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California Walks for Prader-Willi Syndrome

Don't miss PWCF's 12th Annual *Walking for Prader-Willi Syndrome* awareness and fundraising events. This year there are two new and exciting locations.

April 29 – Griffith Park, Los Angeles

May 5 – Woodward Park, Fresno

May 5 – Crissy Field, San Francisco

The Walk events are fun! Organized exercise-incorporated games, arts-and-crafts activities, face painting, and music to dance to at every event. Meet with other families in an easy, fun atmosphere. A hosted picnic lunch will be served in Los Angeles; bring your own healthy picnic lunch to the Fresno and Frisco *Walks*.

Honor your loved one or family friend with a Footprint Sign to be posted along the *Walk* path of your choice. Your company's business can show its support with a Footprint Sign while they advertise their good name.

The Walking for Prader-Willi Syndrome video and DVD make it easy to raise awareness and funds! Introduce your potential donors and sponsors to Prader-Willi syndrome and the importance of supporting a *Walk* by sending them a link to the video at www.PWCF.org or www.youtube.com/watch?v=UMr7qGUNZuI or send them a DVD (free with a \$5 donation suggested to help offset mailing costs). Invite the support of your extended family, friends, co-workers, your child's therapists, physicians, teachers, employer – *everyone* you know!

Your brochure will reach your mailbox soon, but you can get started today at

www.pwcf.org/WalkingForPWS.htm

Create your own personalized *Walking for PWS* website to spread the word through the WalkingForPWS site. Every time you speak with someone about the *Walk* you increase awareness of Prader-Willi syndrome!

Not able to attend a *Walk*? You can still make a big difference by collecting donations and increasing awareness.

Funds raised through the *Walking for Prader-Willi Syndrome* events support PWS Clinics; PWCF's Camp; PWS group homes; residential and vocational work staff training programs; Support Groups; educational conferences; educational articles including this newsletter, books, brochures, and DVDs; local and national research, school and Regional Center advocacy; medical crisis support, a statewide toll-free line, and so much more. This year, PWCF is teaming up with Prader-Willi Syndrome Association (USA)'s national *On the Move* campaign, so net proceeds will also benefit national programs and services.



Your support of the *On the Move Walk* events is absolutely vital. We can only continue to do what we do with your help.

Support your loved one, family friend, employee, student, or patient with your donation to *Walking for Prader-Willi Syndrome*

Have fun, honor your loved one or friend and...

Walk with us!



**PRADER-WILLI
CALIFORNIA FOUNDATION**

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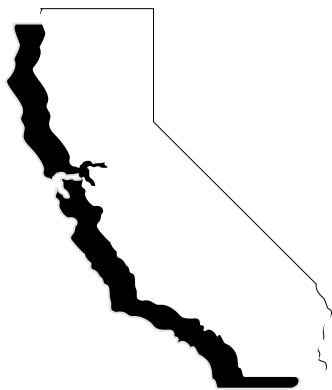
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“The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families.”

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Wendy Young	415-380-0721	wmydmy@gmail.com
Sacramento	Diane Kavrell	530-753-5928	brandon.kavrell@cexp.com

Central California

Debbie Martinez (Teens & Adults with PWS)	559-227-0294	martinezds@gmail.com
Paula Watney (Teens & Adults with PWS)	559-299-8171	mikewat1@sbcglobal.net
Jennifer Rinkenberger (Infants & Children with PWS)	559-930-7834	jenrink@mac.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
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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.yahogroups.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 caseworkers, residential staff persons, etc. To join the group, go to www.yahogroups.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

Parent to Parent

Does anyone's child or adult child with PWS experience bullying and if so, how do you help your child/adult child respond to it?

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 to him. Before we knew it, all three boys went over to our group and began pushing them on the swings. It just so happened that 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*

Next issue's Parent to Parent question is "*Our son is 3 years old and we'd like to get him a pet. What experiences and ideas can other parents share about how this has worked out for you? Which pet do you think is best for a child with PWS?*"

New Look for PWCF

Beginning in 2012, the Prader-Willi California Foundation will have a brand new look. Our new logo was fashioned by **Julie Casey, Dan Casey, Tom McRae, and Mike Moore** with input from **Lisa Graziano** and **Drew Marich** and designed by graphic artist **Craig Jann** of Eye-Con Design (www.eye-condesign.com). Tom is working hard with our webmaster and a brand new website will be revealed in 2012. These exciting changes reflect the commitment and dedication of PWCF's Board of Directors to ensuring the highest quality of life for persons with Prader-Willi syndrome and their families.



New Home Study Exam and Certificate of Training Available with PWCF's New Prader-Willi Syndrome Residential Staff Training DVD



PWCF now gives you another tool to help provide training your Group Home or Supported Living Services staff. PWCF Board Member **Roger Goatcher** created a **Home Study Note-Taking Guide** to help staff capture the important information contained within the training DVD. Then, to assess their understanding of what they've learned, Roger created a **Home Study Examination**. When staff successfully pass their Home Study Exam, PWCF will send a **Certificate of Training** that you can proudly hang in your group home!

Visit www.PWCF.org to order your *Prader-Willi Syndrome Residential Staff Training* DVD and download the Home-Study Note Taking Guide and Home Study Examination, or call the PWCF office at 310-372-5053 or within CA 800-400-9994.

Tea for a Cure

Last October PWCF member **Laura Shea** elevated tea time to the height of elegance.



Laura & son Jacob

Laura and her dear friend Lynn timer poured their hearts and souls into organizing a *Tea for a Cure*, a Fashion Show and Afternoon Tea. The event, which wouldn't have taken place without Lynn timer's knowledge and expertise, was held at the beautiful and elegant Westgate Hotel located in San Diego. The afternoon included a fashion show with local vendors' clothes modeled by awesome volunteers, a full tea service, raffle, and auction. Says Laura, "We had over 60 guests in attendance. It was a great afternoon and an incredible opportunity to educate and spread awareness of PWS. We were overwhelmed with all the donations and support that we received!" Proceeds of Laura's *Tea for a Cure* benefited the national PWSA (USA) and PWCF. Thank you, Laura, for a job *beautifully* well done.



Food Tip

This Food Tip was submitted by Gretchen Golub



The Zoku Popsicle maker comes in different sizes depending on how many popsicles you want to make at once. For a Popsicle maker it is expensive, but I think worth it. You can control the ingredients you put in it including calories, and if you want to add protein powder, pureed veggies, fruit, yogurt, or just about anything. When making the popsicles it really does take less than 10 minutes to freeze, viola instant gratification! No waiting hours for it to freeze and hearing "is it done yet?" A healthy treat, fun to make, and slow to eat/slurp. www.zokuhome.com

Gadget Tip

Submitted by Linda Ryan of Newhall

Now there's a small, inconspicuous piece of security equipment that's stylish, sleek, and effective that can help protect your family and simplify your life. It's called a door or window sensor and it's made by Vivint (yup, the same company from whom PWCF won \$30,000 in 2010!). The sensor is a two-part product. One side is installed on the door jamb, and the other piece on the door itself, all without damaging your door, of course.

And even though it's tiny (and therefore, inconspicuous to intruders), it has tons of features, like non-emergency alerts. Basically, non-emergency alerts help you monitor and manage your home when you're not there. Let's say you have small kids in the house and you want to keep them out of the cupboard where your cleaning products live. Just install one of these little puppies and every time that cupboard is opened, you get a text message sent to your phone.

You can put a door sensor on exterior doors so that when that door is opened, it sends a signal to the Vivint [Go!Control panel](#) which alerts the central monitoring station. Each sensor is also tamper-proof, which means if someone tries to pull it off the door or break it, the monitoring station will be alerted as well. These tiny little jewels might not seem like much, but they sure are powerful! For more information visit www.vivint.com.



Executive Director's Column

Lisa Graziano, M.A.



Last week I spoke with a mom about a PWS Training we recently provided for her child's school staff. The location of the school was outside the driving range of the Prader-Willi California Foundation's staff, so we presented the training remotely, providing the school with a toll-free conference call number and projecting our PowerPoint training materials onto their computer screen. The questions the staff asked were great, and I am confident that the strategies we brainstormed will be helpful.

The mom shared with me that she'd not been active with the Foundation during her child's younger years because, she said, quite frankly she was too exhausted just keeping up with the day-to-day tasks of life. She said if she'd known earlier how helpful the Foundation could be, she would have called us a lot sooner.

And so, as we start off the New Year, I thought it might be helpful to remind families and professionals about the myriad supports and services that are available from the Prader-Willi California Foundation, and remind you just how helpful the Foundation can be.

The types of resources that the Prader-Willi California Foundation makes available to families and professionals boil down to five major categories: Education, Advocacy, Awareness, Support, and Research.

Education

PWCF has many educational materials available for parents and professionals. There are brochures, articles, abstracts, and journal articles on a multitude of PWS issues. We produced or helped produce five educational and awareness-raising DVD's: *Food, Behavior & Beyond*; *Understanding the Student with Prader-Willi Syndrome*; the *Brain & Behavior in Prader-Willi Syndrome*; *Walking for Prader-Willi Syndrome*; and our newest DVD *PWS Residential Staff Training* which now has a Note Taking Guide, Home Study Examination, and Training Certificate for passing scores (these materials are also available for the *Food, Behavior & Beyond DVD*). The national PWSA (USA) has a great many more helpful books, DVDs and resources available.

Newly identified parents receive an information-packed application packet and a *Member Handbook and Records Keeper* binder when they join. A Parent Mentor is assigned to each newly diagnosed family who can guide the new family and provide ongoing support.

PWCF can provide PWS training to your social worker, case manager, therapists, and teachers either in person or remotely.

PWCF produces an information-packed newsletter each quarter. Each issue contains information about Support Groups and support contacts, Food Tips, helpful PWS-related Gadget Tips, informative articles, and questions asked and answered in the Parent-to-Parent section.

If you have an adult child who lives in a group home or is assisted by a supported living agency, PWCF can provide that home's staff with fantastic PWS training provided by our Professional Residential Training Consultant, Theresa McGrath. Since the inception of this program in 2009, PWCF has provided training sessions throughout California to bring important information about Prader-Willi syndrome to hundreds of group home staff, supported living staff, vocational work site staff, Regional Center staff, and even families in crisis.

An annual educational conference is produced especially for families and professionals each and every year, and other PWS trainings and conferences are scheduled throughout the year as often as possible. This year's conference will be held in Northern California on November 3.

Advocacy

If you need advocacy services, PWCF can help. We can help you advocate for appropriate services provided by your Regional Center. We can help you advocate for growth hormone or some other appropriate therapy. We can help you advocate for educational supports or services. As you now know, if we can't make it in person to your IEP meeting or provide in-person PWS training, we can be there remotely. If you cannot get what you need for your child or loved one, you can look to Prader-Willi California Foundation and we will work hard to help you advocate effectively and successfully.

Awareness

Another of the Foundation's major focuses is to raise the public's awareness of the syndrome because we believe that with increased public awareness comes increased appreciation of the complexities and challenges of the syndrome. This year marks our 12th annual statewide walkathons held in Southern, Central, and Northern California, and we are excited to bring the *Walking for Prader-Willi Syndrome* events to brand new and even more public sites at Griffith Park in Los Angeles and Crissy Field in San Francisco. To help get the word out about the *Walk* events, we distribute Public Service Announcements and Press Releases. This year, as we did last, we will distribute to the CEOs of some of California's top companies our *Walking for PWS DVD* which provides a great deal of information about Prader-Willi syndrome and the work of PWCF.

Continued on page 11...

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.

1. 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."

Sample Behavior Analysis Table

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. For example, 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, 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.

Continued on page



**PWCF'S CAMP AT
EASTER SEALS CAMP HARMON
JUNE 21-26, 2012
Register Today at www.PWCF.org**



Don't miss PWCF's 2nd annual PWS Camp at Easter Seals Camp Harmon *exclusively* serving persons with Prader-Willi Syndrome ages 8-65.

Camp Harmon is located in Boulder Creek, California in the beautiful Santa Cruz Mountains. Last year's programming included a welcome campfire, daily swimming, arts & crafts, a hike, impromptu basketball games, quiet time, a horse-drawn wagon ride, a dance and the *best* camp counselors! This year we're hoping to add – but cannot guarantee – horseback riding and maybe even archery. Male and female nurses are onsite to administer all medications. Staff to camper ratio is 3:1, with 1:1 available. The menu is all healthy low cal/low carb, and exceptionally delicious. Above all, access to food is strictly secured. Camp Scholarships are available to PWCF members in good standing that bring registration costs down to \$500 (PWCF will pay \$226 of your registration!). Non-member price is \$726.

What's Camp like? Here's what some of last year's campers had to say:

"As I was walking to my cabin my heart was bouncing with excitement. I thought, 'What will I do? What will I eat?' Anyway, my cabin mates were good and the cook was awesome. The dance, campfire, movies, and sleepovers were the best. When I left, I felt like I was crying inside. Leaving the best camp was sure a disappointment. Overall, I would like to go back." Cameron Graziano, age 12

9 year old Emile seemed to have the time of her life, says her mom. We are hearing new stories everyday and she has written three different people letters to tell them all about her time at Camp Harmon. She is already asking for me to sign her up for next year. I was equally impressed with the kindness of the counselors and how they so easily accepted our children into their hearts

15 year old Chanie said this was the most fun she's ever had and she cannot wait until next summer.

19 year old Lauren talked the whole way home about camp. She now knows she isn't the only person on Earth with PWS, and she has a whole new and improved perspective on having the disorder. She's now enthusiastic about her life... and she has a new best friend.

Whitman, age 21, had a FANTASTIC time, the best EVER. He enjoyed his cabin-mates, counselors, and all the activities. He was happy about the daily snacks and the delicious desserts, and even lost 3 lbs during camp week – wow! He's been on the phone with new friends he made at camp.

For more information about programming, menu, or if you need help registering online, contact PWCF 310.372.5053

Behavior Analysis continued from page 6 ...

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. When my son gets noncompliant, we quietly move him to a dark bathroom. He sits in there for a few minutes (or longer if he's crying or carrying on, but this doesn't happen anymore because he's used to the procedure). When we let him out, using a neutral tone of voice we tell him it's time to listen. 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 and 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.

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 5 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.

Research Opportunities

Latino Families with a Child with Prader-Willi Syndrome: Identifying Needs for Support ~ Familias Latinas con un Hijo con Síndrome de Prader-Willi: Identificando la Necesidad de Apoyo This study by San José State University graduate student and PWCF member Carina Chaij seeks to get a better understanding of the challenges and needs for services that Latino families of children with PWS face, assessing in particular the needs for sibling support groups.

The study includes one interview with the mother of a child with Prader-Willi syndrome (PWS), and one interview with one of his/her siblings of at least 12 years of age. Interview questions attempt to capture information regarding families' challenges and experiences of having a family member with PWS. Each interview will take approximately an hour.

For more information or to participate contact Carina Chaij 909-518-4266 or carinachaij@gmail.com.

Skin Picking Research Study: Stanford University seeks persons with Prader-Willi Syndrome ages 6-25. Does he/she engage in skin picking or other severe problem behavior? We are conducting a study to evaluate how the environment and/or brain affects the display of skin picking and related problem behaviors commonly exhibited by individuals who are diagnosed with PWS or other developmental disabilities. Our hope is that the results of this study will lead to a better understanding of how learning and neural processes influence behaviors that are characteristic of the PWS phenotype and individuals with other developmental disabilities.

Participation involves:

- Travel to Stanford University, located in the San Francisco Bay Area for 3 days, or a researcher will travel to your home (if your child is unable to travel to Stanford)
- Behavioral assessment
- Cognitive testing
- MRI scan (if traveling to Stanford)
- Behavioral treatment evaluation (if required)

Benefits of participating:

- Potential improved understanding of the variables that influence your child's display of problem behavior
- Potential improvement in your child's behavior
- You will receive an honorarium of up to \$100 for your participation
- All travel-related expenses will be provided free of charge

For more information, or to enroll, contact Dr. Scott Hall at 650-498-4799 or hallss@stanford.edu or Dr. Jennifer Hammond at 650-723-7255 or hammond1@stanford.edu

Everything can be taken from a man but one thing: the last of the human freedoms – to choose one's attitude in any given set of circumstances, to choose one's own way.
~ Viktor Frankl

Home-Based Physical Activity Program for Children with PWS: Interested in having your family be more physically active? We are looking for children with PWS 8-15 years and one parent or guardian to participate in a 24-week home-based program using interactive console and playground games provided to them at no cost. Participation also requires four to five visits (3.5 hours long) to the California State University Fullerton campus. During the visits, the child will complete a health assessment, a very easy and accurate body fat measurement, and movement-related assessments. Children and parents will also complete questionnaires. Incentives include 1) \$30 gift cards for visits; 2) keeping the provided sports and media equipment; 3) \$60 gift cards during the program. Parents/guardians will be reimbursed for mileage for visits to CSUF. For more information or to participate in the study, contact the research office at 657-278-8737, 657-278-3671 or pwstudy@fullerton.edu or contact Dr. Daniela Rubin at 657-278-4704 or drubin@fullerton.edu. Hablamos español.

Study of Behavior in Prader-Willi Syndrome: This NICHD funded study is a continuation of the current Elisabeth Dykens PWS study to characterize and accurately describe the behavioral features of Prader-Willi Syndrome (PWS) and how these can be different based on age, gender, family history and genetic subtype of PWS. The study looks at key psychiatric features of PWS, like rigid and repetitive behaviors, insistence on sameness, tantrums, aggression and depression and how these change over a lifespan. We want to see if intervention timing is related to successful outcomes and effectiveness.

We hope to see 170 families with children aged 5 and up through adulthood with PWS for a one day visit at Vanderbilt Kennedy Center in Nashville TN over the next 5 years. We want to see how children with PWS change and we will follow them every other year to track changes. Parents will receive a written feedback report of all results and behavioral management tips during visit. There are travel funds to help with expenses. Parents who are interested should contact Elizabeth Roof at elizabeth.roof@vanderbilt.edu or 615-343-3330 to get more information about the study.

PWS and Early-Onset Morbid Obesity Natural History Study – All Persons with PWS: Conducted by 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 Medical Center 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.

In the Trenches

Vol. 7

by Jessica Patay

Whenever Ryan has a horrific tantrum, especially in public, I feel a sick wave inside. Internally and immediately, I ask myself, "What will this look like when he's 13? 18? 28?"



Ryan & Jessica

I feel panic and fear. All the while, I'm utilizing my tantrum-reaction strategies and trying to appear calm and cool. When the tantrum is over, Ryan moves on but yet I am reeling inside. I'm left with the "oh-my-gosh-HOW-will-I-handle-this-when-he's-older-bigger-louder-stronger" questions.

Why do I put myself on this futuristic rollercoaster? Whenever that "wave" hits, I fast-forward and start projecting how HARD it will be. I automatically assume it's going to become intensely challenging as the years go on in Ryan's journey with Prader-Willi syndrome. It is certainly not going to get easier. None of the symptoms or behaviors goes away as children age. They don't "grow out" of any of it. (Damn... Too bad there isn't a special needs fairy that grants every family one wish to remove one aspect of their child's disability.) My perception of my future with PWS is it's scary, intense, stressful, and possibly unmanageable. As I write this, even my adrenals are firing and my heart is racing like I just ate a handful of espresso beans!

As I was sharing, (ok, really venting and complaining), with a true-blue girlfriend about my current wave, she short-circuited me with a question.

Friend: Jess, what is in your hula-hoop?

Me: What?

Friend: What can you hold in a hula-hoop?

So I then walked outside to pick up my daughter Kate's silver sparkly hula-hoop. I put it around my waist. Literally. Its 27 inches in diameter. And with me inside of it, it does not leave much room.

The message my girlfriend was trying to get into my fearful, worry-wart head was that I need to focus on today, this week, or at best, *just this moment*. All I have permission to think, feel, and worry about is what I can fit into my hula-hoop. THAT'S IT AND NO MORE.

A huge struggle in special needs parenthood-dom is to let our hopes for our children outweigh our worries and our fears. The future will be the future. I cannot control it or change it or make it infinitely better by *freaking out* now. I am only doing my marriage, my family, and myself a giant disservice by ruminating about what life will look like when Ryan becomes a teenager or adult.

Now where's that hula-hoop?

Editor's Note: After reading this article, *Carrie Hassanzai*, a personal friend of Jessica, excitedly set to work to craft a tangible image of the hula-hoop metaphor. Carrie has designed beautiful Hula Hoop necklaces especially for our PWS families, and will donate a portion of the proceeds to PWCF! An Order Form is located inside this newsletter. **Order your beautiful necklace (or two!) today and support PWCF!**

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

PWCF Announces Position Available: Family Support Coordinator

The Prader-Willi California Foundation (PWCF) is a charitable organization dedicated to serving persons diagnosed with Prader-Willi Syndrome and their families. We are located within the Beach Cities Health District in Redondo Beach, California and are the only organization in California that is focused solely on assisting persons with Prader-Willi Syndrome, a rare and complex medical disorder that causes multiple symptoms, of which the two most commonly recognized are behavior problems and an insatiable appetite.

PWCF was established in 1979 to ensure that persons with Prader-Willi Syndrome may pursue their individual hopes and dreams to the full extent of their talents and capabilities. Over the years we have expanded the supports and services we provide to families and professionals in order to meet their multifaceted and growing needs. The Family Support Coordinator will help families obtain the supports and services they need in order to uphold the Prader-Willi California Foundation's overall mission to improve the quality of life of persons with Prader-Willi Syndrome.

Key Responsibilities include but are not limited to:

1. Help families access state and county services including Medi-Cal, Medicare, IHSS, Regional Center eligibility/services acquisition, medication prescription cost assistance, health insurance issues.
2. Organize and facilitate Support Group meetings in the Los Angeles and/or Orange County areas. Assist with the organization of Support Group meetings for other counties throughout the state.
3. Provide information and support to families on the telephone, in writing, and in person. Perform necessary administrative duties such as database entry and dues billing.
4. Help families identify medical and therapeutic professionals to treat their child.
5. Provide advocacy assistance to help families receive the services they need for their child and for their family via letter writing, phone calls, in person meetings as necessary.
6. Provide Prader-Willi Syndrome in-service trainings to schools and Regional Center personnel.
7. Write informational-type articles on a quarterly basis for newsletter.
8. Assist with all educational seminars and public awareness events.
9. Provide assistance and support as assigned and as needed.

Job Requirements and Skills:

Education: Masters Degree in Social Work, Counseling, Psychology, or some related field. Social work background/experience required; Licensed Clinical Social Worker preferred.

Requisite Skills: Must be self-driven with a positive outlook and a clear focus on providing assistance to families and professionals. Must be articulate, possess excellent communication, telephone and writing skills. Bilingual in Spanish preferred. Must be proficient with Microsoft Word, PowerPoint, and Excel. Working familiarity with Microsoft Access Database a plus.

Hours & Salary: Part-time, Monday through Thursday, flexible 20-30 hours per week, which can include some telecommuting. Salary commensurate with experience. Contract Personnel status if feasible.

Contact: Lisa Graziano, Executive Director, Prader-Willi California Foundation 310-372-5053. Email or fax resume to PWCF1@aol.com or 310-372-4329.

Save the Dates

- | | |
|---------------------|---|
| April 29 | Walking for PWS Awareness, Griffith Park, Los Angeles |
| May 5 | Walking for PWS Awareness, Woodward Park, Fresno |
| May 5 | Walking for PWS Awareness, Crissy Field, San Francisco |
| June 21 – 26 | PWS Camp at Easter Seals Camp Harmon, Boulder Creek |
| June 22 | Putt for PWS Golf Awareness Event & Fundraiser, Healdsburg |
| November 3 | General Education Meeting, Northern California |



Last year many of you attended a PWS Family Day at an Oakland A's baseball game or at an L.A. Galaxy soccer game, and we are working to schedule more of these fun events again this year. We are excited to announce that PWCF member **Sam Cropper**, is coordinating a Putt for PWS golf awareness and fundraising event on June 22 (see page 17).

Support

There are many opportunities for support available to families and professionals. PWCF will continue to maintain our 24 hour PWS-related medical crisis line to connect California physicians with a PWS expert physician somewhere in the country.

PWCF funds three PWS Clinics located in San Diego, Orange County, and Fresno. 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 and we can provide you with a referral list.

While there are too few in-person Support Groups, there are two active groups in the North Bay/San Francisco area and in Los Angeles County. Support is available, however, on the telephone and online with PWCF's information-sharing Yahoo groups as well as PWSA's eSupport Groups. Parent Mentors help guide newly identified parents through the ropes that are often so difficult in the beginning years.

PWCF is currently interviewing for a newly-created position of Family Support Coordinator. Among other duties and tasks, this position will help answer families' questions about Medical, Medicare, SSI and Disability insurance, and more. If you know a great Licensed Clinical Social Worker who lives in Los Angeles County would may interested in learning more about this position, please let them know (see page 10).

PWCF's very own PWS Camp, in cooperation with Easter Seals Camp Harmon, exclusively serves persons with PWS age 8-65. Last year fifty-six campers received a scholarship from PWCF to reduce the cost of camp, and this year we anticipate we will exceed these numbers. If your child is between the ages of 8-65, register today to attend this year's PWS camp from June 21 through 26 (see page 7)!

Research

There is a *lot* of very exciting progress being made in the area of research. PWCF supports both local and national research by helping to get the word out about various research studies going on around the country. We highly encourage families to participate in as many research opportunities as they are able and feel comfortable (see page 8).

PWCF offers many resources to families and professionals and we will offer more as funding for these resources is available. But we need your help. Any donation you make throughout the year, large or small, helps us help the families we are working so hard to serve.

Happy New Year



Welcome to Holland Parenting a Special Needs Child

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this:



When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans: the Coliseum, Michelangelo's *David*, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills – and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy ... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away, because the loss of that dream is a very, very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Attitude is a Choice

This story was recently circulated through the internet. It is shared here as our wish to you that your New Year be graced with optimism and hope

John is the kind of guy you love to hate. He is always in a good mood and always has something positive to say. When someone would ask him how he was doing, he would reply,

'If I were any better, I would be twins!'

He was a natural motivator.

If an employee was having a bad day, John was there telling the employee how to look on the positive side of the situation.

Seeing this style really made me curious, so one day I went up and asked him, *'I don't get it! You can't be a positive person all of the time. How do you do it?'*

He replied, *'Each morning I wake up and say to myself, you have two choices today. You can choose to be in a good mood or ... you can choose to be in a bad mood.'*

I choose to be in a good mood.'

Each time something bad happens, I can choose to be a victim or...I can choose to learn from it. I choose to learn from it.

Every time someone comes to me complaining, I can choose to accept their complaining or... I can point out the positive side of life. I choose the positive side of life.

'Yeah, right, it's not that easy,' I protested.

'Yes, it is,' he said. 'Life is all about choices. When you cut away all the junk, every situation is a choice. You choose how you react to situations. You choose how people affect your mood.'

You choose to be in a good mood or bad mood. The bottom line: It's your choice how you live your life.'

I reflected on what he said. Soon hereafter, I left the Tower Industry to start my own business. We lost touch, but I often thought about him when I made a choice about life instead of reacting to it.

Several years later, I heard that he was involved in a serious accident, falling some 60 feet from a communications tower.

After 18 hours of surgery and weeks of intensive care, he was released from the hospital with rods placed in his back.

I saw him about six months after the accident.

When I asked him how he was, he replied, *'If I were any better, I'd be twins...Wanna see my scars?'*

I declined to see his wounds, but I did ask him what had gone through his mind as the accident took place.

'The first thing that went through my mind was the well-being of my soon-to-be born daughter,' he replied. 'Then, as I lay on the ground, I remembered that I had two choices: I could choose to live or...I could choose to die. I chose to live.'

'Weren't you scared? Did you lose consciousness?' I asked.

He continued, *'... the paramedics were great.'*

They kept telling me I was going to be fine. But when they wheeled me into the ER and I saw the expressions on the faces of the doctors and nurses, I got really scared. In their eyes, I read 'he's a dead man'. I knew I needed to take action.'

'What did you do?' I asked.

'Well, there was a big burly nurse shouting questions at me,' said John. 'She asked if I was allergic to anything 'Yes, I replied.' The doctors and nurses stopped working as they waited for my reply. I took a deep breath and yelled, 'Gravity!'

Over their laughter, I told them, 'I am choosing to live. Operate on me as if I am alive, not dead.'

He lived, thanks to the skill of his doctors, but also because of his amazing attitude... I learned from him that every day we have the choice to live fully.

Attitude, after all, is everything.

Board Corner

PWCF Board of Directors Meeting and Retreat January 27-29, 2012 by Chris Patay

Board Members Present: *Renee Tarica, Julie Casey, Chris Patay, Kim Morgan, Paula Watney, June-Anne Gold, M.D., Whitney Bras, Roger Goatcher*

Others Present: *Lisa Graziano, Executive Director, Nisha Mehta, Strategic Planning Facilitator*

Board Members Absent: *Tom McRae, Don Carlson, Julie Tauscher*



Whitney Bras & Chris Patay

Board Orientation – Lisa Graziano led a Board Orientation discussing the mission of PWCF, basic Board member duties, who we serve, what we do, and how we do it. Lisa also reviewed the key committees including Executive Committee, Program Committee, Finance Committee, Awareness Committee, Fundraising Committee, Residence Liaison Committee, and Nominating Committee. The Board meets in person 4 times per year and has 2 teleconferences each year. The Executive Committee (comprising the President, Vice President, Treasurer, Secretary and Executive Director) has authority to take actions on behalf of the Board so long as their actions receive unanimous approval among all Executive Committee members.

Election Process and Election of Officers – The Board spent some time discussing the process for nominating and electing officers of PWCF. After further discussion, the Board elected the following individuals to serve as officers of PWCF for 2012:

Julie Casey	President
Chris Patay	Vice President
Renee Tarica	Treasurer
Kimberlee Morgan	Secretary

Committee Reports – Several Board members provided updates on various activities undertaken by the committees.

Walking for PWS Events – After discussion, it was determined that the following dates have been reserved for the *Walking for PWS* Events:

Southern California	April 29 at Griffith Park in Los Angeles
Central California	May 5 at Woodward Park in Fresno
Northern California	May 5 at Crissy Field in San Francisco

PWSA On The Move Campaign – Lisa Graziano and Julie Casey advised that PWSA (USA) has proposed launching a national fundraising and awareness campaign called *On The Move*, which would involve various events incorporating some type of physical activity. PWSA desires that all Chapters and Affiliates be involved and donate a portion of the fundraising amount to PWSA. The Board approved (6 in favor, 1 opposed) to participate in the *On the Move* Campaign in collaboration with the annual PWCF Walk and other activities with a contribution of 10% of the net proceeds from the Walk Events and other events designated by the Board as an *On the Move* event. It was noted that PWCF typically provides financial support to PWSA(USA) each year, and our regular on-going support could be provided through participation in the *On the Move* Campaign.

Putt for PW – Paula Watney provided the Board with an update on the *Putt for Prader-Willi Syndrome Golf Tournament* to be held on Friday, June 22, 2012 at the Windsor Golf Club in Sonoma County, California. Sam and Kristin Cropper will host the event. Registration will be opening soon.

Residential Services Liaison Committee – The *PWS Residential Staff Training DVD* is complete. Copies are now available for sale. Lisa proposed that PWCF create a home study guide and exam to accompany the DVD and develop a certificate of completion to award to each group home staff member that successfully completes the exam. The Board recognized the long standing and valuable support provided by Fran Moss a leader of the Residential Services Liaison Committee and her service as Residential Services Consultant. The Board also approved the appointment of Paula Watney as a Residential Services Consultant and begin the process of developing a description of the service position for review and additional input.

PWCF 2012 Camp Update -- Planning for the 2012 camp session is underway. The camp will be held from June 21-26, 2012. The deposit for the 2012 camp was made in 2011. The website has been updated to support registration. Last year we had 56 campers and this year we are budgeting for 60. The Board approved again underwriting the cost of \$226 per camper so the overall cost per attendee is \$500. The Board agreed that PWCF will pay the extra expense for those individuals identified and approved by PWCF as needing 1:1 support in order to attend camp, as determined on a case-by-case basis.



Renee Tarica & Roger Goatcher

Continued on page 14 ...

2011 PWSA Conference Update – Julie Casey provided an updated of the Chapter Leaders Conference held in conjunction with the 2011 PWSA Conference. Lisa and June-Anne provided updates on promising research with respect to appetite suppression and treating anxiety, including preliminary research results with respect to Oxytocin. The Board approved financially supporting Lisa Graziano, Julie Casey and June-Anne Gold’s attendance at PWSA’s 2012 Hyperphagia Conference. There will not be a separate PWSA Conference meeting in 2012.



June-Anne Gold, Julie Casey,
Lisa Graziano & Roger Goatcher

2012 PWCF Conference – The 2012 PWCF Conference will be held on November 3, 2012 at the San Jose Hilton. Lisa reported on the Program Committee’s progress planning the event.

Website Update – Tom McCrae provided a written report in his absence with respect to progress on the new website development. The design and site map have been completed. The staging website is being completed. Content for each page will need to be created and loaded via volunteers.

Strategic Planning – The Board spent a substantial portion of Saturday afternoon dedicated to strategic planning. PWCF member Nisha Mehta facilitated the planning session. The Board spent some time discussing short term goals and strategies before dedicating a significant portion of the session to long-term goals and strategy. A number of follow up action items were developed to move forward with the “California Partnership” initiative to improve the residential facilities and day programming for persons with Prader-Willi Syndrome. Additional reports will be provided in the coming months.

Health Bridge PWS Crisis Center Update – Lisa provided an update with respect to the proposal by HealthBridge Children’s Hospital of Orange, California to open a crisis clinic to treat persons with Prader-Willi Syndrome. It was reported that they are making progress in creating protocols and interviewing psychiatrists for a position with the hospital. Their target date for opening the crisis center is summer 2012. They would initially have four rooms, each with a single patient/bed.

Grant Requests – Lisa Graziano presented grant requests from The Arc of San Diego and the PWS Clinic at Genetic Medicine Central California in Fresno. After discussion, the Board approved a \$1,500 grant to Arc of San Diego and \$7,815 grant to support the Fresno PWS Clinic.

Treasurer’s Report – Renee Tarica circulated the current statement from PWCF’s Smith Barney investment accounts showing PWCF’s current holdings. Renee also led a discussion in review of the 2011 financial statements and 2012 operating budget. After considerable discussion, Lisa Granziano agreed to revise the draft 2012 Operating Budget and circulate it for review with the goal to approve the budget at the next board meeting.

Executive Director’s Report – Lisa Graziano provided a written report detailing her activities since the last meeting. The activities included, among other things:

- Various office administration activities including rollout of the new logo on stationary, business cards and signage.
- Transition of Lisa Graziano from consultant to employee as required by new tax laws.
- Working with PWCF’s grant writer, Maureen Spindt of YES! Communications.
- Revisions to Membership Renewal forms and Information & Membership Application Packets. Lisa also provided an update on new members.
- Lisa has been engaged in numerous activities with respect to Awareness, Education, Advocacy & Support Services initiatives.
- The Residential Staff Training DVD has been rolled out and Lisa also reported on the work of Theresa McGrath, which continue to receive high marks.

Throughout the two-day Board meeting were interspersed various team-building activities.



"Goofy" team-building activities
build a cohesiveness Board

PWCF 2012 Officers

PWCF’s Officers for the 2012 term are:
President – **Julie Casey**
Vice President – **Christopher Patay, Esq.**
Treasurer – **Renee Tarica**
Secretary – **Kimberlee Morgan**

**PWCF’s Board of Directors warmly thanks
Julie Tauscher
for her service as Secretary for the 2011 term**

We Get Mail



Dear PWCF: I have good news. The administrative law judge who presided over our state hearing decided [our son] Jeff requires protective supervision within the IHSS [In Home Support Services] program.

The IHSS social worker testified that protective supervision is to be authorized for a “non-self directed” person and was of the opinion Jeff is self-directed and was unable to get himself into any situation that would prove dangerous to him.

Under his initial observation and his questioning of Jeff, the judge agreed with the social worker. However, after reading the letters and PWS literature we submitted, and hearing our testimony and that of our witnesses, the judge found that because of the symptoms and complications of PWS, Jeff is not self-directing. He concluded Jeff must be monitored 24 hours a day, every day, to ensure his health and safety.

I want to thank you for your letter in support of our request for IHSS protective supervision hours. The information you provided strongly supported the need for these services for Jeff and others with PWS. If other families request your help in similar situations we would be glad to share our experience with them. Thanks again. *Sincerely, Bud Bush, father of Jeff age, 54 years*



Dear California Families: We just completed a very positive six month experience in the CSUF exercise study. They would like to enroll more participants (8+ years) and I would happily answer any questions if you are thinking about it.

Dr. Rubin and her staff provide all needed materials and great support including weekly calls and emails if that benefits your family. The activities are fun (50% are Wii based) and you get a trunk load of really good exercise/game equipment. All exercise routines are spelled out step by step with visual aids – no guesswork on your part and the child can learn to implement a lot of it on their own. The four 45-minute sessions per week are fun for siblings, parents, and play dates to engage in as well.

You travel to CSUF a total of four Saturdays over six months, but all travel costs are covered (including gas if you are local). The kids are motivated by a really generous Target gift card reward through the study. Nick bought over \$200 of Lego’s during this study so I never had to make him participate because he was motivated!

I don't think I can share actual results at this time but I will say that if your child has weight to lose, this is a great tool. My child did not have weight to lose so I wasn't sure of the outcomes but was pleasantly surprised with body fat and lean muscle ratio outcomes.

We were a family who exercised pretty well...walks and swimming, etc. But hearing things about Nick needing weight bearing exercise or this and that, I always wondered how much good each type of exercise was doing his body. Now we have an exercise routine confirmed by Dexa Scans and Sensory Motor tests, etc. that show me exactly how and where his body is responding. I feel it's been a really motivational and helpful tool for us.

Let me know if I can answer any questions for you or put you in touch with this really caring team of researchers (see page xx inside this newsletter). This is funded by the department of defense...let's get as much data as we can! *Jenn Paige Casteel*

Renew Your PWCF Membership

The 2012 Membership Renewal & Dues Forms are on their way to your mailbox. Please renew your membership and continue to receive all of your PWCF benefits.

Membership dues help support the work of the Prader-Willi California Foundation, and your renewal keeps our numbers strong. Remember, if you cannot afford all or part of your dues, send what you can or check the “Dues Waiver” box.

As we reach out to more organizations for grant support, we are being asked about our membership demographics.

Please mark your child's ethnic background and your family's income level to help us increase our potential to receive grant funding. *Know that this information will be kept strictly confidential.*

Get the Newsletter Even Faster

**If you'd like to receive the
PWCF News quarterly newsletter by email
instead of U.S. post,
just let us know!**

**E-mail us @PWCF1@aol.com
or call 310-372-5053**

The Grinch Who Stole Nick's Christmas

by Lisa Peters, Massachusetts



Nicholas and I are at it again.

I am in clean house-ivity mode, anxious to get things done and put things away.

Nicholas is still in the holiday mode.

He loves to watch the warm, colorful lights on the Christmas tree. He delights in lighting the candles in each window every night. He enjoys living in a house filled with decorations. If it were up to Nicholas, Christmas would never end. Holiday lights and magic would continue throughout the year.

But this month my need to control clutter has escalated. I am starting to notice a trend. It seems that when I receive difficult medical news or another new diagnosis for one of my children, my pathetic need to control "something" in my life goes into overdrive. I go on a cleaning rampage.

Nicholas, seems to instinctively understand this quirky characteristic in his mother, and goes on high alert.

He becomes the Decoration Detective of the House. Throughout the day, he makes his Christmas patrol around the home to ensure his wacky mother has not hijacked any of his holiday cheer. He carefully counts the lights in the windows and the ornaments on the tree, performing a careful inventory inside his little head.

I, on the other hand, have become more like the Grinch, tip-toeing through each room removing the bamboozles, the woozels, the clumtrumpets and trains.

Today, I see Nicholas distracted in the living room, and pounce on my chance to de-Christmas the house.

I hug our life-sized Frosty the Snowman and head up to the attic, quietly climbing the stairs to carefully hide the white plastic man from my adoring young son.

"Mummy, what are you doing?" I hear Nicholas shout from the living room.

"Oh, nothing...." I say and kneel on the steps. I try to become more quiet but bang my head on Frosty's giant mittens instead. Like a bullet fired from a gun, Nicholas climbs the stairs to investigate.

"Not my Frostyyyyyyyy!" he screams and starts to cry.

Fat tears fall from his eyes like rain. "Mummy, you can't put Frosty awayyyyyyy!" he says as if I am sentencing our chilly friend to a lifetime of hard labor.

"No Mummy, pleeeeeease!" he says, and now I too feel like crying.

"Wait Nicholas, I have an idea!" I say and immediately he stops crying. Once again those four little words have saved my life.

"Why don't we put Frosty in your room! That way you can still be near him. He can watch over you when you sleep! What do you think?"

And like a happy switch has flipped on in his brain, he immediately shouts, "Yeah!" "Oh Mummy, that's a great idea!" he shouts.

I carry poor, old Frosty back down the stairs and place him at the foot of Nicholas's bed. As I plug him into the light socket, Nick smiles and jumps onto his bed. He lies back and is immediately mesmerized by the cheery face of the watchful snowman. He is happy.



"Nicholas, I am going to put some of the other Christmas things away now." I say delicately to my son.

"OK, Mom," Nick says agreeably.

The warm glow of the smiling plastic man has relaxed my anxious son. Like a powerful sedative, it has calmed him. I too am suddenly mesmerized by the vision of the tall silent snowman standing at attention by the foot of my son's bed. But this vision seems familiar to me. What is it? I think to myself. Something standing watch over my son.....? And suddenly I remember the words from a story I wrote shortly after Nicholas was born,

My son lay limp upon his hospital bed. A yellow feeding tube was taped harshly to his soft cheek; it traveled up his nose and into his stomach. To his soft skull another plastic tube was taped, pumping antibiotics into his fragile veins. Around his floppy body, a brace made out of thick straps and stiff Velcro held his weakened hips in place. Feeding machines and intravenous poles surrounded him like quiet metal soldiers standing at attention. Everywhere, alarms sounded, a constant reminder that this was hell and we now lived in it.

Continued on page 17 ...

Putt for Prader-Willi Charity Golf Tournament Benefits PWCF
Friday, June 22, 2012 at the Windsor Golf Club, Windsor, CA

Registration	11:00 AM
Lunch	12:00 PM
Shotgun Start	1:00 PM
Appetizers, Silent Auction & Dinner	6:00PM
Cost	\$140 per player
\$40 dinner only (\$15 for children 10 yrs and under)	
Full entry fee includes: Green fees, Golf Cart, Range Balls, Lunch & Dinner	
Fees must be in by Friday, June 8, 2012	

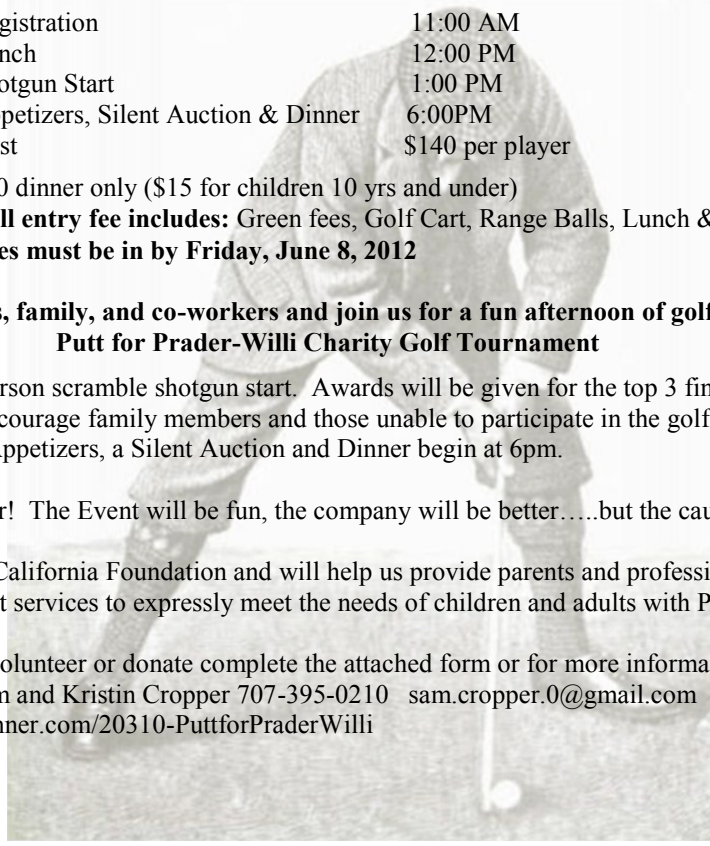
**Gather your friends, family, and co-workers and join us for a fun afternoon of golf to support the
Putt for Prader-Willi Charity Golf Tournament**

The tournament will feature a 4-person scramble shotgun start. Awards will be given for the top 3 finishing teams, longest drive, closest to the pin and more. We encourage family members and those unable to participate in the golf to join us afterwards. Activities for children start at 4:30pm. Appetizers, a Silent Auction and Dinner begin at 6pm.

Be a player, a sponsor, or volunteer! The Event will be fun, the company will be better.....but the cause is why you will be there!

Proceeds benefit the Prader-Willi California Foundation and will help us provide parents and professionals a statewide network of information, advocacy, and support services to expressly meet the needs of children and adults with Prader-Willi Syndrome.

To register, provide sponsorship, volunteer or donate complete the attached form or for more information, contact PWCF Members and event organizers Sam and Kristin Cropper 707-395-0210 sam.cropper.0@gmail.com Online registration will soon be available at <http://golfdigestplanner.com/20310-PuttforPraderWilli>



Volunteer Corner



PWCF's Board of Directors expresses its most sincere appreciation to PWCF member **Nisha Mehta** for expertly assisting the Board with its Strategic Planning Session. Nisha's strategic planning skills are as sharp as the day she last professionally used them, before the arrival of her three beautiful kids. Thank you, Nisha!

Continued from page 16 ...

As I see the quiet snowman standing at attention at the foot of Nicholas's bed, my eyes start to water.

I am reminded of his infancy when instead of joyous snowmen, metal feeding pumps and tall IV poles stood watch over my fragile child. And although Frosty the Snowman may now take up permanent residency in my son's room, I am thankful for this joyous new image. I am thankful for Nick's health, his strength, his love for life.

My desperate need to clean the house is suddenly over.

My curse has been broken.

"And the Grinch found the strength of ten grinches, plus two"



To read more about our family adventures, please visit us at www.onalifelessperfect.blogspot.com.

**California Department of Insurance Complaints:
Get Your Medical Bills Paid Without All the Hassles**
by Pattie Kelley-Huff, Illinois, Parent of a Child with PWS

Life with a special needs family member presents enough challenges with the day-to-day care without the hassles of constant fights and appeals with your insurance company that are energy-draining and time-consuming. There is an alternative to the appeals process with the insurance company that is often unknown to the insured and can be far more effective and has more leverage than the insurance company appeals process, namely the filing of a complaint against your insurance company with California's Department of Insurance (DOI). In my experience,

I have found far more success getting legitimate medical expenses paid by using the DOI complaint process than exhausting the insurance appeals process.

Hiring a lawyer can be expensive and it can take a very long time for your case to be placed on the docket for a hearing and with no guarantees regarding the outcome. I learned there is no fee to file a complaint with your state DOI. Again, there are no guarantees, but if you understand your insurance coverage and which expenses should be paid by your insurer, you probably have a good chance of the DOI advocating on your behalf.

In a nutshell, the DOI is a state agency funded by your state tax dollars and its job is to license insurance companies, ensure that state mandates regarding insurance are adhered to by the insurance companies, and investigate and make determinations of complaints filed against them, as well as look for troubling trends of unacceptable practices and try to prevent them. They do have the ability to recommend action to the insurance companies and can impose sanctions and fines if necessary. One of the advantages of utilizing the DOI complaint process over the appeals process within the insurance company is that there are statutes that determine the length of time that an insurance company may take to respond to a complaint and subsequent communication exchanges. In my experience, I have had the insurance company take months to decide if they will pre-authorize a medical procedure or equipment. The DOI in my state, Illinois, allows no more than 45 days for the insurance company to respond to a complaint. Typically, one would file a complaint after payment has been denied, but in the case of a plan that requires pre-authorization, I have had success in filing a complaint when a pre-authorization was not granted or was stalled for an unreasonable amount of time. I have filed numerous complaints with the DOI and have been successful in determinations in my favor in every single case. In two cases, it required the DOI to impose fines on a daily basis for unlawful practices until the insurance company paid. One of the folks at the DOI said that insurance companies make millions, if not billions, of dollars because they expect some folks will not fight a claim, don't stand their ground for the duration of the appeals or complaint process, and ultimately either pay the claim or allow their credit to be effected if they are unable to pay. It's amazing how willing providers are to work with you and the DOI when they know you are actively involved with an open complaint on file with the DOI.

In cases when the providers' representatives did not have the ability to prevent credit bureau reporting, the DOI representative contacted them directly and was successful each time in preventing a bad mark being placed on our credit report.

Complaints are not difficult to file but you must be sure before you file the complaint that it is legitimate and they are deserving of your complaint. You need to be thorough in your explanation about the situation, e.g. the procedure/expense, the reason for denial of payment. I make it a practice when I file a complaint to provide all letters, bills, letters of medical necessity, all documentation, etc., *anything* that is relevant to the complaint, to avoid delays at the DOI when trying to get the file together and complete to present to the insurance company. Even though initially it may take a little extra time to submit all the information you have regarding the complaint, it will save you much time in the future when they inevitably ask for the information anyway. This also prevents your insurance company from responding back to the DOI with what I like to call a "garbage response," e.g. "We never received the bill," "We never received the claim," or "The claim wasn't filed in a timely fashion." If you send all bills, claims copies, denial letters, etc., you pre-empt these frustrating replies by simply pointing out that all documentation was provided when the complaint was filed.

The response times and how to file a complaint (internet versus mailing) vary from state to state but essentially they serve the same function and are *the* agency that has some leverage and power over insurance companies. It has also been my experience that since I have been filing complaints for about two years now, I have had a much easier time getting services, procedures or equipment pre-approved and paid in a timely fashion. I would venture to say that the insurance companies probably track trends as well, and when they realize certain members will routinely hold them accountable to their obligations, they tend to be more attentive since they know they have nothing to gain with this particular person, i.e. "The squeaky wheel gets the grease."

California's Department of Insurance: 800-927-4357 www.insurance.ca.gov/

Enforces many of the insurance-related laws of the state. The department protects insurance consumers by regulating the industry's practices.

California Department of Corporations: 888-466-2219 www.hmoHELP.ca.gov/default.aspx

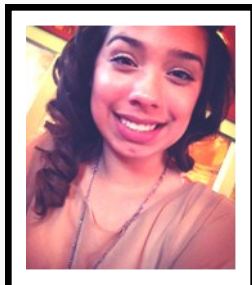
Establishes national benchmarks for Health Maintenance Organization (HMO) regulation, policy, patient advocacy and consumer awareness

Below is a link within which you can find each state's Department of Insurance:
http://www.healthinsurancefinders.com/cr_state_department_of_insurance.html

I wish everyone who has medical expenses in this country was aware of the mostly untapped potential of their local state department of insurance. I urge you to utilize your state department of insurance that is funded by your hard-earned tax dollars to help improve your ability to get claims paid and minimize your hassles.

Beauty Teen Raises Awareness of PWS

PWCF member **Ivette Ramos'** older daughter **Aliya** was chosen to compete in this year's Miss Teen California Pageant, representing Teen Vallejo. Aliya's charity of choice? Prader-Willi California Foundation!



The Ramos family also held a garage sale on March 10 and distributed PWS Brochures and our cool glow-in-the-dark wristbands to raise even more awareness. Thank you to Aliya and the entire Ramos Family!

Oral Hygiene Care for Persons with Prader-Willi Syndrome

Dental problems are common in individuals with Prader-Willi syndrome, many of which can be reduced or even eliminated by increasing saliva flow. Saliva is the mouth's natural protective agent against bacteria and is released from three pairs of salivary glands controlled by the pituitary gland. For some reason, most people with Prader-Willi syndrome do not produce enough saliva which then often leads to dry mouth, also called xerostomia, and causes soft tooth enamel, cavities, and gum disease.

Dry mouth symptoms may look like:

Bad Breath
Cracked Lips
Bleeding Gums
Dry, tough tongue
Thick sticky saliva
Impaired speech articulation
Crusting around corners of mouth



Products which help stimulate the body's production of saliva, such as Biotène Oral Balance toothpaste, mouthwash, chewing gum, and mouth moisturizing gel, can reduce or eliminate many dry mouth symptoms and dental problems. A pea-size amount is generally considered safe for **toddlers**, and Biotène's fluoride-free *First Teeth* toothpaste is made especially for **babies**.



MEMBERSHIP ACTIVITY

January-March 2012

We are fortunate and grateful that the majority of families renew their membership each year. In the interest of space, therefore, we list only new Individual and Family Members. All new and renewing Extended Family, Family Friends, and Professional Members are listed.

New Family Members

Natalie Sierra & Neal Snider

New Professional Members

Nancy Harjani Muirhead, Psy.D., ABPS, Attention & Learning Services

Renewed Extended Family Members

Carina Chaij
Linda Hedstrom

Renewed Professional Members

Suzanne B. Cassidy, M.D., Clinical Professor of Pediatrics, University of CA San Francisco
Susan J. Clark, M.D., Director, Endocrinology, Children's Hospital Orange County
Carlos Flores, Executive Director, San Diego Regional Center
June-Anne Gold, M.D., Loma Linda University Medical Center
Michael Gottschalk, M.D., Children's Hospital, San Diego
Laurie Jordan, Rainbow Connections, Tri-Counties Regional Center
Larry Landauer, Executive Director, Regional Center of Orange County
James L. Shorter, Executive Director, Golden Gate Regional Center
Richard Swartwout, Pfizer Endocrine Care



It has come to our attention that for some inexplicable reason, the U.S. Post Office returned to sender a number of Shining Star donations that were mailed in the Shining Star pre-addressed envelopes.

The address printed on the pre-addressed envelopes was indeed our correct address.

If you sent your tax-deductible Shining Star donation and it was returned by the Post Office, we

thank you and hope you will re-send it. Please accept our sincere apologies for any and all inconvenience.

PWCF's Mailing Address is 514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277

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

Prader-Willi California Foundation is grateful to each of our donors for helping us 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 don't 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 ~ January-March 2012

SHINING STAR DONATIONS

Sirius (\$1,000 or more)

Nancy & John Jenkins in honor of Cameron Graziano
M & P Thorrrington in honor of the Patay Family
The Nararo Foundation

Canopus (\$500 - \$999)

Jacki & Jeff Lindstrom in honor of Julia Lindstrom
Dennis Martino in honor of Lilli Martino-Moore
Linda & Mark Ryan

Alpha Centauri (\$250 - \$499)

Barbara Gow
Mr. & Mrs. Bob Morgan in honor of Samantha Morgan
Melinda & Chuck Morrow in honor of Cameron Graziano and
in memory of Olive, Sweet Pea, Max and Mel
People's Care

Arcturus (\$100 - \$249)

Catherine & Rudy Alvarez in memory of Daniel Alvarez
Karen U& Russell Benedikt in honor of Barbara Olson
Lisa Ann Bonk in honor of Nolan Carl Bonk
Patricia & Donald Carlson in honor of Mark Carlson
Julie & Dan Casey in honor of Ryan Casey and in honor of
Richard Willis' October 28th birthday, Craig Jann's
November 16th birthday, April Bennett's birthday on
November 27th, June Reifeiss' birthday on December 9th
and in honor of June & Bob Reifeiss' Christmas present
Patricia & Richard Casey in honor of Ryan Casey
Judy & Bill Castle
Sally & Chet Collom in honor of Jennifer Collom
May & Peter Chiang in honor of Rocky
Carolyn & Gordon Jones in honor of Duncan McRae
Rita & James Koerber in honor of Alison M. Koerber
Carole & Tom LaBossiere
Phillip DK Lee, M.D.
Marie-Claire Leon in honor of Ryan Casey
Hien & Ed Mann in honor of Maddox Alexander Rutledge
Ita & Nick Moran in honor of Samantha Morgan
Fran Moss in honor of Melissa Moss
New Life Homes II
Bie Chuan Ong & Lucy Jao
Kathy & Ralph Paige in honor of Nicholas Paige
Tracy & Brad Patay in honor of Ryan Patay
Jacqueline Smalley of the Austin Smalley Living Trust
Judith Steinhart

Peter Stoughton
Jeanne Tumanjan

Vega (\$1 - \$99)

Kyra Allen in honor of Faith Allen
Marilyn & John Bintz in memory of Page Bintz
Yakuko & Ira Bloom
Bev & Bud Bush in honor of Jeff Bush
Carter Family in honor of Dan Carter
Wanda & Steve Faivre
Cameron Graziano in memory of Sweet Pea
Barb & Larry Gunter in honor of Brandi Sherman
Linda Hamilton
Janae Jimenez in memory of Matthew Klotz
Nancy & Jim Kaiser
Mary & Kay Kavanagh in honor of Brad Kavanagh
Jamilet Knox
Ignacio Martinez in honor of Ignacio Martinez
Carolyn Meyer in honor of Cameron Graziano and in memory
of Peter Meyer
Jennie & Edward Pedersen in honor of Nolan Bonk
Julia & Jeremy Rutledge in honor of Maddox Alexander
Rutledge
Joyce & Norman Smith in honor of Justin Hibbard
Lucia & Peter Smith
Plonneke & Martin Thoolen

Magnanimous General Donations

Comcast Corporation at the direction of Michael Moore
Maureen Kelly IRA

Laura Shea Tea for a Cure Event

Laura Shea

General Donations

Ana Amaya-Garcia via United Way California Capital Region
Bud Bush
Suzanne B. Cassidy, M.D.
Carina Chaij
Linda Hedstrom
Brian Hughes
Karen Jobe
Renee Lovern
Barbara & Yale Rabin
Ron Vogrin in honor of Oscar Hill
Kimberly Wilkerson
Amy & Paul Wissmann via United Way, Inc.

Prader-Willi California Foundation is a non-profit 501(c)(3) public charity. Established in 1979, PWCF is the *only* organization dedicated *exclusively* to serving the needs of Californians impacted by Prader-Willi Syndrome. PWCF is comprised of parents, extended family, friends, dedicated professionals and care providers, and is supported solely by dues and donations.

Prader-Willi California Foundation proudly maintains an affiliation with the national Prader-Willi Syndrome Association (USA).



Hula Hoop Custom Made Necklace:

The Hula Hoop Necklace is more than just a necklace. It represents and reminds us to live in the moment. As a parent of a special needs child, I remind myself to think, feel and worry only about the things that I could fit into my hula-hoop and no more.

Each Necklace is custom made and tailored to your liking. Please choose from the following:

* 16 or 18" Sterling Silver Rope Chain with spring ring clasp

* 4 mm Swarovski Crystal

Swarovski Birthstone Chart



Shipping: USPS First Class Mail. Please allow 2 weeks for the creation of your hand made item to be completed before item is shipped.

Please note: the letters are not perfectly straight which lends itself to the unique look of each necklace.

** A black leather cord can be substituted for the sterling silver chain.

✂

The creator of these beautiful necklaces, Carrie Hassanzai, is a personal friend of PWCF member and author of the *In The Trenches* series, Jessica Patay. After reading Jessica's article featured in this issue of the newsletter which encourages us to "think, feel, and worry about only what we can fit into our hula-hoop," Carrie excitedly set to work to craft a tangible image of this wonderful metaphor. These beautiful Hula Hoop necklaces are designed especially for our PWS families, and Carrie will donate a portion of the proceeds to PWCF! Order your beautiful necklace (or two!) today and support PWCF!

✂



PWS Hula Hoop Custom Made Necklace Order Form

Mail this form with your payment to the PWCF Office 514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277

Please send me _____ PWS Hula Hoop Necklace(s) priced at \$65each (plus shipping and postage)

Name: _____

Shipping Address: _____ Telephone: _____

City, State, Zip: _____

I have enclosed my check made payable to "Carrie Hassanzai" Please charge my Visa MasterCard Amer Express

Name as it appears on card _____

Credit Card No. _____ Email: _____

Expiration Date _____ Security Code (on back of card) _____

Billing Address _____

(if different from shipping address above)

Signature _____