless solutions are requested).
- Be aware of what you want / need. Ask directly and clearly for what you want / need. "I just want you to listen" or "I want your opinion" or "I need some alone time."
- Request your spouse's opinions and input. Don't ask for an opinion and then discount or ignore it.
- Presume your spouse's competence.
- Presume your spouse has your and the family's best interest at heart. If you believe he/she doesn't, presume there's too much stress getting in the way of his/her compassion and work to help reduce it.
- We all have about the same level of emotional competence as our partner. We may be more competent in one area and our spouse more competent in another, but overall *we tend to pick a partner who matches our own level of maturity*. Believing ourselves "better than" our spouse is an indication the marriage is off track.
- At times of anger or emotional distance, remind yourself *that* you love your spouse, remind yourself *why* you first fell in love with your spouse, and remind yourself why you love your spouse *now*.
- Spend time doing chores together, side by side washing dishes, gardening, taking a walk around the block, doing an art project. Talking is not necessarily necessary; just be together.
- Time together doesn't have to cost money. Do a family picnic or camp out at the park, the beach, in the woods, or in your back yard. Break out the camera so it *feels* like a vacation.
- Don't be afraid to talk about the kids on one of those rare dates! This is one huge area where you definitely have something in common!
- Work together to create at least 30-60 minutes alone with your spouse before going to bed.
- Retire to bed *with* your spouse more nights than not.
- Eat dinner together as a family more nights than not.
- Screen phone calls. Schedule times during day to return calls, make appointments, etc. Protect your time together by not
- answering or returning calls "after hours".
- Negative thoughts promote negative feelings. Positive thoughts promote positive feelings. Force yourself to change your negative thoughts into more positive ones. It will make a *huge* difference.
- **Create new dreams with your spouse and build them together.**

Love is not just looking at each other,

but looking in the same direction.

Antoine de Saint-Exupery

Functional Behavioral Analysis

by Cindy Leahy cyleahy@yahoo.com

In order to change or stop a behavior, one needs to first answer the question, 'Why is the individual doing what he or she is doing?' In other words, the function of that behavior must first be determined. The method to obtain this information is called a Functional Behavior Assessment (FBA) and should preferably be performed by a Board Certified Behavior Analyst (BCBA). Your Regional Center caseworker and/or an IEP Team can request such an assessment.

There are four main reasons why anyone does anything: 1) to get social attention (positive or negative); 2) to escape or avoid a demand; 3) to obtain a preferred item or activity; or 4) for sensory stimulation. Depending upon the situation, the child may display the same behavior at different times for a different reason. For example, a child with limited speech skills may bite others in response to a child taking a toy away (biting in order to get the toy back) and may also bite another child if that child is not paying attention to her (motivation is social attention). The intervention and prevention strategies used must be based on the child's motivation. In the first situation she should be redirected to request in a more appropriate manner that the toy be returned to her. In the second example, she should be prompted to tap the other child on the shoulder in order to gain attention.

Below is a form I use as a Behavior Specialist when I perform an FBA. I often leave the form with parents or teachers to fill out. Once you figure out the motivation(s), a Behavior Intervention Plan (BIP) should be developed. The plan should consist of: 1) not letting the behavior get the child what she wants; 2) teach the child an appropriate, alternative behavior that matches the motivation; 3) catch the child being good!

If the motivation is for social attention, the child needs lots of praise for the times she uses an appropriate means to gain attention. This is a very important part of any behavior change procedure, but one that is often overlooked.

If the child does display an unwanted behavior, the unwanted behavior should be ignored with no verbal attention given, with the adult quietly intervening if necessary. Using the example from above, the adult should remove the offending child's mouth from the other child's body and quietly help the offending child perform the wanted behavior, such as physically guiding the child to tap the shoulder of the other child. After the child taps the shoulder, she may be given positive attention.

Collecting Data on Challenging Behaviors

The first step to change a challenging behavior is to learn WHY the child demonstrates that behavior. This can be discovered by analyzing what happens immediately BEFORE (the antecedent) and immediately AFTER (the consequence) the child engages in the behavior. Fill in the following sheet for at least 3 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 lasts longer than 5 seconds."
2. Each time the child 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 Data Collection Sheet:

A-B-C Data Collection Sheet

Name: ________________________ Age: ___________ Behavior of Interest: ____________________________

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

Fish Oil Supplement

A parent of a 29 month old child with PWS wants to start giving him a Fish Oil supplement because she's heard it's so often used by other parents of kids with PWS. Two specialists provide guidelines for using Fish Oil Supplements.

Norma Terrazas, RD, **LD**., a Pediatric Clinical Dietitian in the Department of Gastroenterology, Hepatology, and Nutrition at Texas Children's Hospital responds, notes that "Coromega makes a fish oil for kids, available in Lemon Lime and Orange. Calories are 20 kcals/packet, 850mg fish oil. I have heard some of our parents say the kids like it. The company is pretty reputable. The Coromega website is www.coromega.com. There is a $5 printable coupon also available online. How much to give is the bigger question. I would try 1 packet every 2-3 days for starters and see how the Coromega sits with him. Definitely let his Pediatrician know if you put him on fish oil."

Jennifer Miller, M.D., a Pediatric Endocrinologist at the University of Florida adds, "We typically recommend starting the fish oil when the child is over 1 year of age and on milk rather than formula or breast milk or if they are 6-12 months of age and taking less than 20 oz per day of formula or breast milk, because both formula and breast milk contain the essential fatty acids found in fish oil supplements.

"Coromega has a product that is a mixture of fish oil and CoQ10 which a lot of parents like because that way they only have to give the one packet and not both fish oil and CoQ10 (the less meds they have to give, the better). It is called "Coromega Healthy Heart" and is the same price as the regular Coromega. Coromega is palatable for most children and easy to mix with yogurt or applesauce if the child doesn't like the taste of the product alone.

Many families like the Nordic Naturals brand of fish oil and they have an infant formulation. The website for Nordic Naturals is www.nordicnaturals.com. Also, both Nordic Naturals and Coromega will send parents samples to try before they order a big supply so they can make sure the kids will tolerate the product – parents just have to call the company (phone numbers are available on the websites) and ask.

"Lastly, there is a prescription-grade fish oil (Lovaza) that some parents like because some prescription drug plans will cover the cost of it. It is a capsule, but the parent can puncture it and put it with yogurt or something. If the insurance won't cover the cost, it is definitely not worth spending the money for as it is much more expensive than Coromega or Nordic Naturals, but if it is covered then it is worth it for some families."

We sincerely apologize to the family of Ashleigh for the omission in our last newsletter of the last lines of the tribute written by her brother.

Ashleigh Lininger
10/26/1989 – 5/16/2010

Last Thoughts of Ashleigh

By Christopher Lininger, brother to Ashleigh

It is time. Time for time.
Time gone for mother's breast and mother's hand and father's teaching.
The ice cream shops are closing, the toy stores have the lights off, and it
is too late to go for a walk around the park.
But for you, little sister everything is open.
Open.
For much seemed closed to you in your life, but all you saw was the opening you created.
Time is open for you now.
The plum blossoms are falling. Each blossom honored life.
You have honored life, little sister.
You have honored us all.
From every question to every smile.
You gave us much. You gave us everything.
And now you take the journey, so take it well.
Know that you are loved. Take your journey well.
"Death is the remedy that all great singers sing of."
Take the new dream, leave your mind in the grass of
your choice, it's all the same.
Take your remedy, "no more suffering for you.
I know where you've gone. It is good."

♥ ♥ ♥

PWCF Provides Connection for Families and Professionals

If you're a Family or Extended Family Member and not already a member of the PWCF Members Yahoo email group, or if you're a professional and not already a member of the PWS Professionals Exchange Yahoo email group, you're missing out on valuable information-sharing opportunities.

The purpose of the Yahoo groups is to help families and professionals help each other with important issues such as therapies, food security and weight management strategies, vitamin supplements, growth hormone shots, and help answer questions about Regional Center services, insurance issues, school system needs, etc. Members should feel free to pose questions or ask for information from the group about anything PWS related.

To join the group, go to www.yahoogroups.com. Enter PWCFmembers or PWSProfessionalsExchange in the search box in the middle of the page under the "Join a Group" heading. Click on the group name and follow the instructions to join. If you have any questions or need help joining please let us know.

Board Corner

PWCF Board of Directors Meeting – September 25, 2010

Summarized by Michael Moore

Resignation of President – Chris Patay, Vice President, announced that for health reasons, Ken Knox will step down as President and resign from the Board. [It is with great relief that we report that Ken's health is stable and he continues to do well.] Chris indicated that due to Ken stepping down he will run today's meeting, but he does not wish to serve as President yet and nominated Julie Casey. A motion was made and seconded and all voted to name Julie Casey as PWCF President effective immediately.

Executive Committee Actions Report – Chris reported that the Executive Committee recently approved an increase of expenditures for the General Education Meeting due to the speakers' increased honorarium fees. The Executive Committee also named Albert Salaz Jr. Productions as PWCF's official videographer.

Treasurer Report – Randy Trost, CFA of Morgan Stanley Smith Barney, PWCF's investment firm, presented, upon invitation, a review of PWCF's financial portfolio and an overview of their services. In light of the presentation there was discussion around whether or not interest income should or should not be included in the Income Statement as part of usable funds; the matter will be discussed further as the next Board meeting. Renee Tarica, Treasurer, met with PWCF's accounting firm who is currently preparing the 2009 tax forms. Renee will forward the draft Form 990 tax forms to Board members for their review and authorization prior to filing. Renee also reported that New Life Homes finished paying their $25,000 loan taken in August 2007 and that the owner donated an extra $300.

Executive Director's Report – Lisa Graziano reported that Dr. Lynne Bird, who directs the San Diego PWS Clinic, requested authorization to use some of their PWCF grant funds to hire a Spanish language interpreter to help facilitate their upcoming support group meeting; authorization was granted. The relationship with the Foundation for Prader-Willi Research was discussed regarding what, if any, formal policy PWCF should have with it and other Prader-Willi syndrome organizations. The Board agreed that PWCF should collaborate with other entities benefiting individuals with PWS but that items that could represent a potential conflict of interest must be discussed on a case-by-case basis. Lisa received a request from the Richard de Leon Special Housing Project to serve on their Advisory Board. The Board agreed this is fine as long as the PWCF name isn't used to imply partnership or endorsement. The Board agreed to provide them with a PDF file of our PWS Synopsis brochure so they may print as many copies as they'd like to distribute at their events to help raise awareness of Prader-Willi syndrome.

Program Committee Report – Lisa distributed an updated General Education Meeting budget and noted that honorarium fees for the speakers increased significantly since 2005 when they last spoke at a PWCF conference. PWS Camp Update: Linda Ryan presented her written report. Unfortunately, the Painted Turtle will not offer PWCF a week-long camp therefore other camp options are being researched. Linda and Don and Patty Carlson reported on two potential camps: Easter Seals Camp Harmon and Tuolumne Trails. The Board agreed to pursue a week (6 days/ 5 nights) at Camp Harmon next August. Specific details regarding PWCF subsidies are pending.

Fundraising Committee Report – Julie Casey reported on the APX Gives Back check award presentation ceremony. She shared how generous the APX executives were and what a nice event they hosted. The *Walking for PWS* Events' Online Registration and Donations Update – Because the current online system with Active.com is somewhat complicated to use, Drew Marich has been researching alternate systems. He reported that there is an alternate program that is supposed to be very good but is also extremely expensive. Drew reported that Active.com is scheduled to make upgrades to their site before our 2011 *Walks* which we hope will resolve our issues. Alternative *Walk* locations were discussed for the 2011 *Walks.* Since none of the desired new locations for the Southern California *Walk* are feasible for 2011 it was agreed to hold the Southern California *Walk* in the same location. Mike Moore was unable to attend this Board meeting to update an alternate Northern California location, but has investigated the Warming Hut at Crissy Field near the Golden Gate Bridge and has a *Walk* permit application submitted to the Golden Gate Parks Department pending approval. Kauai Fundraiser Update: Flyers and ticket booklets have been distributed for the Kauai Opportunity Raffle. Grant Writer Report: The Board reviewed Linda Hedstrom's Grant Writer activity, noting that letters of inquiry were sent to the Public Welfare Foundation and to the California Endowment's Building Healthy Communities Initiative.

Residential Services Liaison Committee Report – Filming for the new Residential Staff Training DVD is almost finished. The producer, Albert Salaz, recommended and the Board approved, adding an additional $1700 to the project, hiring a professional voice-over. Fran Moss, in absentia, submitted a report that noted the Arc of San Diego homes are now full, and the Marjan home in Corona recently admitted someone to fill their vacancy. The scope of practice for the Residential Training Consultant Theresa McGrath was broadened to include training/consulting, on a case-by-case basis, to families who are in crisis and whose child lives at home. Ms. McGrath submitted a request to the Board to increase her fees which the Board approved.

Awareness Committee Report – Julie Casey delivered the Facebook & Twitter reports. The report of the Advocacy Awareness and 2011 Awareness Events were skipped due to Mike Moore's absence.

Website Update – Tom McRae reported that about 20% of the PWCF web content has been migrated to the new site and some additional changes have been made per input received from Board members.

Strategic Planning – Significant time was spent discussing results of a recent Board poll to guide the direction of our long-term goals. The consensus was that the most effective use of PWCF's funds will be to support existing residential homes, day programs, and vocational work sites and encourage the development of new PWS group homes, vocational work sites, and day programs. PWCF will develop "Standards of Excellence" and outline the requirements to meet these Standards of Excellence in order to obtain PWCF recognition. A questionnaire will be created to gather input from parents of children/adult children who live in a residential facility, attend a day program, and/or attend a vocational work site. Questionnaires will also be sent to residential facility owners and managers, day program and vocational work site owners and supervisors, and Regional Center managers and case workers. 2011 Goal Setting was also discussed.

Executive Director Column continued from page 5 …

A great deal of behind-the-scenes progress was made on our new website which will be completed in 2011. The new Residential Staff Training DVD we've been working on for so long is in the editing stage and will be available for distribution in 2011.

This year we had a good 'ole time at our PWS Benefit Concert in Northern California at the Craneway Pavilion. Flyers were sent to local businesses and notices were placed in local papers' Calendar sections. We gave out hundreds of PWS Awareness Wristbands and PWS Synopsis brochures at the Oracle Arena at a Warriors basketball game, and coordinated an interview with PWS spokesman Clint Hurdle who raised awareness of PWS of thousands of radio listeners.

Public awareness was increased significantly because PWCF and other PWS organizations across the U.S. and Canada participated in the APX Gives Back contest. Because so many of you voted every single day for PWCF, we won $30,000 which will fund the new Residential Staff Training DVD and help fund our new camp. PWCF's videographer posted the award ceremony on our new YouTube account (also on our website) so now *everyone* can learn more about Prader-Willi syndrome! This represents *tremendous* progress in public awareness.

PWCF offers many, many resources to families and professionals, but there could be and *should* be many more. Donations and funding sources once available to PWCF are decreasing at the same time we are seeing an increase in the number of families who need services, and an increasing number of families who cannot afford even the nominal fees associated with those services. Any donation you made this past year, large or small, has helped us help the families we are working so hard to serve and we sincerely thank you.

Being a rare disorder, there are many who have not yet heard of Prader-Willi syndrome, but this *is* changing; we *are* making progress. When my son was born 11 years ago, there was never a time when I mentioned Prader-Willi syndrome that I wasn't met with "Prader-*who*?" or "Prader-*what*?" Now it's not uncommon that I hear "Oh yeah, I've heard of that. That's that disorder where people don't feel full." (If only it were that simple!)

Oh, and about my son's progress… When he started his Karate class two summers ago he could barely balance on one foot past the count of three. This year he earned his Purple belt (three levels up) and today he broke a board with a step-behind-side kick. Now *that's* progress.

PWCF Thanks Outgoing Board of Directors

PWCF extends our heartfelt gratitude to the members of the Board of Directors who have work hard during their tenure on the Board and whose terms of service expire at the end of this year: **Michelle Freier** and **Betty Olson**.

Ken Knox, who served as PWCF's President for the past two years, resigned earlier this year for health reasons. We are extremely happy to report that Ken is doing quite well.

The Board unanimously elected **Julie Casey** to serve as President.

Julie Casey with son Ryan

PWCF Welcomes Incoming Board of Directors

The recent election confirmed incoming Board of Directors **June-Anne Gold, M.D., Tom McRae**, and **Paula Watney**. **Don Carlson** has been appointed by the Board to serve out the duration of Ken Knox's term. PWCF welcomes its newly elected and appointed Board of Directors and looks forward to their enthusiasm, dedication and work to improve the quality of life of Californians impacted by Prader-Willi Syndrome.

Photo
Not
Available

Don Carlson

June-Anne Gold, M.D.

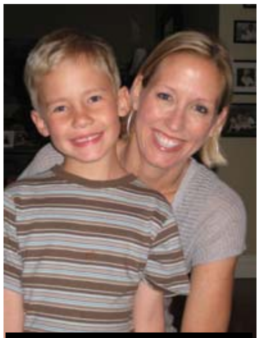
Tom McRae

Paula Watney

In the Trenches

Vol. III

By Jessica Patay



Ryan & Jessica

Behavior therapists are aggravating and life-saving at the same time. They encourage you and scold you (or so it feels that way!). They hold your hand, and then slap that same hand, but ever so gently. When receiving counsel, you cry tears of relief and sometimes cry tears of embarrassment. To invite a behavior therapist into your home, to analyze your child, your home-life, and your parenting skills, is NOT for those with "thin skin." It takes courage, commitment, and a humble, teachable attitude. And it's worth it. It truly is.

October of 2009 Ben (not his real name) walked into our family's life, and really MY life, and our parenting issues. Ben wasn't there to follow Ryan around and apply behavior analysis and intervention constantly. He was there to meet with me, (or, my husband, Chris and I) for two hours, once a week to discuss and teach me behavior strategies to implement. He was a behavior modification expert who was to unleash his knowledge upon me, so that I could help Ryan decrease his tantrum episodes (the target behavior). Ryan had been having daily tantrums, and the potential for more was always there.

In our case, we were the beneficiaries of a really good, skilled, and discerning therapist. He put careful thought into his suggestions and ideas for our particular struggles with Ryan. He helped me to learn and re-learn practical techniques to help Ryan, and even our other kids. We had 2-hour sessions, once a week, for four months. He would ask about our week and how we applied the tantrum-reaction strategies he gave us. He would tell me how I handled it right or wrong. He'd model certain interventions and communications with Ryan so I could see the theories and lessons come to life. He would bring real life, helpful, and effective applications to our daily struggles.

So why was Ben, our behaviorist-knight-in-shining-armor so aggravating and frustrating? Because he required that *I change* and he held me accountable weekly. As much as I like to think of myself as self-aware and willing to change, my buttons of insecurity as a mother were pushed again and again. Wasn't Ben there to focus on Ryan and get RYAN to change? It was like having my own "supernanny" in our house for four months. It felt like my weaknesses were constantly on display in the Macy's store window for all to see. Yet at the same time, I had a sympathetic and caring ear each week, a strong shoulder to lean on as I worked on changing my ways and learning new ways to communicate with Ryan (and my other children Kate and Luke). Each week my head was stuffed full of information and it was extremely beneficial, IF I applied it, and stayed really consistent.

A Few Highlights From What I Learned From Ben/Behavior Therapist Extraordinaire:

1. Have "family rules" written up and posted for all to see. Review them from time to time with kids. Have "car rules" as well.
2. Have a schedule posted (morning, afternoon/evening and bedtime).
3. Schedule non-preferred activities (chores) before preferred activities (dinner).
4. Logical consequences work to change behavior. Punishment may stop behavior temporarily, or not at all.
5. Be aware of your own ego when responding to your child's negative choices, defiance, and noncompliance. Our egos being bruised by our child's poor behavior leads us to get into power struggles and use punishment.
6. Give positive specific praise for *all* things, even things you think your child "should do" just because it's the right thing. "Thank you for sitting down so nicely all through dinner."
7. Have higher expectations of your child's growth, cognition, and capabilities. You may be surprised! "A goldfish will only grow as big as the bowl you grow it in."
8. Be consistent, be consistent, and be consistent.
9. Keep Ryan on a "need-to-know" basis about future plans and activities. Otherwise he perseverates about the upcoming plans (like a vacation). Stay focused on today's plans and schedule, or even the part of the day you are on (morning, afternoon or night).
10. Ryan needs to know there is a beginning, a middle, and an end. Keep this in mind on weekends, summers, holidays, vacations, and outings when the schedule changes or there is no schedule. Communicate and teach before he gets into an anxious, perseverative mode.
11. Reinforce the family rule that "In our family, when the schedule changes, we go with the flow." Reinforce and praise heavily when your child does switch gears more easily with changes.
12. Let Ryan know in advance of changes, but not too far in advance.
13. Never withhold information for fear he will have a tantrum. Walking on eggs to avoid triggering tantrums is not the goal. The goal is to teach him how to handle his anxiety properly.
14. Always re-direct to the schedule. Staying tight to his schedule keeps him secure and less anxious.

A year later we are still applying what Ben taught us. I follow a schedule. I have a token system. I follow the tantrum–reaction strategy he taught us. I am probably not as consistent or as intentional as I was when he was here weekly. (Just being honest!) BUT I will say we have seen a decrease in Ryan's tantrums and perseveration. Ryan is still an anxious bundle of nerves. Yet now I have begun to understand better how to respond to him, how to communicate, and when to ignore or disengage. I am getting in fewer power struggles (with all my kids) and recognizing where my ego, my need for control, and my agenda get in the way of my parenting. OUCH! The Behavior Therapist-Bens out there are worth pursuing if you have never had one in your life and household. Don't be afraid or too proud. It just might change your life.

PWCF Gets Mail…

Dear PWCF: The [July - September edition] newsletter was fantastic. This is the first time I've read the "electronic" version which makes it even better as the photos are better in color than black & white. [The article, "Laughter Through Tears: Creating a Strong, Supportive, Healthy Marriage and Family, Part III] was especially good. Hopefully I'll remember some of the excellent advice it gives. Great job! *Sincerely, Tom McRae*

~~~~~

Dear PWCF: I just wanted to let you know how impressive and useful your wonderful newsletter is. I don’t usually have the time to look through it carefully, but this one I did, and I really thought it was great.

I’d like to express my gratitude for the fact that PWCF continues to support my PWS clinic in Fresno [Genetic Medicine Central California]. It continues to be well-attended, and I feel that we serve a very important function in that area that does not have the proximity of lots of resources for people with PWS. I hope that the evaluations you get from those who come reflect benefit.

Thanks again for all that you do for PWS!! And please know that I really appreciate having such a great PWS chapter locally to which I can refer all my newly diagnosed families. I also try to spread the word to the trainees in genetics that I work with. *All the best, and thanks again, Suzanne Cassidy, M.D., Director, PWS Clinic at Genetic Medicine Central California*

~~~~~

Dear PWCF: I wanted to thank Theresa McGrath very much for presenting at [our] staff training on October 25. I cannot tell you how many employees expressed appreciation for the information [she] presented. I am sorry that time did not allow for a longer presentation. Perhaps next year, we can establish a timeframe to obtain the whole presentation. We would love to hear more about the tools and strategies that … work best for the consumers we serve.

Thank you again for your time, presentation and sharing your knowledge and experiences with my employees. It was greatly appreciated by all 83 in attendance. *Sincerely, Laura Trost, Executive Director, Choices Transitional Services*

~~~~~

Dear PWCF: Mary Jane and I really appreciate the time [Lisa Graziano] spent with us on the phone a couple of months ago. I am writing to let you know that today's Prader-Willi support group meeting was very beneficial to my family and I believe it was good for others as well. We had a spectrum of ages. Couples who have children that are less than 3 years old up to the featured speaker’s family who brought their daughter [with PWS] who is 28 (here name is Heather and she is a real inspiration).

I normally don't follow up with emails, however I felt very charged up after attending the Prader-Willi support group meeting … today. For me the meeting was emotionally charged. Everyone had their story and everyone was concerned about hearing what the other families were going through.

Another reason I am writing is to tell you that Michelle and her son Joe were extremely helpful. I did not get a chance to express my appreciation to Michelle. Michelle took the time to get up early in the morning and drive to San Diego to participate. All of her comments were extremely insightful as were her son Joe's. If you talk with her please let her know that her presence was really appreciated.

I am grateful for the Prader-Willi California Foundation and for people like you and others like Michelle who support the cause to help and make the lives of families with Prader-Willi better.

From Mary Jane and I, we hope your family and your son especially are doing well. *Thank you and God Bless, Richard Rust, Mary Jane Morris, and Lauren (18 year old with PW)*

~~~~~

Dear PWCF: I received the PWS package you sent and wanted to thank you for all the valuable information you provided. I’ve been reading and re-reading all of the documents and am so happy to have all of this reference information. I’ve already shared much of it with my mother-in-law and her first statement was ‘Everyone in the family needs to read this information.’ So that’s the plan, as well as making sure all the people at school become informed. My husband and I plan to become members and also have penciled in next November for the next conference, since we can’t attend the one next week in San Jose. ...I talked with Suzanne Cassidy [, M.D.] last week and she was very helpful. I’ll be talking with our local Endo in the next week and asking if he would be willing to assess [my daughter] for a clinical diagnosis of PWS. Dr. Cassidy volunteered to help with this process as much as she can. Also, Dr. Forster and I have plans to talk next week. I can’t tell you how much I appreciate getting me connected with these resources. *Thanks again, anonymous mom*

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PWCF General Education Meeting

This year's conference aptly reflected its title, *The Behavior Toolbox*, and provided a vast amount of specific, detailed and *immediately* helpful information to help parents and care providers modify, alter, and adjust our child's or adult's environment in order to reduce and avoid unwanted or maladaptive behaviors that are so common amongst persons with Prader-Willi syndrome.

The speakers were PWS specialists **Janice Forster, M.D.** and **Linda Gourash, M.D.** of the **Pittsburgh Partnership, Specialists in PWS** (www.pittsburghpartnership.com) and covered a wide array of PWS topics including but absolutely not limited to: the basics of Food Security; developmental age periods and what families can do during that age period to encourage more cooperative behavior; recommendations for interacting with the Hyper-RE-active individual with PWS; an overview of TRAIN (Tool to Reduce Anxiety, Insecurity and Noncompliance) which is a "tool to reduce syndrome-specific characteristics by managing the interaction between the person and the environment;" tips for using Behavior Plans; behavioral challenge tips for professionals, an overview of common psychiatric issues and medication usage, and an overview of sensory integration deficits and therapy. The overall thrust of the day's lectures underscored how closely linked are anxiety and maladaptive behaviors, and emphasized how important it is that care providers alter *our* behavior in order to reduce to a manageable degree the level of anxiety experienced by the individual with PWS. Due to myriad physical and biochemical challenges associated with PWS, persons with PWS are generally not able to manage their own level of anxiety and therefore require the aid of an outside support network. Clever PWS-related songs and ditties written and sung by the speakers helped lighten the mood and minimize brain overload.

Program Committee members **Wendy Young** organized translation services for Spanish-only speaking families, and **Mary Hill** oversaw the Education Booth with help from **Tracy Goatcher** and **Maddy Fluhr.**

We couldn't have a successful and well-attended annual conference without a stellar Youth & Adult Program. This year's directors were **Linda Smith** who directed the Youth Program, **Kristen Amarasekera** who directed the Teen Program and supervised **Kevin Amarasekera's** oversight of the 6-12 Years Program, and **Julie Yamamoto** who directed the Adult Program. To help with this year's program, Kristen flew all the way from Chicago where she attends medical school!

Julie Casey organized all of the volunteers who were recruited from San Jose State University. The vast majority of volunteers were students from the Kinesiology (physical therapy) Department. Other volunteers consisted of students from the Public Nursing program, the Social Work program, Pre-Dental students, and the Department of Psychology. Julie Yamamoto, Adult Program Director, shares her high praises for some of her volunteers: *"Awesome volunteers! Tremendously helpful! I cannot thank them enough for their support during the conference. They were all wonderful and generous. I am especially thankful to Hau Le and James Nguyen for continuing throughout the day (without being asked) even though they were only scheduled for the morning. I would also like to thank Hau, James, and Mike West for their kind displays of patience and gentleness with all the guests. No hesitation to jump right in and lend a helping hand."*

The PWCF business meeting was held during the lunch hour where **Julie Casey** presented both the President's and the Secretary's Reports, **Renee Tarica** presented the Treasurer's report, **Lisa Graziano** presented the Executive Director's Report, **Chris Patay** presented the Nominating Committee report, and Easter Seals' Camp Manager **June Stockbridge** provided a brief overview of PWCF's new PWS-exclusive camp at Camp Harmon in 2011.

Distinguished recipients of this year's President's Awards were:

Ken Knox *in recognition and appreciation of his work on Prader-Willi California Foundation's Board of Directors to improve the quality of life for persons with Prader-Willi syndrome and your leadership during your term serving as President;*

Kristen Amarasekera *in recognition and appreciation of her extraordinary dedication and service that benefits children, teens and adults with Prader-Willi Syndrome;*

Theresa McGrath *in recognition and appreciation of her expertise and commitment to providing the highest quality training to professionals serving the residential needs of persons with Prader-Willi Syndrome;*

Michelle Freier *in recognition and appreciation of her work on Prader-Willi California Foundation's Board of Directors to improve the quality of life for all persons with Prader-Willi syndrome;*

Mary Hill *in recognition and appreciation of her sustained dedication to improving the quality of life of California's families;*

Paula Watney *in recognition and appreciation of her work to establish a successful Walking for Prader-Willi Syndrome* awareness and fundraising event in Central California;

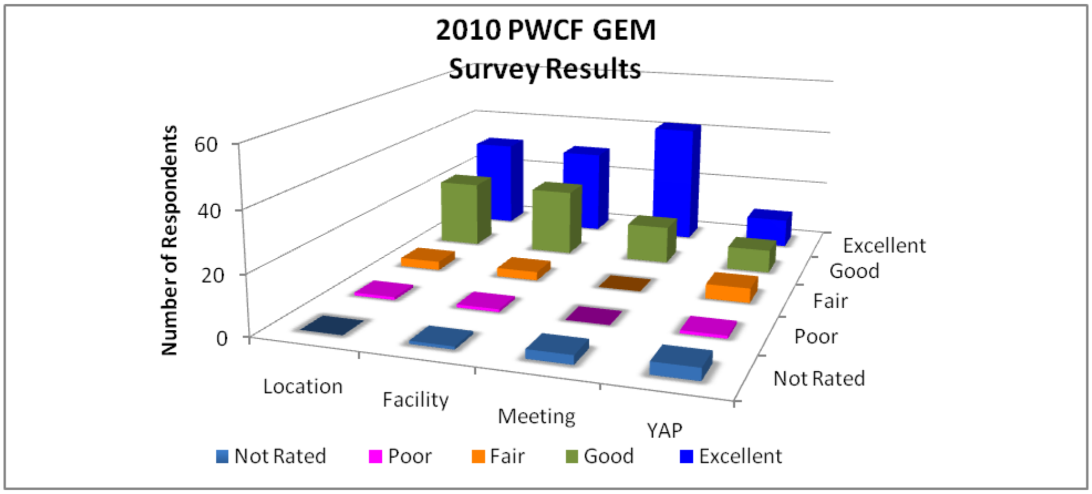
Surprising ***Julie Casey****, Vice President Chris Patay presented her with an award in recognition and appreciation of her work to create PWCF's Facebook page which led to winning $30,000 from the APX Alarm Gives Back Project and continues to increase awareness of Prader-Willi syndrome.*

An Opportunity Drawing was held to raffle items acquired by **Renee and Henry Tarica**, **Julie and Dan Casey**, and **Drew Marich**. The winner of seven glorious nights at the Pono Kai Resort located in Kauai was **Cherise Bennett-Dunham! Lisa Graziano** was the lucky winner of two nights at the beautiful *Laguna Riviera Resort on the Beach*, and **Alyssa DiFilippo** won $150!

Continued on page 15 ...

General Education Meeting continued from page 14 …

The conference was *very* well received as can be seen from **Mary Hill's** summary of the Evaluation Forms shown below:



Some comments about the conference included:

The doctors are doing a wonderful job; we truly enjoyed their last presentation in So. Cal but this year's presentation is even more enjoyable.

Loved today's topic and presenters! Very motivating and practical.

The Pittsburgh Partnership Drs. were fantastic. Very knowledgeable and motivational to parents.

Please keep up the research and good work, to support the PWS population!

If you missed the conference, you can still learn some of the important information the speakers provided by purchasing the DVD ***Food, Behavior and Beyond: Practical Management for the Child and Adult with Prader-Willi Syndrome*** featuring Drs. Gourash and Forster. This DVD was updated in 2008 with Spanish subtitles and is available from PWCF either at our online store (www.PWCF.org) or by calling the PWCF office.

Don't miss the 2011 General Education Meeting in Southern California tentatively slated for November 5!

MEMBERSHIP ACTIVITY

October - December 2010

Please note that because we are fortunate to have the majority of our families renew their membership each year and in the interest of space, effective January, 2009 we will no longer list renewing Individual and Family members. We will continue to list all new members and all renewing Extended Family, Family Friends, and Professional Members.

New Individual Members
Michaela Lango

New Extended Family Members
Verona Murray
Judith Steinhart

New Professional Members
Kenneth Richard, Peak Performance

Renewed Extended Family Members
Karen & Russell Benedikt
Bob Graziano
Mary & Pat Williams

Renewed Family Friend Members
Mel Goldberg & Dolores Horn
Jan & Steve Grogan
Ronnie Raffaniello

Renewed Professional Members
Zylnna Andaya Oliva, New Life Homes
Lulu & Oscar Cachuela, Cachuela Homes Corporate Office
Susan Clark, Children's Hospital Orange County
Vicki Cox, M.S., UCSF Genetics Office
Tony Kueter, People's Care Inc., Corporate Office
Phillip D.K. Lee, M.D., Univ of Texas Medical Branch
Renee Lovern, Educator
Ron Newfield, M.D., Rady Children's Hosp of San Diego

The *PWCF News* is the newsletter of the Prader-Willi California Foundation (PWCF) and is sent to all its members. The opinions expressed in the *PWCF News* represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the Officers and Board of Directors of the Prader-Willi California Foundation. For contributions to this newsletter, questions or comments, please write: Attention Editor, *PWCF News*, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277 – or phone – 310-372-5053 ~ 800-400-9994 (within CA), or email us at PWCF1@aol.com

PWCF is grateful to the following supporters for helping us continue to provide quality supports and services to individuals with Prader-Willi syndrome and their families. Thank You!

We work hard to recognize all donors who wish to be recognized. If you do not see your name listed, please accept our sincere apologies and allow us the opportunity to include your name in the next issue by contacting us at 310.372.5053 or PWCF1@aol.com

DONATIONS ~ October-December, 2010

SHINING STAR DONATIONS

Alpha Centauri ($250 - $499)
Susan & Mark Ojeda in honor of Eric Ojeda

Arcturus ($100 - $249)
Lisa Ann Bonk in honor of Nolan Carl Bonk
Mary & Holger Bracht in honor of Kian Bracht
T.L. Canales
Judy & Bill Castle
Laura & Raymond Esau in honor of Rebecca Loewen
Janet & Joel Goldberg in honor of Ryan Patay
Barbara & David Gow
Lisa & TJ Graziano in honor of Cameron Graziano
Karen & Tim Jobe
Rita & James Koerber in honor of Alison M. Koerber
Miriam & Elias Liberman in honor of Yvette Tarica
Carol & Chris Lininger in memory of Ashleigh Noel Lininger
Phyllis Mase in honor of Haley Kavrell
Bie Chuan Ong and Lucy Jao
Laura Rakowitz in honor of Whitman Donaldson
Rose M. Sakurai
Heidi & Jonah Steinhart in honor of Annika Steinhart
John Storr
Monique & Peter Thorrington in honor of Chris and Jessica Patay

Vega ($1 - $99)
Gary & Cindy Arstein-Kerslake
Kyra Allen in honor of Faith Allen
Molly Carter in honor of Dan Carter
Sally & Chet Collom in honor of Jennifer Collom
Thelma & Tom Davidson in honor of Ian Davidson
The Hill Family in honor of Oscar Hill
Jay Kavanagh in honor of Brad Kavanagh
Donna Lucia in memory of Dawn Lucia
Diane Naegeli in honor of Kathryn Morine
Lianne & David Noddle in honor of Yvette Tarica
Ralph Paige
Robin Rose
Judy Schlafer in honor of Timothy A. Schlafer
Carol Williams in honor of Melissa Moss

Magnanimous General Donations
The Jeremiah and Maureen Kelly Family Charitable Foundation, Inc.

Donations to Support PWCF's 2010 General Education Meeting

Julie Casey
Linda Hamilton, Lee Street Homes
Helen & John Lim
Patti & Tom McRae
People's Care, Inc.
Paula Watney
Wendy & David Young

General Donations

Zylnna Andaya Oliva, New Life Homes
Cherise Bennett-Dunham
Yasuko & Ira Bloom
Julie & Dan Casey
Julie & Dan Casey in honor of Ryan and for Sharon Casey's September 21st Birthday
Peter Chiang
Jeremy Frend
Mel Goldberg and Dolores Horn
GoodSearch
Susan & Daniel Hedstrom
Brian Huff in honor of Brooke Marich
Jill Katz in honor of Oliver Young
Alison Krull
Susan & Mark Lewis
Kathy Parker
Nancy & Steve Player in honor of Judy and Peter Steinhart
Clara & John Steinhart
Carmen Stuhlmuller in honor of Annika and the Steinhart Family
Debby Yashar

Donations in Honor of Samantha Morgan
Suzanne Privette

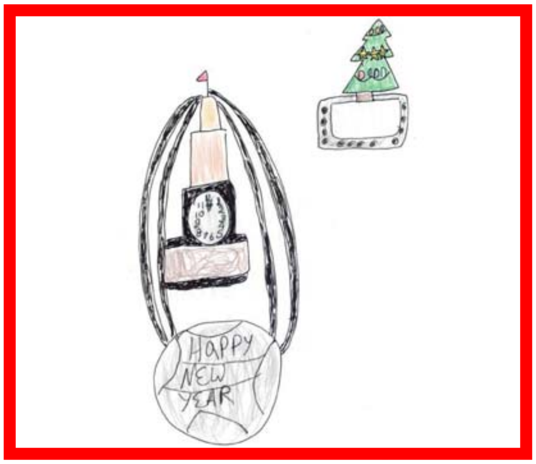
Prader-Willi California Foundation is sincerely grateful to the

Joseph Drown Foundation

for providing a generous grant to support PWCF's programs and services

Prader-Willi California Foundation is a nonprofit, 501 (c) (3) corporation established in the state of California in 1979. Prader-Willi California Foundation is an affiliate of Prader-Willi Syndrome Association (USA) and shares in their quest to serve individuals and families affected by Prader-Willi syndrome. PWCF's vision is that people with Prader-Willi syndrome may pursue their individual hopes and dreams to the full extent of their talents and capabilities and that we will help them achieve their goals.

Front of Cards:



Use PWS Holiday Note Cards for your holiday Thank You's and raise awareness of Prader-Willi Syndrome!

These cards are beautifully designed by a young man who has PWS. Blank on the inside, these cards are perfect for writing all of your holiday thank you's. Each time you use a note card you increase awareness of Prader-Willi syndrome.

8 cards per set // $6 per set // Two sets for $10
Plus $3 shipping & handling

Yes! Please send me _________ sets
Name: ____
Address: ____
City/State/Zip: ____________________________________
Phone/Email:_______________________________________

☐ I've enclosed my check made for $_______________
(Make checks payable to Prader-Willi California Foundation)

☐ Please charge $_____________ to my ☐Visa ☐MC ☐AMX
Name on Card: _____________________________________
Card No.: ____
Exp. Date: _______________ Security Code: ______________

Mail Order Form with your payment to
PWCF, 514 N. Prospect Avenue,
Suite 110-LL, Redondo Beach, CA 90277
Call PWCF at 310-372-5053 to place your credit card order by phone

Back of Cards Read:

Prader-Willi California Foundation

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

Artwork on this card was designed by Joshua Groom, age 33, who has Prader-Willi syndrome (PWS). PWS is a life-threatening medical disorder that affects one in 10,000 - 15,000 people. PWS causes a host of symptoms including low muscle tone, global developmental delays, learning disabilities, behavioral problems, and its hallmark symptom, an insatiable appetite. No medication eliminates or even reduces this insatiable appetite, making living independently impossible. Without appropriate interventions and continuous supervision, PWS leads to morbid obesity and premature death.

There is no cure for PWS yet, but there is hope. And you can help.

Prader-Willi California Foundation, a non-profit 501(c)(3)charitable organization, is dedicated to providing education, advocacy and support services to people with PWS, their families, and the professionals who care for them.

To learn more about PWS or to make a tax-deductible donation contact
Prader-Willi California Foundation
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www.PWCF.org | 310-372-5053 | 800-400-9994 toll-free within CA