

January ~ March
Volume 25 Number 1

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Team PWCF runs the ASICS LA Marathon, Charity Relay, and LA Big 5K!

The sun was shining bright for Team PWCF as we ran together to raise awareness of Prader-Willi syndrome across Los Angeles. It was a full weekend! On Friday morning Family Support Coordinator **Katherine Crawford** set up the PWCF Charity Booth at the NutriBullet Health and Fitness Expo. PWCF had a great location across from the Marathon Participant Name Wall. PWCF got to mingle with expo-goers and spread awareness of Prader-Willi syndrome and share the important impact groups like PWCF have on families and communities.



On Saturday Team PWCF brought a vivacious crowd to the 5K. PWCF President **Julie Casey**, Executive Director **Lisa Graziano** ran with Team PWCF. Katherine met with runners that morning and gave a final race-day pep talk. After a good run, each person got their own LA Big 5K medal to commemorate their success. One note of inspiration: we had four people with PWS in the 5K this year: two running and walking (**Trevor Ryan and Cameron Graziano**), and two in strollers!

The next day brought the distance runs: the Charity Relay and the ASICS LA Marathon. It was an extra early morning for everyone involved: not only did shuttles begin to take runners to the start line at 3:00am, but it was also Daylight Savings! We had an all-star team of runners for the inaugural Team PWCF run this year. Vice president **Kim Morgan** and past vice president **Chris Patay** were among the Team PWCF marathon runners. Board member **Diane Kavrell** and her husband, **Brandon**, and Board member **Daniela Rubin** and her husband, **Ricky**, lead the way for the Team PWCF Charity Relay runners, each running a half-marathon in support of PWS awareness.



Kim Morgan (left) & Chris Patay



Marathon and Charity Relay runners were cheered along by **Team PWCF Cheer Squad at Mile 15, for the 15th Chromosome**. Families and friends joined up at the intersection of Doheny and Alden to ring cowbells, spin noisemakers, and cheer on the runners for the big day. We had a fantastic group! Cheer Squad members brought their best smiles, clapping hands, and high spirits to Mile 15. We handed out over 100 awareness-raising wristbands to runners along the way. In the end, well over 20,000 people passed PWCF's Cheer Squad. What an amazing weekend. Please see page 17 for a full list of our runners and donors. **Thanks to everyone on Team PWCF!**

Team PWCF Volunteers

Thanks to the **Katherine Crawford** and **Kim Morgan** for their work to organize the event. Thanks to the **Martinez-Ali** family, the **Policarpo** family, and the **Patay** family for their support on the Team PWCF Cheer Squad! Thanks to **Trevor Ryan** for his assistance sorting and mailing Team PWCF shirts. Thanks to **Jackson Crawford** for assistance with booth set-up, banner-holding, and Cheer Squad.



Linda, Trevor & Mark Ryan

**PRADER-WILLI
CALIFORNIA FOUNDATION**

A Full Life Without Limits

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E-mail: info@pwcf.org

Web address: www.PWCF.org

Facebook: www.facebook.com/pwcf1



Our Mission

Individuals with Prader-Willi syndrome should have the opportunity to pursue their hopes and dreams to the full extent of their talents and capabilities. The success of people with Prader-Willi syndrome depends greatly upon the knowledge and support of the community around them. The Prader-Willi California Foundation provides individuals with PWS, their families and professionals with a state network of information, advocacy and support services.

PWS Support Groups and Contacts

Northern California

San Francisco Bay Area	Patti McRae	408-920-8003	pattimcrae@sbcglobal.net
Sacramento	Diane Kavrell	530-753-5928	brandon.kavrell@cexp.com

Central California

Paula Watney (Teens & Adults with PWS)	559-299-8171	mikewat1@sbcglobal.net
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Southern California

Los Angeles County	Lisa Graziano	310-372-5053	LisaG@pwcf.org
	Julie Casey	818-843-7321	julie.casey@att.net
Orange County	Jenn Paige Casteel	949-735-0472	marchroses@hotmail.com

Inland Region Area

San Bernardino County	Ester Del Real	909-213-5992	esterdelreal@ymail.com
	Maria & Ken Knox	909-421-9821	teachknox@aol.com

Spanish Speaking

Mercedes Hernandez (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	vbaz92@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*. Click and follow instructions to join the *PWSProfessionalsExchange* group.

PWSA (USA) Online eSupport Groups www.pwsausa.org Click Enter. Click "Support"

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

International PWS Organisation

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

PWS Share & Support Groups Meeting Calendar 2014

Southern California

Beach Cities Health District
514 N. Prospect Avenue
Redondo Room (Lower Level/Bottom Floor)
Redondo Beach
2:00 p.m. – 4:30 p.m.
Sunday, April 6
Saturday, July 26
Sunday, October 26
Childcare available ONLY for children under age 12. RSVP to PWCF 310-372-5053

Northern California

Support for Families of Children with Disabilities
1663 Mission Street, 7th Floor
San Francisco
10:30 a.m. – 1:30 p.m.
Saturday, April 19
Saturday, September 20
Saturday, November 15
Childcare available. RSVP to SFCD 415-920-5040 x 135

Parent to Parent

How do you manage the attention jealousy that occurs when your other children see you focus your time and energy on your child with PWS?

My children are all grown now but when they've mentioned in the past they do realize that a lot of the attention was focused on Monique, i.e. her behaviors, doctor visits, etc. What I did do to avoid the resentments was to try to focus time with each one (there are four total) and let them realize just how special each one was. It might be something as simple as a movie with one, shopping (not groceries) with another, etc. Also, as they got older I was always open with them regarding the issues that arose with Monique. At times they resented the attention she got but have grown to be more compassionate due to their experiences. *Anita Tapia, mom of Monique, age 36*

We always try to emphasize that their brother needs special attention due to the fact that he has PWS. It's very important that they are informed about the dangers and limitations that their brother faces on a daily basis. They also understand that he cannot do most of the things that they can (going out with friends to eat, save money just to buy special treats, or just enjoy lunch with friends...). We try to have special outings with each one of them and praise them for every single time we caught them helping their brother. Our daughters adore their brother and they push him to excel in life. *Diana Vega, mom of Pablo, age 7*

In our home situation, the child with PWS over time has learned to pit one parent against the other. When one parent corrects the child for some problem, the child goes to the other parent and complains. If both parents are not on the same page, they could easily step into the disagreement arena. Parents must sort this out quickly and come up one solution to correct the behavior problem. Parents need to be consistent and mutually supportive. *Russ Graff, dad of Mark, age 47*

We try to compensate with "special dates," either one of us or both of us with one of our other children. *Jessica Patay, mom of Ryan, age 10*

Foundational would be making sure the sibling(s) of a child with PWS understand what the situation is, at a level they can comprehend. Still, jealousy can rear its ugly head in the best of us so here are some practical tips to use. As a mom of 7 children it seems there is always one of my children who needs attention! There are two main things I focus on to keep a balance between siblings to minimize jealousy: 1) Focus on the child's gifts. I look at each of my children and ask myself: What is this child's gifting? What do they like to do? What kind of personality do they have? Once I have answered these basic questions I have a conversation with my child and ask them what they would like to pursue. I can help them with suggestions if they are not sure. When a child has a skill to focus on, they gain confidence and it is easier to praise them. They feel special and are less likely to be jealous of their sibling(s). Also, you will most likely now have something positive to engage with your child about, not just nagging over chores and homework. 2) Spend time alone with each child. In our family we call it a "special time" when one child gets to go with Mom or Dad wherever we happen to be going. This doesn't happen too often, but when it does we make sure they get a little treat (sugar free gum, hot chocolate, smoothie - okay it doesn't need to be food, but keep it simple and simply get to enjoy one another's company. In this way we ensure no one is getting ignored or passed over because of being too busy with life. Having these two things in place doesn't eliminate jealousy but it goes a long way to keeping a healthy balance for all your children. *Allison Gobbell, mom of Madison, age 14* [Madison is a very talented artist. Watch for her artwork on future PWS Artcards!]

My children understood what PWS meant and so I made them part of the "helpers" when they were young. One spent time "teaching" her things and the other felt it was his job to watch her if she was food seeking and report back if he thought she was "bothered" by something. So for now while they are young, make them part of the "team" and ask for their feedback on the situation, even as young as a 2yr old can help. Alone time with each child while hard is 100% necessary *and get rid of the guilt of not including your child with special needs in everything*. One thing I always remembered over the last 26 years is being told "if you have a dysfunctional child do not let it turn into a dysfunctional family." My kids now 32, 26 and 20 are exceptionally kind to all people with special needs they meet. Being a sibling gives you empathy that will be with them all their life. *Angela Garcia, mom of Ashley, age 26*

I think the word "manage" is such a great way to describe the attention jealousy that occurs with our typical children when the child with PWS often gets the most attention. I say that because I have found there is really no way around it, attention jealousy occurs in typical families as well, they just don't have the major behavioral and food issues we PWS parents do! I try to set aside special time with each child daily. Whether it is walking the dog with my child with PWS or private time with my non-PWS child, giving each one a bit of just "me" seems to help. I finally applied for respite companions through the Regional Center. The respite companions allow me to spend time with my typical daughter, taking her to after school activities, etc., while giving my child with PWS a companion to do her own things with. I also try and take my typical child out without her PWS sibling so that she can spend time doing some of the things her sibling cannot do. Continue to have talks with the typical children that their sibling often needs the extra attention and try to enlist them to help. Maybe they can be in charge of exercising or helping with homework. I'm not sure the attention jealousy ever goes away but we can at least try to manage it. *Wendy Higgins, mom of Lexi, 15 years*

Next issue's Parent to Parent question is "What tips or advice do people have for healthy and successful visits to restaurants, whether they be fast food or nicer restaurants?"

Food Tip

Is there such a thing as a “healthy” Easter Basket?

If you’re making an Easter Basket this year for your little one, have no fear! There are ways to include lower-calorie treats without feeling like you’re skimping. Read below to see just how big a difference in calories there can be, even between similar candies! **We’ve highlighted the lowest calorie option in each category so you can see at a glance your best candy options.** Bear in mind: *candy, like all things sweet, should always be eaten infrequently.* Many Easter Bunnies are known to include toys in their baskets in lieu of or in addition to edible treats.



Jellybeans	
10 Jelly Belly jellybeans	40
10 Starburst jellybeans	110

Easter Eggs	
1 hard-boiled Easter Egg	76
1 Cadbury Crème Egg	170
1 Cadbury Caramel Egg	190
1 Cadbury Caramel Egg	190



Chocolate Treats	
1 “fun size” pack plain M&Ms	88
1 “fun size” pack of Peanut M&Ms	90
1 “fun size” pack of Peanut Butter M&Ms	95
8 robins eggs malted milk candies	170
1 box of Milk Duds	230



Chocolate Bunnies	
1 small chocolate bunny - 1 ounce	140
1 medium hollow chocolate bunny, 1 3/4 ounce	260
1 large chocolate bunny - 7 ounces	1050

Gadget Tip

Conversation Starters

The most popular product for teaching conversation skills. Students learn to answer and to initiate conversation. But most of all, they learn to stay on topic. Comes in such a convenient size you can clip them to your key ring for spontaneous teaching throughout the day. Simply brilliant technique to teach conversation skills!

Children practice conversation in simple steps. They learn the flow of information continues about the same topic. These are not learned social scripts. They teach spontaneous conversation as the child fills in the blanks.

How do they work?

The Conversation Starters employs two stages for teaching. The first stage teaches children to spontaneously answer questions while the second stage teaches children to inquire about other people and to initiate conversations.

Each set includes six different topics with a yellow card signifying the start of each new topic for immediate access.

Known as a Speech Teacher's Dream, they're so convenient you can carry them in your pocket or clip them to your key ring and use them throughout the day.

The front of each card poses a fun and interesting question about the topic. Flip it over and the beginning of the answer is on the back, encouraging children to fill in the blanks.

Available from Natural Learning Concepts \$35 Order online at:

http://nlconcepts.com/productdetails/21/132?inf_contact_key=fe5ebd9979df1bec8e27fb3ad78b1848f1640817ff97c01ac6386f8cb5c6aff7



Executive Director's Column

by Lisa Graziano, M.A.



2014 marks PWCF's 35th anniversary. Thirty-five years providing supports and services to Californians with PWS and their families. That's a long time!

Before PWCF was formed in 1979 there was no internet from which to gather information about the syndrome. There were no PWS support groups where families could connect, share, and learn from each other. The average cost of airfare for a domestic round-trip flight was \$450 in the late '70s, so families weren't flying to educational conferences – which didn't exist anyway. There were no books about the syndrome, no newsletters, no brochures. There were no DVDs to help train teachers or residential services providers. There was no growth hormone medication and very little was known about other therapies we now know are crucial to overall development. Families had nowhere to turn when their loved one, for whatever reason, needed to live outside the family home. There was a great deal of seclusion and isolation.

A lot was going on, though, in the disabilities world in the seventies. The Rehabilitation Act of 1973 was expanded to include people with disabilities. Section 504 under this Act provided disabled persons with new national protections from discrimination where none had existed before. In 1975 the newly established Prader-Willi Syndrome Association (USA) focused national attention on PWS for the first time. The US Supreme Court proclaimed in 1979 that programs receiving federal funds must make "reasonable modifications" so that disabled individuals could participate in them (*Southeastern Community College v. Davis*). The Disability Rights and Education Fund (DREDF), established in Berkeley in the early 1980s, went on to become America's leading disability rights legal advocacy center and later participated in landmark litigation and lobbying in the 1980s and 1990s.

It wasn't until 1979, when our founding fathers and mothers established PWCF, that there was an organization that was *solely* focused on meeting the needs of California families. Thirty-five years ago, thanks to the vision and determination of a small group of pioneers, PWCF emerged as an entity that families could turn to for local support, education, guidance... and hope.

A lot has changed since the early days of darkness and isolation. PWS research and science have made tremendous progress, bringing us closer to what each of us hopes will be breakthrough relief from PWS' appetite and behavioral symptoms.

And then again, *some things haven't* changed. PWCF has been and continues to be an exemplary organization that builds upon the hard work of previous generations. We continue to work to meet the unique and complex needs of people with PWS and their families, providing an ever-increasing number of educational, advocacy, and support services.

We continue to benefit from the extraordinary dedication and guidance of long-time members. Members like **Renee Tarica**, who has served as PWCF's treasurer for literally decades; **Fran Moss** whose service has spanned from board member to executive director, newsletter editor, and residential services consultant; PWCF's current president **Julie Casey** who works long into the early morning hours for PWCF; and *countless* others who give of themselves whenever possible – and some, *continuously* – and make it possible for PWCF to provide the services and supports our families need.

So, Happy 35th Anniversary, PWCF. May you always attract bright and energetic people to your Board of Directors and committees, and may you continue to serve your families with the dignity, dedication, and professionalism they deserve.

PWCF Retains Social Worker to Assist Families



For the past couple of years PWCF has been on the lookout for a professional who can assist families who have complex medical insurance and other questions that are best addressed by a social worker.

PWCF is proud to announce we have retained **Sheila Umeda, M.S.** to serve as PWCF's social worker to consult with families as needed.

Sheila has a Bachelors in Social Work with a minor in Psychology from Pacific Union College, Angwin CA (1992), and has a Masters in Social Work with honors from California State University, San Bernardino (2004). Professionally, she has extensive experience in areas of case planning and management working with adolescents, adults, seniors, and their families in varied health care and social service settings. During her social work career, she was employed as a Consumer Services Coordinator at Inland Regional Center, advocating for support services and community integration to individuals with special needs.

Sheila currently lives in Loma Linda with her husband Charlie and two young children, Katie and C.J. In addition to her new role as social work advocate for PWCF, she also enjoys serving as part-time staff at her children's elementary school. Sheila's hobbies include; reading, exercising, singing karaoke, traveling, and engaging in outdoor activities with her family.

Sheila is proud to be part of the PWCF team. In fact, she and her son CJ ran the LA Big 5K with Team PWCF! We are excited that Sheila looks forward to providing social work support to PWCF members.

Life on the Tough Road

by Cameron Graziano

Ever since I was little, I've been diagnosed with a rare medical disorder called Prader-Willi syndrome (PWS). This is a life-threatening disorder that affects every part of my life. For a short scoop, hyperphagia is one of the symptoms that cause me to feel that I'm not full, thus I can just eat and eat till I die. Another symptom is hypotonia which causes low muscle tone, thus your muscles are weaker than others. Some have mental retardation. Through my life, I experienced life-threatening events that without the help of yearly school supervisors, I wouldn't be here. Let me explain some of them.

From the time I was in 3rd grade to 5th grade I stole food from the school's cafeteria and I liked it. That's because I was in a club called the Food Stealers. Eventually, I decided to quite. One day at lunch, I told my "friends", "NO, I'm not going. It's not healthy for me. You go ahead, but don't be crawling back to me." That was a moment of good triumph and judgment.

Then, in 5th grade, I ate out of trash cans, which [contained] already eaten food. I kept eating and eating it during nutrition break. Thank god I didn't get sick. Until one day, my friend caught me and told my mom. That night I was caught, and I was on my way to supervised town. From that day on, there was no way I was going to be free.

Ever since then, I tried not to get into trouble, but I just couldn't help myself. I kept getting in trouble. But now I'm [a Freshman] in high school and just received a 3.875 GPA [for the first semester]. Now, I've decided to help all you parents out there who are done with this. To all the kids out there who have this, I'm going to help you out too! I'm going to do a fundraiser to try to help find a cure for it because you're my inspiration. Thank you all who know me and support me for who I am. There's still hope in the world, so keep your head up and be good! Thanks to all and to all who care.



Prader-Willi Syndrome Research

Recent Publications from the Kimonis and Gold group

Frequency of Prader-Willi syndrome in births conceived via assisted reproductive technology.

Gold JA, Ruth C, Osann K, Flodman P, McManus B, Lee HS, Donkervoort S, Khare M, Roof E, Dykens E, Driscoll DJ, Butler MG, Heinemann J, Cassidy S, Kimonis VE. *Genet Med.* 2013 Aug 8.

Previous studies have suggested an increased risk of other imprinting disorders in children conceived by assisted reproductive techniques. This study was designed to determine the association between assisted reproductive technology and Prader-Willi syndrome. The proportions of assisted reproductive technology births in the Prader-Willi Syndrome Association (USA), Rare Diseases Clinical Research Network, and University of California, Irvine Medical Center populations were 1.0% (18/1,736), 1.0% (1/98), and 2.0% (1/50), respectively (overall 1.1%; population frequency for the United States was 1.0%). Of note, 2.4% (45/1,898) of participants were co-twins (11 born after assisted reproductive technology procedures); US twin frequency is 1.6% (P = 0.007). The proportion of individuals with maternal disomy 15/imprinting defects born after assisted reproductive technology was higher than that in the total sample, 55.6% (10/18) and 34.5% (431/1,250), respectively.

This study found no association between assisted reproductive technology and Prader-Willi syndrome. There was an increased frequency of twinning. The number of individuals with maternal disomy 15/imprinting defect was nearly double in the assisted reproductive technology group as compared with the total Prader-Willi syndrome participants.

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#### **Effect of Genetic Subtypes and Growth Hormone Treatment on Bone Mineral Density in Prader-Willi syndrome.**

Khare M, Gold JA, Wencel M, Billimek J, Duarte B, Pontello A, Galassetti P, Cassidy S, Kimonis V.

We recently published a paper evaluating the effects of growth hormone and of the different genetic subtypes on bone mineral density (BMD) in Prader-Willi syndrome (PWS). We evaluated BMD in 79 individuals with the common subtypes of PWS (48 with deletion and 27 with UPD) and the effect of growth hormone treatment (N=46) versus no growth hormone treatment. The results showed 44% of the individuals studied had whole body, hip or spine BMD <-1SD and 10% had a BMD <-2 SD. BMD Z-scores and total BMD (gm/cm<sup>2</sup>) of spine were significantly higher in the growth hormone group. With each year of growth hormone treatment these values increased by a factor of 0.207 and 0.011 (p= 0.006 and 0.032) respectively. Individuals with uniparental disomy revealed higher spine BMD compared to deletion subclass however the differences were not significant.

Conclusion: This study emphasizes the importance of evaluating bone mineralization in individuals with PWS and the beneficial effects of prolonged treatment with growth hormone. There was a trend for a higher BMD in individuals with uniparental disomy.

# In The Trenches

Vol. 14  
by Jessica Patay

## The Top 10 Things NOT to Say to a Parent of a Child with PWS



*We have all been annoyed, hurt, or angered by someone's comments to us about our child. It's usually someone well-meaning, and just absolutely unaware of PWS or what it's like to have a disabled child. We cannot expect others to understand or to know what to say or not to say. We must give them some grace. However, with that being said, I thought I would compile this list for us parents. Forgive my snarkiness.*

- 1. Oh, you have such a quiet baby. You are so lucky.** *How we wished our child would cry and scream, but he cannot.*
- 2. Your kid is such a good eater!** *Yes, it's his hobby.*
- 3. I love how many questions he/she asks. He must be really smart.**  
*And then:*
  - 4. It's ok, he/she can keep asking me questions.** *No, really we are teaching him NOT to talk to strangers, and not to ask more than two questions.*
- 5. Oh, my kid likes to eat all day long, too.** *As if it's the same thing. No, it's not life-threatening for YOUR child to eat whatever and whenever.*
- 6. You must be a special family if \_\_\_\_\_ was entrusted to you.**
- 7. I don't know HOW you do it.** *Because I have to. I don't have a choice. I will not crawl in a hole. I will be a Mama Bear Advocate for my child and you would too, if you HAD to.*
- 8. Maybe he/she will grow out of it.** *No, but that is a nice sentiment. He will not grow a chromosome 15 someday.*
- 9. I hope he/she will be ok.** *Well, he DOES have a life-long disability. So probably not.*
- 10. Oh, really? But he/she looks so normal.** *Because he should have a 3<sup>rd</sup> eye or something? Yes, he is very beautiful and sweet. But trust me. It's very complex, and NOT a normal genetic disorder at all.*

## Congratulations to PWCF's Newly-Elected Board of Directors for the 2014-2016 Term

| <u>Name</u>          | <u>City of Residence</u> | <u>Profession</u>                        | <u>Age of Family Member</u> |
|----------------------|--------------------------|------------------------------------------|-----------------------------|
| Diane Kavrell        | El Macero                | Homemaker                                | 15                          |
| Tom McRae            | San Jose                 | Software Engineer Manager                | 14                          |
| Jacki Lindstrom      | Burlingame               | Owner, General Building Contracting Firm | 28                          |
| Daniela Rubin, Ph.D. | Fullerton                | Kinesthetics Researcher                  | --                          |

## Attention Employers: Why You Should Hire Someone With Prader-Willi Syndrome

Persons with Prader-Willi syndrome will work hard to earn your praise for a job well done. Given the correct environmental structure and supports, someone with PWS can be one of your most hard working and valued employees.

When it comes to tasks like shredding, sorting, adhering stamps onto cards, repetitive responsibilities of this nature, and some computer work, employees with PWS often have tremendous patience and perseverance, often more so than other workers.



Prader-Willi syndrome is a rare and complex medical disorder that affects an important supervisory center in the brain that controls many functions of the body including muscle strength, growth, metabolism, appetite regulation, and the management of emotions. Beginning some time in childhood, the brain fails to regulate appetite normally. For the individual with PWS there is a constant preoccupation with food accompanied by an unrelenting, overwhelming physiological drive to eat called hyperphagia. Normal satiety—the feeling of fullness after eating—does not exist no matter how much food is eaten. At the same time, the metabolic rate is about half what it should be, so individuals with PWS can gain a great deal of weight in a very short period of time. There is currently no known medication that will control or even reduce the drive to eat, though research is making great progress toward developing a medication specifically for persons with PWS.

When access to food is secure and managed well, the individual with PWS can focus on the task at hand and perform a job well done. To maximize performance and minimize behavioral problems, employers must control access to food items throughout the worksite. For most worksites, it is realistic and manageable to make relatively minor changes to accommodate the employee with PWS in order to help him be a productive, valued, and valuable employee.

Keeping food items out of sight and inaccessible will help reduce behavioral problems in the workplace. Individuals with PWS know they're not supposed to eat "out of bounds" foods, they simply cannot overcome their biochemical drive to eat.

It is often helpful to someone with PWS to post the day's work schedule, including snack and lunch breaks. Having a concrete schedule to view and refer to can be quite helpful. Keeping employee lunches and other food items in a manager's office or in some other secured area is highly recommended. Limiting access to vending machines and/or limiting access to money that may be used to purchase food items from the cafeteria, mobile food trucks, local fast-food restaurants is also highly recommended.

The Prader-Willi California Foundation is a non-profit organization dedicated to serving persons with PWS and their families. PWCF will provide free training to employers who hire someone with PWS. PWCF will help you create an environment in which your employee with PWS can thrive.

### Helpful Hints for the PWS-Friendly Worksite

- Post a daily work schedule
- Keep food out of sight and inaccessible
- Manage food-related stress
- Have clear, written expectations for workers
- Maintain a calm atmosphere
- Praise a job well done

With Prader-Willi syndrome, the emphasis is always on prevention. With the right supports a person with the syndrome can be a great contribution to society and to the work site. You will know these supports are working when the individual is happy, productive, and focused during the work day.

Working together, we can help individuals with PWS live a meaningful and productive life and pursue their hopes and dreams to the full extent of their talents and capabilities. With your help, the person with PWS will be a happy and productive worker and member of society.



For more information about Prader-Willi syndrome or to speak with someone about how to organize or manage your worksite to assist your employee with PWS, contact PWCF:  
310.372.5053 • 800.400.9994 Toll-free in CA  
info@pwcf.org • www.pwcf.org

## Food Security at School for the Student with Prader-Willi Syndrome: Critical Information for Educators



### Prader-Willi syndrome Causes an Insatiable Appetite

Prader-Willi syndrome (PWS) is a non-inherited genetic disorder that causes a host of symptoms including hyperphagia, or insatiable appetite. Persons with PWS do not feel full no matter how much they eat; the brain continuously and relentlessly drives someone with PWS to seek out and eat more food. At the same time, the body metabolizes food at about half the normal rate, so someone with PWS will gain weight at a tremendous rate on few calories.

There is no known treatment or appetite suppressing medication to eliminate or even reduce PWS' hyperphagia symptom. There is no "behavior modification" in regard to food. It is not realistic to expect that the student with PWS can "learn to control himself" and not eat food that is available. While some children may be able to manage their behavior for a day or even a week or two, this does not constitute genuine modified behavior; there will come a day when the child, despite knowing that he should not, will attempt to eat excess food. Individuals with PWS know they're not supposed to eat "unauthorized" foods; they simply cannot overcome their biochemical drive to eat.

For the student with PWS the emphasis is always on prevention. The key to managing the hyperphagia caused by PWS and reduce the incidence of food-related behavior issues is to restrict access to food within the school environment and provide continuous supervision of the student at all times during the school day.

### But Just "One" Can't Hurt... Can It?

For the child with PWS, just "one" or just one food binge *can* hurt... It can even be deadly. Here's why:

#### Rapid Weight Gain

Due to a reduced metabolic rate and other endocrine issues persons with PWS can quickly gain large amounts of weight on very few calories. A diet considered healthy for a child without PWS can cause rapid weight gain for the child with PWS. The daily caloric intake of the child with PWS must be strictly monitored; even just one cookie or one extra slice of pizza every now and again can mean the difference between a healthy weight and a tip of the scale into morbid obesity. If a child is known to have obtained extra food during the school day parents must be notified so that they may compensate and reduce the child's caloric intake for the remainder of the day or week.

#### Choking

Choking is a particular hazard for persons with PWS who often eat much too quickly and do not adequately chew their food before swallowing. Sneaked or stolen food will be eaten very, very quickly to avoid detection or loss of the forbidden item. Low muscle tone and poor oral-motor coordination exacerbate the choking risk.

#### Severe Gastric Illness

Abdominal distention or bloating, pain, and/or vomiting may be signs of life-threatening gastric inflammation or necrosis and is more common in PWS than in the general population. Thinner individuals are at even greater risk. Rather than localized pain the student may complain of a general feeling of unwellness. If a child with PWS has these symptoms, especially following a known or suspected binge episode, immediate parental notification and hospitalization is warranted as this may be a life-threatening situation.

#### Lack of Vomiting

Vomiting rarely occurs in individuals with PWS due to an impaired Central Nervous System. Emetics may be ineffective and repeated doses may cause toxicity. The presence of vomiting may signal a life-threatening illness and warrants immediate notification of the parents and possible hospitalization.

### The Principles of Food Security

Food Security is a term coined by PWS specialists Linda Gourash, M.D. and Janice Forster, M.D. and refers to "the ready availability of nutritionally adequate and safe foods with an assured ability to acquire acceptable foods in socially acceptable ways."

Continued on page 10 ...

Continued from page 9 ...

### The Principles of Food Security are:

**No Doubt** when meals will occur and what foods will be served **plus**

**No Hope/Chance** to obtain additional, unauthorized foods **equals**

**No Disappointment** related to unmet expectations. **No disappointment means fewer behavior problems.**

### The Hand is Quicker Than the Eye

Regardless of cognitive function, a child with PWS can be quite adept at obtaining food. Educators should be aware that children with PWS have been known to:

- Take food out of someone else's lunchbox or off another's lunch tray, or from the teachers' lounge
- Trade valuable items for food such as jewelry
- Steal money to purchase food from the cafeteria, vending machine, and other students
- Eat their own packed lunch and attempt to obtain more food from the cafeteria
- Take half-eaten or discarded food from the trash
- Take food from backpacks left in corridors while on the way to the restroom
- Eat all of their lunch on the bus while on the way to school

Maintaining Food Security  
in the school setting is  
imperative  
at all times  
and in all circumstances #

Children with PWS may not be truthful about whether or what they've eaten regardless of the "evidence." It is generally recommended not to ask "Did you eat that?" but rather presume food was eaten and notify the parents.

### PWS' Impact in the Classroom

It is unrealistic to expect a student with PWS to maintain focus on the task at hand when he knows that a food or beverage may be obtainable; the drive to eat is too strong and will affect behavior and school performance. For most students with PWS, having any food anywhere in the classroom will impede their ability to concentrate and learn. Maintaining Food Security will help improve learning and the overall behavior of the student with PWS.

### Tips to Maintain Food Security

- Educate and inform *all* people working with the student including bus drivers, custodians, secretaries and volunteers.
- Secure access to food across all settings including the cafeteria, lunch boxes, hallways, vending machines and money.
- Supervise food exposure at all times, including during bus rides and especially in the lunchroom and wherever there are food related activities. In some cases the student may need to eat snack or lunch in his classroom with a peer or friend. Some students may require supervision in hallways.
- Post the schedule for snack and lunch times.
- If the student states he has not had breakfast call the parents or caregiver *before* giving food. The child may have already eaten a healthy breakfast and is hoping to obtain more food.
- Lock up all sources of money including purses. Avoid allowing the student to carry money.
- Address any stealing or trading of food in private. Never be punitive—stealing and lying are symptoms of the syndrome!
- Never try to take food out of the child's hand unless it is spoiled or dangerous as this may lead to meltdown behavior. Instead, encourage the individual to put the food down and later inform the parents of the eaten food. Secure that food source to ensure against a reoccurrence.
- Follow parental guidelines for treats or eating of extra food. Communication with home is very important.
- Don't delay snack or lunch when at all possible. If delays are necessary discuss ahead of time with the student.
- Limit availability and visibility of food. Remove candy dishes. Do not offer a food treat to another child in the presence of the child with PWS who cannot also enjoy that food treat.
- Do not use food as a reward, incentive, or punishment. Instead, the use of other systems of reward or incentive are encouraged, such as stickers, small toys, tokens for the "purchase" of small toys, etc.
- Be aware of food aromas. There is nothing like the smell of popcorn or cookies to make a student with PWS agitated and increase the potential for anxiety and a behavior problem.
- When going on a field trip or other outing, discuss all food-related issues *ahead* of time. Will you bring a snack along or will it be purchased? If purchased, what will it be? Will the outing interfere with the time of a meal?
- Obtain weekly weight by school nurse if indicated.



### For More Information about PWS

For more information about PWS or to speak with someone about how to organize or manage the classroom setting to assist the student with PWS, contact PWCF at 310-372-5053 [info@pwcf.org](mailto:info@pwcf.org) or visit [www.PWCF.org](http://www.PWCF.org)

# Research

**Parental Coping** Are you a parent or caregiver to a child with Prader Willi syndrome? Following on from an earlier study, the University of Newcastle would like to further understand how your child has impacted your life and how you have coped. You can do this study even if you participated in the Disclosure study in 2012/2013. To read more, or complete the survey go to [www.wix.com/c3094005/geneticdisorders](http://www.wix.com/c3094005/geneticdisorders)  
Jane Goodwin, PhD Candidate, School of Psychology, University of Newcastle E: [Jane.Goodwin@uon.edu.au](mailto:Jane.Goodwin@uon.edu.au)

**Clinical Study of a New Investigational Drug to Treat Hyperphagia in PWS** The purpose of this study is to evaluate the safety of and effect of a new investigational drug on hyperphagia and energy expenditure in PWS patients. The investigational drug is a new form and formulation (once-per-day tablet) of an approved drug that has been safely used in neonates, children and adults for several decades.

**WHO:** Persons with a confirmed diagnosis of Prader-Willi syndrome ages 5-20 years cared for in the home.

**WHAT:** After a screening visit to qualify the patient for the study, patients enrolled in the study would be expected to complete 9 visits over 20 weeks. After a 4 week baseline period during which no drug is administered, all patients will receive the active drug for a period of 12 weeks followed by 4 weeks in which they may or may not be switched to placebo. Patients will be compensated for each visit.

**WHERE:** UCI Medical Center and General Research Centers at UCI Med Ctr. and Children's Hospital, Orange County in Orange, or Irvine, CA.

**CONTACT:** Virginia Kimonis, M.D. at 714-456-5791/949-824-0571 or email at [vkimonis@uci.edu](mailto:vkimonis@uci.edu) or Marie Wencel, research coordinator at 949-824-0521 or email at [mwencel@uci.edu](mailto:mwencel@uci.edu).

**Study Examining Swallowing Function in PWS** PWSA (USA) is sponsoring a research grant that is a pilot study examining swallowing function in persons with PWS. The principal investigators are Roxann Diez Gross, Ph.D. and Gregory Cherpes, M.D. at The Children's Institute in Pittsburgh. The study is examining the phases of swallowing and assessing for evidence of risk factors associated with aspiration and choking. The six-month interim report has already revealed some striking preliminary findings that could change how we look at eating and drinking in persons with PWS. At this point 16 of the participants have already completed the research procedures. The goal is to have 30 participants with PWS. To learn more about this study or if you are willing to consider your person with PWS (ages 4 to 55) as a participant call Ronit Gisser, M.Sc. at 412-420-2249. There will be some compensation for your time and expenses. This study will have important and immediate implications for PWS care.

**MICHIGAN STATE UNIVERSITY** **Social Behavior** Marisa Fisher, Assistant Professor of Special Education at Michigan State University, is conducting a study about the social behaviors of adolescents and adults with and without intellectual/developmental disabilities. For this study, parents/guardians of a child who is 12 years and older are invited to complete a short online survey about their child's social behaviors. These questions will ask about the child's background, ways the child interacts with others, and whether the child displays any behaviors that might make him/her more vulnerable to social victimization. The survey should take about 20-45 minutes to complete.

Dr. Fisher is collecting this information in an effort to better understand whether certain social behaviors are related to increased social vulnerability. She will use this information to develop specific interventions to teach the individuals to protect themselves from victimization. She hopes that you will also find this information useful and will forward the results of the study to interested participants. To participate in the study go to: [https://msucoe.qualtrics.com/SE/?SID=SV\\_9XED9I2U9uwXZ2d](https://msucoe.qualtrics.com/SE/?SID=SV_9XED9I2U9uwXZ2d) For more information contact Dr. Fisher at [fishermh@msu.edu](mailto:fishermh@msu.edu) or 517-432-3926.

**Stanford University** **Individuals with Prader-Willi Syndrome Who Engage in Skin Picking Age 6-25 Years Needed for Stanford University Research Study** Does your child with Prader-Willi syndrome engage in skin picking? We are conducting a study to evaluate how environmental and/or neural factors influence the display of skin picking commonly exhibited by individuals with PWS. Our hope is that the results of this study will lead to an increased understanding of why skin picking occurs in PWS and thus inform more successful treatment approaches in the future. We are looking for individuals with PWS who engage in skin picking on a daily to hourly basis, producing tissue damage on a regular basis (e.g., sores, open wounds). Because the study involves an MRI scan of the brain, individuals who engage in skin picking on their head will not be able to be included. Participation involves: Travel to Stanford University (San Francisco Bay Area) for 3 days; behavioral assessment; cognitive testing; MRI scan. Benefits of participating: Potential improved understanding of the variables that influence your child's display of skin picking; honorarium of up to \$50 for participation. There will be no travel or lodging costs to families for participation. For more information or to enroll contact: Megan Klabunde, Ph.D., [mklabunde@stanford.edu](mailto:mklabunde@stanford.edu) (650) 723-7255.

**SAINT LOUIS UNIVERSITY** **The Effect of Growth Hormone Replacement Therapy on Physical and Behavioral Sexual Development in Persons with Prader-Willi Syndrome** Drs. Myers and Whitman of St. Louis University are performing a study to examine the impact of growth hormone replacement therapy (GHRT) on the sexual/gonadal maturation and functioning, and sexual behavior of males and females with Prader-Willi syndrome (PWS). This study is supported by FPWR. The subject population will include 20 adults (10 males and 10 females ages 18 years and over) and 20 youngsters (10 males and 10 females between the ages of 10-14 years) with Prader-Willi syndrome. Adults will be divided between 10 adults previously treated with growth hormone replacement therapy (GHRT) and 10 naive to GHRT. Youngsters will be drawn from those currently receiving GHRT. GH is provided free of charge by Pfizer. A small stipend towards travel may be available for some families. For more information contact Dr. Barbara Whitman, Saint Louis University School of Medicine (314) 268-4027.



Orange County in Orange, CA.

**CONTACT:** Virginia Kimonis, M.D. at 714-456-5791 or email at [vkimonis@uci.edu](mailto:vkimonis@uci.edu) or Marie Wencel, research coordinator at 949-824-0521 or email at [mwencel@uci.edu](mailto:mwencel@uci.edu).

**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 Medical Center and Children's Hospital,

# Prader-Willi Syndrome and Supplemental Security Income

by Molly Clarke, Social Security Disability Help Blog

Raising a child with a health condition or disability can cause significant financial distress. If your child has been diagnosed with Prader-Willi Syndrome (PWS), you may be eligible to receive Supplemental Security Income (SSI) on his or her behalf. SSI can help cover the cost of day-to-day expenses as well as the additional costs required to maintain your child's health and well-being.

The following article will provide you with a general overview of the SSI program and will prepare you to submit an SSI application on behalf of your child.

## What is Supplemental Security Income?

SSI is a needs-based benefit program governed and distributed by the Social Security Administration (SSA). To qualify for SSI benefits, a child must have a qualifying disability and must fall within the financial restrictions set by the SSA. Because children are not typically responsible for their own finances, the SSA will evaluate the income and resources of the applicant's parents to see if he or she qualifies.

The process of allocating a parent's income and resources to the record of a child is called deeming. Learn more about deeming here: <http://www.disability-benefits-help.org/blog/parental-deeming-process>.

Learn more about SSI eligibility, here: <http://www.socialsecurity.gov/ssi/text-eligibility-ussi.htm>.

## SSI Medical Eligibility

To qualify for SSI benefits, a child must be disabled. According to the SSA, a child is disabled if he or she has a physical or mental condition that causes significant limitations in his or her daily life. In addition to this broad definition of disability, your child will also have to meet medical criteria specific to his or her particular symptoms. The SSA uses a publication called the Blue Book to define, evaluate, and classify all qualifying disabilities. A child must meet the criteria listed under his or her particular condition in order to qualify for SSI benefits. Although no listing currently exists for PWS, a child with this condition could potentially qualify under a listing associated with his or her specific symptoms. For example, a child with PWS who also has diabetes and significant intellectual disabilities may be able to qualify for SSI under one or both of the listings associated with these conditions.

Related listings may include:

|                                                 |                                        |
|-------------------------------------------------|----------------------------------------|
| Listing 100.00—Growth Impairment                | Listing 112.02—Organic Mental Disorder |
| Listing 101.04—Disorders of the Spine           | Listing 112.05—Intellectual Disability |
| Listing 102.00—Special Senses and Speech        | Listing 112.08—Personality Disorders   |
| Listing 110.08—Catastrophic Congenital Disorder |                                        |

Be sure to review each of these listings to determine whether or not your child's symptoms qualify him or her for SSI benefits. If you do not understand the medical or technical language used in the Blue Book, schedule an appointment with your child's doctor. A medical professional will be able to explain the different medical requirements and conduct the tests necessary to prove your child's eligibility.

## Preparing and Submitting Your Child's Application

Before beginning the application process, parents should first contact the SSA to determine if the family's income qualifies the child for benefits. If the child meets the income requirements, the parent can then begin to prepare for the application process.

In preparation for the application process, the parent should gather records from medical professionals such as doctors, psychiatrists, speech therapists, and school personnel (teachers, instructors, etc.) detailing the child's condition and limitations. Necessary records may include—but are not limited to—documentation of your child's diagnosis, treatments, medications, Individual Education Plans (IEP's) or Individual Family Service Plans (IFSP's). For a complete list of items needed to apply for SSI, visit the following page: <http://www.ssa.gov/disability/Documents/Checklist%20-%20Child.pdf>

Once you are ready to begin the application process, you should call the SSA to schedule an interview appointment. At the interview, you will be able to ask questions about your child's claim and fill out the necessary forms.

Be sure to provide detailed information about your child's daily experience with PWS. Also include information regarding any other conditions that your child has been diagnosed with. The SSA will evaluate the combined effects of all conditions that your child has. Any missing or incomplete information could cause your child's claim to be delayed or even denied.

## Awaiting a Decision

Typically, it takes around 3-5 months to receive a decision regarding an initial SSI application. Unfortunately, more than half of all initial disability applications are denied. If this happens to your child's claim, do not be discouraged. You have the right to appeal the SSA's decision within 60 days of receiving your notice of denial. It is important that you don't give up. Many more applicants are approved during the appeals proceedings than during the initial application submission.

Although the task of applying for SSI may seem overwhelming, these benefits are often a necessary form of support for many families. Once your child is awarded benefits, you will be able to focus on his or her well-being rather than your finances.

## PWCF High Five's Board Member Roger Goatcher and Son Jacob

by James Burns, Managing Editor, Manteca Bulletin



There is a special bond that exists between father and youngest son in the Goatcher household, and it almost always reaches a crescendo about this time of the year.

Basketball season.

Whether in the stands or in front of the television, Roger and Jacob are on equal footing when watching their beloved Sacramento Kings.

None of their differences – as pronounced as they may be – seem to exist. Not Roger's age. Nor Jacob's disability.

"I love basketball," Roger said, "and my son loves basketball."

Roger is the Director of Special Education for the Manteca Unified School District, a role that has undoubtedly prepared him for the struggles Jacob has and will encounter in life. The 12-year-old suffers from Prader-Willi syndrome, a rare congenital disease rooted in obesity and developmental delays. Roger says Jacob is always hungry as a result of Prader-Willi, but

his metabolism is only half that of a normal person.

With an insatiable appetite – it is not uncommon for someone with Prader-Willi to rummage food from the garbage – Jacob runs the risk of becoming obese and accruing a host of other issues related to rapid weight gain. But all of that fades away when the Kings' young but mercurial talent DeMarcus Cousins positions himself on the low block, or journeyman scorer Rudy Gay hoists up a 3-pointer.

The Goatcher boys are fans with a common rooting interest ... as woeful as the Kings might be. "They're our favorite team," Roger said without a hint of buyer's remorse. "Bobby Jackson was our favorite player. I got (Jacob) a stuffed Bobby Jackson doll once. He's always wearing a Kings jersey or Kings hat. He's definitely a Kings fan."

"Jacob is drawn to any team his dad likes," said Tracy Goatcher, Jacob's mother. "But he loves talking about the Kings players and different things. If the game is on, he gets excited."

Jacob has added a new piece to his basketball wardrobe, introducing a Kings jersey courtesy of the Manteca Parks and Recreation Department. On Saturday, Parks and Rec, along with a handful of volunteers with the school district, celebrated the conclusion of the first-ever Challenger Basketball League, a seven-week campaign for the area's severely handicapped children and young adults.

"It was like a breath of fresh air," Parks and Recreation Supervisor Toni Lundgren said.

The 23 players were split into two teams, and as they did all season, the Kings and Warriors locked horns in a game that featured balanced scoring attacks on both sides. In the Challenger league, everyone gets to dribble the ball up the floor. Everyone gets to shoot. Everyone gets a chance to pass. How loose and free is the play on Saturdays? "Sometimes we put five to a side," Roger said, "sometimes we put six." No score is kept. Instead, everyone is crowned a champion, from the players to the adult volunteers and coaches to the fans who filled the stands inside the elementary school gymnasium.

"You could tell from the first practice to the end of the season, they learned a ton," said Roger, who served as one of the Kings coaches. "Kids that couldn't dribble, but by the end they were dribbling and participating. "One of the reasons we did the Challenger League wasn't just about the sport but being around other kids. It brought them together in a team spirit. They were high-fiving each other and having a good time. It was like a perfect season. They didn't lose a single game. They basically had all wins."

Roger says he won't soon forget the look of sheer elation that followed [as each player scored a goal]. "Their eyes would light up and they'd just be ecstatic. 'Look at me, I did this.' It wasn't just baskets. They enjoyed dribbling, jump-stopping and spinning. They loved the activity," said Roger, whose oldest son, Chance, also shares an affinity for the game. "It was a lot of fun."

Roger and Lundgren collaborated on the Challenger Basketball League, ironing out the logistics of hosting a new seven-week season amid the city's other established leagues, orchestrating registration, gym times, uniforms and coaches. The real spark, though, was Jacob. After playing on teams and in leagues in Stockton and Modesto, the last of which simply went away, Jacob was suddenly without playing options. "One of the things I'd seen, because I have a child with special needs, we didn't have a basketball league for kids with special needs," Roger said.

Now, for the foreseeable future, it does. Lundgren said the league could grow to include other sports, such as soccer, baseball and softball. "Basketball is just one of many sports, but my son loves basketball," Roger said. "So it was a natural to bring in basketball."

*[There are Challenger Leagues for all types of sport activities including baseball, basketball, football, soccer, and even cheerleading. Check with your city's local Parks and Rec department or search online for Challenger Leagues near you.]*

# Board Corner

## Summary of Board of Directors Meeting

PWCF Offices (Redondo Beach)

January 25, 2014

Submitted by Jacki Lindstrom

Board Members present: Julie Casey, Roger Goatcher, Diane Kavrell, Jacki Lindstrom, Tom McRae, Nisha Mehta, KimMorgan, Daniela Rubin, Ph.D., Renee Tarica, Julie Tauscher. Board members absent: June-Anne Gold, M.D., Whitney Bras. Others present: Katherine Crawford, Lisa Graziano, Fran Moss.

The following reports were prepared and distributed prior to the meeting: Executive Committee Report, Executive Director's Report, Public Awareness Committee Report and Social Media Report, Program Committee Report, Support & Advocacy Report and the 2014 Calendar of Board Meetings.

The Board voted to keep the current Executive Officers in their positions. President: Julie Casey; VP: Kim Morgan; Treasurer: Renee Tarica; Secretary: Nisha Mehta. The Board welcomed and introduced incoming Board members Daniela Rubin and Diane Kavrell.

The Board expressed their heartfelt respects to June-Anne's mother who recently passed away.

At the Board Orientation for the first meeting of the year, members introduced themselves and gave a background on why they joined the Board. The Board consists of 11 members. Lisa Graziano, Executive Director, conducted the Board Orientation, which consisted of a review of the Vision and Mission statements, and an overview of Board Member Basics and Administration.

*Our Vision: A Full Life Without Limits*

*Our Mission: Individuals with PWS should have the opportunity to pursue their hopes and dreams to the full extent of their talents and capabilities. The success of people with PWS depends greatly upon the knowledge and support of the community around them. PWCF provides individuals with PWS, their families, and professionals with a state network of information, advocacy, and support services.*

Discussion Items:

Residential Services Update: It was suggested that we revisit the role and resources dedicated to the Residential Services Committee. It was agreed that the committee continue to focus on annual group home site visits. The Board will work to identify committee members who live close to some of the group homes to help with the visits. Two group homes (near Chico) are being sold.

2014 Member Give Back Suggestions: A suggestion was made to create "Tip Cards" for Restaurant dining to make eating out a smoother process for families. The Board decided this year's Give Back will be a *Restaurant Kit*, which will include cards that can be given to the wait staff, fast food calorie comparisons, and tips for successful eating out strategies.

Committees Development: Committee charges have recently been updated. The goal for 2014 is to increase participation and activity. A Board member shall serve to oversee a committee, form sub-committees and write a report for Consent Agenda.

Legislative Activity: Roger handed out several documents about recent legislations. The Board discussed how to send out the relevant information to members in a timely manner to members, without PWCF endorsements. The Board agreed that Roger would send out the alerts to members directly with the heading "this may be of concern" and offer a link to the action items.

Finance Committee Report: The Board recommends setting up a meeting with our financial advisors to review our investment accounts and strategy. The 2014 draft budget was distributed and discussed. Two items discussed were placing greater emphasis on Grant Development to support program costs, and the amount of monies currently held in PWCF's reserve account. The Board gave the Executive Committee approval to approve the budget with suggested amendments.

Group Home for Children: The Board continues to work with the SAILS group to develop a group home for children in Orange County.

Vocational Services Outreach update: Lisa continues to reach out to Regional Centers to bring PWS training to vocational work sites.

Feedback from the recent "Help Us Help You" solicitation was for more events and activities specific to adult with PWS, and more events held in Orange County and the Inland Empire.

Ideas were discussed on possibilities for future fundraisers. Some possible ideas are online silent auctions, Mahjong cards, and planned giving.

The Board decided to incorporate a new messaging theme and agreed that this year's theme shall be "Join the Parade."

New Business: The Board approved for a member to go the FRED Conference in March which will cover Residential Living topics.

The meeting was adjourned 4:14 pm.

## New & Improved Email for PWCF

Reach PWCF at our new email address [info@pwcf.org](mailto:info@pwcf.org)

Reach PWCF's Executive Director, Lisa Graziano, directly at [LisaG@pwcf.org](mailto:LisaG@pwcf.org)

Reach PWCF's Family Support Coordinator, Katherine Crawford, at [KatherineC@pwcf.org](mailto:KatherineC@pwcf.org)

Reach PWCF's President, Julie Casey, at [President@pwcf.org](mailto:President@pwcf.org)



## PWCF's 4<sup>th</sup> Annual PWS CAMP at Easter Seals Camp Harmon JUNE 19-24, 2014

Registration is now open for PWS Camp at Easter Seals Camp Harmon, *exclusively* serving campers with PWS. Campers LOVE PWCF's PWS Camp!

Camp Harmon is located in the beautiful Santa Cruz Mountains in Boulder Creek, California.

Prior years' programming has included campfire fun, daily swimming, arts & crafts, tie-dying, a hike, impromptu basketball and tetherball games, rap/share sessions, horseback riding, a dance and the *best* camp counselors!

Onsite male and female nurses administer all medications. Staff to camper

ratio is 3:1, with 1:1 available. The menu is healthy low cal/low carb, and delicious. Access to food is strictly secured.

PWCF Members in Good Standing eligible for Camp Scholarship to reduce the cost to \$500. Non-member price is \$726. Space is limited. Register only at [www.PWCF.org](http://www.PWCF.org). For more information contact PWCF at 310.372.5053.

## 2014 Calendar of PWCF Events and Activities

|                                              |                                                                                                                                                                                                                                        |
|----------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>LA Big 5K</b>                             | Saturday, March 8                                                                                                                                                                                                                      |
| <b>ASICS LA Marathon &amp; Charity Relay</b> | Sunday, March 9                                                                                                                                                                                                                        |
| <b>Walking for Prader-Willi Syndrome</b>     | Central CA - Saturday April 26 with Clovis Rodeo, Clovis<br>Southern CA - Sunday April 27 at Griffith Park, Los Angeles<br>Northern CA - Sunday May 4 <sup>th</sup> at Crissy Field, San Francisco<br>Virtual Walk - April through May |
| <b>Ironman Triathlon</b>                     | Oceanside - March 29<br>Kohala Coast, HI - May 31                                                                                                                                                                                      |
| <b>PWS Behavior Management Training</b>      | Thursday, May 29 - Regional Center of Orange County<br>Saturday, September 20 - Northern CA Support Group                                                                                                                              |
| <b>IEP S.O.S. Training</b>                   | Saturday, September 20 - Redondo Beach<br>Saturday, April 19 - Northern CA Support Group                                                                                                                                               |
| <b>PWS Camp</b>                              | June 19–June 24 - Easter Seals Camp Harmon, Boulder Creek                                                                                                                                                                              |
| <b>Annual Conference</b>                     | Saturday November 8 - Northern California                                                                                                                                                                                              |

*Life can only be understood backwards, but it must be lived forwards.*

*~ Soren Kierkegaard*

## PWS Lying, Stealing and Confabulation

One of the lesser known but often troubling symptoms of Prader-Willi syndrome is the potential for some individuals to lie, confabulate or make up stories for no apparent gain, and/or steal both food and non-food items.

PWS specialists **Janice L. Forster, M.D.** and **Linda M. Gourash, M.D.** of the **Pittsburgh Partnership** who are frequent presenters at PWCF's annual conferences, reported in their *Primer for Psychiatrists* (2005) that persons with PWS may lie in attempt to get out of trouble and lie to manipulate others, especially for food. PWS notwithstanding, almost *everyone* would rather not be "caught" in a lie and has probably lied at *some* time in their life to avoid detection or punishment. But because *most persons with PWS have a strong need to be right, they may continue to lie despite any and all evidence.* It is often simply not possible to persuade the individual with PWS to own up to their fib; to continue to engage in finding the truth will likely lead to a power struggle and result in some unwanted behavior.



Drs. Forster and Gourash report that some people with PWS are "creative fabricators, capable of confabulating allegations of abuse, claims of romantic entanglements, and calling 911 with false reports with astounding believability." Drs. Gourash and Forster note that some people possess "massive denial about personal limitations and responsibility for one's actions sometimes borders on the delusional." Stories and confabulations can range from harmless self-important bragging to much more serious confabulated stories of neglect or abuse or "fabricated circumstances in order to obtain admission to [a] hospital" where they may obtain food or unnecessary medical attention. Some people have "medication seeking behaviors that are not related to drug abuse" and "can also be very resistant to changes in medication regimen."

Some people with PWS may lie about feeling pain in order to avoid work or exercise. At the same time injuries can be missed because of abnormal pain awareness. This information is critical for care providers to know so that they look to outside sources to corroborate claims of injury or illness or confirm that no injury exists.

For many parents and care providers, lying and confabulating, especially for "no real reason" and the inability to take responsibility for one's actions can be particularly upsetting. While on the one hand attempts to address the fib, lie, or whopper of a story are often met with escalations of unwanted behaviors, parents and care providers often have great reluctance to simply "let the person with PWS get away with the lie or extreme exaggeration."

Understanding that lying and story-telling are often just another symptom of PWS can help reduce the negative emotional reaction they can provoke in parents and care providers. One suggested response to a blatant lie in which the purpose is to avoid punishment is for the parent or care provider to maintain a calm demeanor while stating it is understood that the individual does not want to be in trouble. It is *not* recommended to point out all of the "evidence" that proves the individual is lying; many people with PWS will try to "protect" themselves by continuing to lie, often irrationally, and become increasingly more upset with every new piece of evidence you present to them. If the lie is about food, it is suggested to simply state that you understand they ate the food. It can be helpful to express regret that the food was left out and made available for them to take, and reassure them that you will do a better job in the future to secure the food.

If the lie is more of a confabulation or story with no apparent gain except that of attention, one suggested response is to maintain a calm demeanor while you share how impressed you are with their wonderful and creative imagination or story-telling abilities. Again, it is not recommended to point out all of the evidence that disproves their story.

Confabulations or stories about abuse or neglect can be extremely challenging because teachers and other specified care providers are required by law to report these to their local police department or child protective services office.

People with PWS may steal both food and non-food items. Stealing non-food items can be related to the obsessive collecting or hoarding symptoms of PWS and the frequent lack of impulse control.

It is recommended that parents and care providers proactively inform your local police department that your child or adult has PWS and that one of the symptoms is lying, confabulating, and stealing. You may wish to provide this article to your local police department, your child's IEP team, Regional Center case coordinator, residential provider, day program provider, and/or employer. If you find yourself in the unfortunate circumstance of having to defend yourself against allegations of unfounded abuse, ask PWCF and/or the national PWSA (USA) for support and assistance.



### We Got Talent!

**Emma Fluhr-Resendes**, age 15, plays in The Magic Makers, a special needs band. Emma is a spirited young lady whose love for music began as a toddler. The Magic Makers held their Spring concert in February in Santa Clara where Emma performed beautifully. Congratulations, Emma! For more information about The Magic Makers visit [www.magicmakers.com](http://www.magicmakers.com).

**Cameron Graziano**, age 15, has played alto and tenor saxophone for the past five years. Now a member of the Wind Ensemble at his high school, Cameron proudly performed a solo piece at their last concert. To hear Cameron's performance go to <https://www.youtube.com/watch?v=t60BpqWpOwM>



*Let us know if you've got a someone who's got talent!*

## Donations to Support Team PWCF in the ASICS LA Marathon, Charity Relay, and LA

### Carol & Brian Bark and their donors

Jeff Mathews • mj, gil, daniel, mindy, lev – *good luck* • Rose Manning • The Bark Family – *You know that a marathon is 26.2 miles, not kilometers? Let's hope you both fare better than the original runner from Marathon to Athens!* • De Eskew and Richie Luther – *Good for you...it's a good cause.*

### April Bennett and her donors

April Bennett • Cynthia Glasser • Shelley Dunn  
Anonymous • Verla Bennett • Heather • Craig

### Julie Casey and her donors

Julie Casey – *Kick-starting the contributions. Please help me reach (or exceed) my goal.* • Team SuperMyka • The Hamlin family :) • Anonymous – *Team Ryan!!!* • Amy Perkins – *Go TEAM Ryan!! We love you so much! xoxo* • Siena Mehta • Evan Postal *Wish I knew sooner.. I would be running too.* • Angie Hudspeth – *May the winds be always at your back in your first 5K :) Much success in your fundraising efforts for PWCF! Go Julie!* • Anonymous • Lori Wade – *Hope you have fun running your first 5k. Next year it will be the marathon? :-)* • Ernie Mercer • Brian & MegAnn Edwards • Melinda Chen – *Go Team Ryan!* • Leo Woodrum – *Go team Ryan!* • Cancunpat – *You've shown us many times that if something seems difficult, you will be the one to accomplish it!* • A. Kennedy – *Good luck Julie!*

### Steve Castner and his donors

Steve Castner – *I'm In!!! Are you???* • Diobel Castner – *You can DO it!* • Diane Castner • Rosma Suansing – *Way to go, Steve!!!*

### Katherine Crawford and her donors

Michael Girdaukas – *Good Luck, Kath!* • Kelsey Roy – *I'm sure you'll be great, Katherine.* • Lillian Weigand • Brent Severson • Renata – *Go Kat!* • Cynthia Krause • Gil & Terry Girdaukas • Dean & Verna Weigand • Karen & Keith Eirich – *Have a great run Katherine!* • Martha & Gary Girdaukas • Sam & Tony – *Yay Katherine! We are so glad to support you in raising awareness through your run!* • Garth & Cindy Stevens – *Very happy to support you in this great event!* • Lisa, Travis, Claire, & Craig – *We are all very Proud of Katherine* • Roger & Alice Girdaukas – *We're with you all the way!* • Gandalf • Patrick O'Connell • Claire Crawford – *Good luck on the run! You'll do great!* • Anonymous • Ceres – *Run fast! In comfortable shoes!* • Katherine & Jackson Crawford

### Gail, Rodney, and Kiran Dong and their donors

Elvira & Gordon Dong – *Good luck! Go Kiran!* • Caroline



Bisarra • Teresa • Manel • Marivic • YuJeo • Katie May, Jasmine, Ella & Gracie • Lusine Akelyan • Zachary Ruiz – *Have fun!* • Sam F – *Good luck with that run in the hills!* • Liz Moreno • Sonia • Carrie • Joven • Lois • Alana • Marivic • Nerissa • Susan • Lisa Lee • Amy • Dr. Shapiro • Dr. Hananel • Juan & Carol • Dan & Grace – *Go Kiran!* • Juris Salas-Chow Misa & Issey • Anonymous • Nestor Caballero & Christine Bischo-Caballero – *Prayers for complete healing for Kiran. Blessings to Kiran and your family* • Rodney Dong

### Cameron & Lisa Graziano and their donors

Carolyn Meyer • Chris Irving • The Bohny Family – *Way to go Cameron and Lisa* • Lee Elliott – *Enjoy the run, have fun, and do well* • Anonymous • Siena Mehta • Jacoby Family – *Great job Cameron and Lisa! We're cheering you on in spirit. Sorry we aren't joining you!* • Paul and Jo Graziano • Aunt Margaret and Uncle Bill – *Cheering you on!!!* • Mary & Pat Williams – *Have fun!* • The Kaiser family •

Nancy & John Jenkins • Stephanie & Mark Boyd •

Anna Kanauka • Tod Holdorf

### Ashley Heath and her donors

Amber Roberson Harkin – *Go aunt ash - love you!* • Robertson – *For my little man* • Heath

### Diane & Brandon Kavrell and their donors

Diane Kavrell – *I believe in the cause! Please join me* •

The Mundy's – *Pretty awesome that you are doing this.*



*Remember... "no matter how slow you go, you are still lapping everybody on the couch".* • Bob Greene – *you guys are studs for doing this- good luck and make sure you have comfy shoes!!* • Phyllis Mase – *Good luck! I am so proud of you both* • David Mase – *Diane and Brandon, I am so proud of the both of you and love Haley so much.* • Maria Denaro – *To Di and all of Haley's supporters Feb 28th is "Rare Disease Day!" But I think of you all through the year. GOOD LUCK in the Marathon!* • Alyssa Mucci – *So impressed & proud of you both!* • *What a rewarding experience for a great cause. Love you.* • Jan & Lynn Roberts • Kevin & Gaelyn Kelly • Nancy & Bob Tate – *This is wonderful... We'll be thinking of both of you!* • Pat & Jud English – *Go get 'em* • David & Grace – *We are so proud of you both.* • JJ and Anthony Mase – *Go Aunt Di. We are rooting for you.* • Kathy DeYoung • The Barth Family – *We're behind you all the way!* • Kathy Chupka – *GO TEAM KAVRELL!* • Nonie Greene – *Pace yourself and good luck!* • Anonymous – *Good luck Ace* • Vitangcol Family – *We are with you all the way* • Anonymous • Perri & Dennis Mucci – *So Proud of both of you!!! Remember – "Pain is temporary, pride is forever."* • Carol & Greg Dobbs • Alan and Julie Mielus • The Soeth Family – *Good luck!* • AJ from Timothy Cline Insurance – *Thank you for including me! I had never heard of this disease and am grateful to know of it. Best of luck in the marathon!* • Noreen & Colin Carter – *While running, Brandon should play the 13 miles as one long golf hole* • John from Petra • Doris & Jim Luna • Arlene Caudle – *It is my pleasure.* • The Senders – *We'll be cheering you on for a great race and a cure.* • Meinert Family – *Nice work Kavrells!* • Savit Family – *We are running with you in our hearts and our souls will be with your soles!* • The Powell Family • Elisa & Chris Stone • Mary Kobane – *I am so, so, so proud that the two • of you, really all 5 of you have embarked on this • adventure! I admire your convictions and wish you well.* • Michelle & Kevin Donaldson – *Wow, impressive! Go Diane & Brandon! Thanks for running for all of us.* • Christina Michel-Albers – *Go get 'um!*

### Cyndie Kelly and her donors

John and Laurie Friend • Alan • Tony Kelly • Steve Salazar Go Cyndie! – *Have fun and remember what you learned in Bhip.* • Marianne & Don • Brian & Debbie • Anonymous – *Go Cyndie!* • Jill Welker – *Sending all of my love to you and your family!* • Wanda Kowalczyk – *All the best, Wanda* • Tom & Diane – *Good for you Cyndie!!! Such a great cause, we know how important this is to all of you!!!!* • Chris Welker – *You're the BEST aunt ever! Know that I will be cheering you on...from the sidelines.* • Pat & Jo Ann Wheatley – *Good luck on your run!*

### Kim Morgan and her donors

JBHS Staff – *Good Luck from Erin Berich, Jodi Levy, Renee Miller, Debbie McHorney, and Room 2104* • Jaime – *Go Kim go! Will be cheering you on from Doheny Drive!* • The Acedo Family – *Best of luck!* • Pat & Jo Ann Wheatley • Diane and Rob B. – *Way to go Kim!! Love and hugs.* • Eric Ziegler – *Good luck Kim!!!* • Niall Kelly • Monty Pal, MD – *Kim, best of luck!!!* • Michelle Hacking –

*Way to go Kim!* • Figlin family • Suzi Siemsen – *Good luck Kim!* • Deirdre Kelly & Howard Privette • Kim Morgan • Dave Bushnell – *Good luck Kim!* • Chris and Michelle Johnson – *All the best and may the wind be at your back!!!*

### Chris Patay and his donors

Chris Patay

### Estevan Policarpo and his donors

Summer Garcia – *I'm so honored to know someone who is REALLY changing the world. Don't stop surprising me.* • Gerry Davison – *Keep up the good work for such a wonderful cause!!!!* • Kelley Potter – *Enjoy Monday Off!!* • Carmelita Fabian – *Good Luck!* • Almanza family – *Good luck Steve* • GConde • Manuel Gutierrez – *Steve thank you man* • Jaime Conde • Maggie Gutierrez – *Thank you Steve* • Manuel F. • Juan P. • Molly Gutierrez – *I love you Juan and Steve!* • Anonymous • Estevan Policarpo



### Daniela Rubin & Ricky Garcia and their donors

Anonymous • Maria Lapetina • Cheryl Cooky – *Good luck with the run, Dani!* • Sandra Gabelli and Abelardo Silva • Kathleen – *Good luck on the race!* • Arsh – *Good luck guys!* • Adam Hyde – *Almost there, good luck!* • Nina, Simon and Joon • Jim H. Alstrum-Acevedo – *Good luck Daniela and Ricky!* • Adrian • Angelica & Clement – *Good luck with event and fundraising!* • Daniela Rubin  
**Kim & Doug Russell and their donors**  
Jessica Sanders • Yvonne – *Way to go! Kick butt on Saturday!* • Julie, Patrick, Susanna and Kate – *Way to go!* • Sandra Forsythe • Garth Terry • David R. Russell – *Go for it! Good luck and best wishes to you!* • Andrea & Ryan – *Have fun!* • Mike, Kaity, Alice, and August – *Go Doug and Kim!* • Galya Rees – *Good luck!!* • Anonymous – *Good luck guys!!!!* • JL • Andrew Russell – *Go Doug and Kim* • Anonymous • Roya Ijadi-Maghsoudi • Kirsten and Sam – *Good luck Doug and Kim!!!* • Anonymous • Kim Russell  
**Linda, Mark, and Trevor Ryan and their donors**  
The Ryan Family

### Shiela & CJ Umeda and their donors

Shiela and CJ Umeda – *Kick starting our fund raising efforts. Please help us meet (or exceed) our goal... thanks!* • Que Huu Do & Phuong N. Nguyen • George and R. Joan Summers • Glenn and Christine Yabuno • Sandy and Ryan Zane – *Way to go Shiela and CJ!* • Anonymous – *Good Luck today and thank you for your support to bring awareness to Prader-Willi Syndrome.* • Anonymous – *I am excited for you both being a part of this great charity and running. Have a wonderful day. Love you both :)* • Melonee Vartanian – *Good job Shiela and CJ!!!* • Alix Vincent



## We Get Mail

Dear PWCF: I wanted to thank you again for our time together today. I've been sharing the information you shared with me all day and I having a feeling of HOPE! *Sincerely, Rachel Velazquez, mother of Marisela, age 14*

Dear PWCF: Enclosed please find a small check from Michelle and me for PWCF. All of us - Sean, Michelle, Sean's siblings, and I - so appreciate all that you've done to enrich Sean's life. You know, I think, that he continues to do well in his apartment, in large part thanks to the training that you provided to his support staff. All the best for a great 2014. As ever, *Mike Raleigh, father of Sean, age 33*

Dear PWCF: Thank you so very much. There are no words for what you and the PWS [associations] have already given us and for what I'm sure will be a lifetime of support for our family. *Natalie Inouye, mother of Sloane, age 1 month*

Dear PWCF: I wanted to thank you for sending me the little booklet medical alerts on Prader-Willi syndrome. My son has Prader-Willi syndrome. I carry it with me always. I [wanted] to know if there is any way you could send me a few more for my son's school and other family members? Thank you, *Lois Ayala, mother of Shawn, age 20*

Dear PWCF: It [was] a really good [school] training. Everyone thinks it is helpful. I am glad to find you to help me. Thanks a lot. I want to update you how Natalie is doing at school. The teacher called me the past two days that Natalie is doing great at school. [The teacher] was able to use some of your techniques to prompt Natalie. And she feels Natalie is starting to talk to her. I think it is very good. I really appreciate your help. *Polly Tsai, mother of Natalie, age 12*

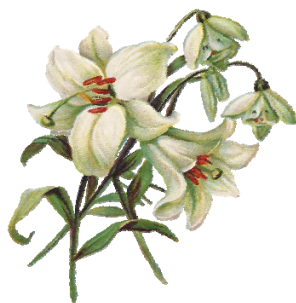
Dear PWCF: Thank you for running the inservice for us on Thursday! The feedback was very positive, and the information as well as your suggestions will be helpful for the team at [our school]. *Linda Spencer, Program Specialist*



## We Remember

### Curt James Martens

May 23, 1971 – December 29, 2013



*Two smiling eyes are sleeping, two busy hands are still.*

*The one we loved so deeply is resting at God's will.*

*May he always walk in sunshine, God's love around his glow.*

*For all the happiness he gave us, only a few will ever know.*

*It broke our hearts to lose him but he did not go alone.*

*For part of us went with him the day God called him home.*



**Carl Martens**, long-time PWCF member and past member of the Board of Directors, bid farewell to his son, Curt, at a lovely ceremony attended by family and friends.

### Debbie "Mamma Deb" Granger

April 15, 1959 - January 29, 2014



With great sorrow in our hearts we mourn the passing of Debbie Jean Granger, known at PWS Camp as "Mamma Deb." Debbie was a beautiful soul who was loved by all who had the pleasure of knowing her, especially our campers.

For the past three years Deb created for our campers healthy, low calorie and yet mouth-watering meal plans. She magically prepared tasty mashed potatoes out of cauliflower, baked the best French fries this side of the Eiffel Tower, tossed a deliciouso taco salad, and whipped up the most amazing desserts.

But it wasn't just her meals that were beloved by our campers, it was Deb herself. Deb shared a special bond with many of our campers, treating them to focused attention and genuine, compassionate caring. She will be greatly missed.

Campers may send a note or color a picture for Mamma Deb to the PWCF Office and we will forward it to her family. To write in Mamma Deb's online Guest Book go to: <http://www.legacy.com/obituaries/santacruzsentinel/obituary.aspx?n=debbie-granger&pid=169666386#sthash.cB2t2kDj.dpuf>



## Join the Parade with PWCF!

### Renew Your Membership

**Membership Renewal Forms** are on their way to your mailbox.

If you owe dues, you

can pay by check or credit card. If you don't owe dues, please return your form so we keep our Database current.

Membership dues are not tax deductible, but donations are deductible to the extent permitted by law. Your support through membership dues and donations keeps PWCF strong so that we can provide vitally needed supports and services to families and professionals who serve persons with PWS. **Renew your PWCF membership today!**



### Member Benefits Survey

**Help Us Help You!** PWCF is gathering information that will help us plan events and services that meet the needs of our membership.

If you have already completed the survey, we thank you!

If not yet completed the online survey, we invite you to please take a brief fifteen minute survey at <https://www.surveymonkey.com/s/2014PWCFMemberSurvey>

*Thank you for helping us help you!*



## State of California Department of Developmental Services

### Governor Appoints New Director

In January Governor Brown appointed **Santi J. Rogers** of Aptos as the new director of the California Department of Developmental Services. Rogers has been director at the San Andreas Regional Center since 1995. He was director of the Agnews Developmental Center from 1992 to 1993 and of the Porterville Developmental Center from 1987 to 1994. Rogers was deputy director at the California Department of Developmental Services from 1983 to 1987 and director of Stockton State Hospital from 1976 to 1983.

PWCF encourages families to send a brief, personal letter to Mr. Rogers to welcome him to his new position, introduce your child or adult, inform him about how PWS impacts his or her life, and let him know how much your family depends upon and appreciates the supports and services provided by the DDS and the Regional Center system. Mail your letter to **Mr. Santi Rogers, Director, DDS, P. O. Box 944202, Sacramento, CA 94244-2020.**

### MEMBER ACTIVITY January-March, 2014

*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 Individual Members

Polly Tsai

#### New Family Members

Bonnie J. Williams, Precious Little Ones

#### New Extended Family Members

PeriAnders

Ashley Roberson

#### New Professional Members

Neil Cowen, Essentialis, Inc.

#### Renewed Extended Family Members

Linda & Stephen Hedstrom

#### Renewed Professional Members

Lynne M. Bird, M.D.

Griffin Family Care Homes

Rasco Luz, Talia Vi Homes

Joe Tontodonato, ARC of San Diego

Daniela Rubin, Ph.D.

### Memorial Donations

#### Donations in Memory of Curt Martens

Beverly & Bud Bush

With love from John Roehl, Terry & Kathy Roehl,

Janice & Ken Horton

Marilyn McCorkle

Fran Moss

Linda & Mark Ryan

#### Donations in Memory of Paul Greskovics

J. & T.M. Igloi

#### Donations in Memory of Ed DeNatale

Katherine Randall

**PWCF News** is the newsletter of the Prader-Willi California Foundation (PWCF) and is sent to all 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 or 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 or 800-400-9994 (toll-free in CA) or email us at [info@pwcf.org](mailto:info@pwcf.org).

**Deadlines for submission: February 5 - Jan-March edition; May 5 - Apr-June edition; August 5 - July-Sept edition; November 5 - Oct-Dec edition**

**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 [info@pwcf.org](mailto:info@pwcf.org)

### **DONATIONS ~ January - March, 2014**

#### **SHINING STAR DONATIONS**

##### **Sirius (\$1,000 or more)**

Nancy & John Jenkins in honor of Cameron Graziano  
Jacqueline Smalley in honor of Emma Resendes  
Monique & Peter Thorrington in honor of Ryan Patay

##### **Canopus (\$500 - \$999)**

Mary & Holger Bracht in honor of Kean Bracht  
Barbara & David Gow in memory of Carolyn Gow  
Dennis Martino in honor of Lilli Moore  
Susan & Mark Ojeda in honor of Eric Ojeda  
Suzanne Privette in honor of Samantha Morgan  
Celeste & Tom Von der Ahe in honor of Steve Diebold  
and in memory of Helen Diebold

##### **Alpha Centauri (\$250 - \$499)**

Candelaria Garcia in honor of Ignacio Martinez  
Jacki & Jeffrey Lindstrom in honor of Julia Lindstrom  
Mr. & Mrs. Robert Morgan in honor of Samantha Morgan  
Lynn & Chuck Morrow in honor of Cameron Graziano

##### **Arcturus (\$100 - \$249)**

Catherine & Rudy Alvarez in memory of Daniel Alvarez  
Lisa Ann Bonk in honor of Nolan Carl Bonk  
Michele Boucher & Scott Rosenthal in honor of Trevor Ryan  
Terri Canales in honor of Tayler Canales  
Molly Carter in honor of Dan Carter  
Julie & Dan Casey in honor of Ryan Casey  
Sally & Chet Collom in honor of Jennifer Collom  
Gayle & Jan Conroy  
Lee, Leslie, & Jaime Elliott in honor of Cameron Graziano  
Wanda & Steve Faivre  
Tony Franco "with loving thoughts of Landon Shea"  
Lisa & TJ Graziano in honor of Cameron Graziano and in  
memory of Yvette Tarica  
Elizabeth & Andrew Greskovics in honor of GiGi and all  
with PWS  
Patricia Grey in honor of Chase Grey  
Jo & Floyd Hatcher in honor of Tristan Hatcher  
Trudy & Randy Hermans in honor of Melisa Hermans  
Patricia & Richard Hill in honor of Oscar Hill  
Karen & Tim Jobe  
Anna Kanauka in honor of Cameron Graziano  
Rita & Jim Koerber in honor of Alison M. Koerber  
Walter Krampf, M.D. in honor of the Donaldson family  
Phillip Lee, M.D.  
Elias & Miriam Liberman in memory of Yvette Tarica  
Raymond Marchant, III  
Phyllis Mase in honor of Haley Kavrell  
Marie-Claire Leon in honor of Ryan Casey  
Linda McGee  
Fran Moss in honor of Melissa Moss  
Ralph Paige in honor of Nicholas Paige  
Nelly & Jalal Rabadi  
Rose Sakurai  
Pam Sharkey in honor of Aspen Felt  
Peter Stoughton  
Plonneke & Martin Thoolen  
Tracy Tran & Dave Nguyen in honor of Christie Nguyen

Pat & Ron Vogrin in honor of Joseph Gunn, Robert T. Golitz, William  
Thomson "Thanks for being in our Wedding Party on 9/21/2013"  
Betty & Evans Warne in honor of Nancy Warne  
Sharon & Richard Willis in honor of Ryan Casey  
William D & Joyce Graziano Family Trust in honor of Cameron Graziano  
Patty & Tony Wong-Dion in honor of Landon Shea

##### **Vega (\$1 - \$99)**

Kyra Allen in honor of Faith Allen  
Judy & Dan Alsnauer  
Arstein-Kerslake Family  
Ira Bloom  
Bev & Bud Bush in honor of Jeff Bush  
Judy & Bill Castle in honor of Jason Castle  
Katherine Crawford in honor of Michael Girdaukas  
Carina Chaij in memory of Andres Chaij  
Joel Goldberg in honor of Ryan Patay  
Eric Elliott in honor of TJ, Lisa & Cameron Graziano  
Barb & Larry Gunter in honor of Brandi Sherman  
Brian Hughes in honor of Ryan Casey  
Jay F. Kavanagh in honor of Bradley F. Kavanagh  
Jamilet Knox  
George Marich in honor of Brooke Ella Marich  
Diana Menzer in memory of Calman Menzer  
Carolyn Meyer in honor of Cameron Graziano  
Ana Laura Ozawa Rico in honor of Harumi Laura Sanchez-Ozawa  
Michelle & Mike Raleigh in honor of Sean Raleigh  
Dana Rotticci in honor of Julia Lindstrom  
Judy Schlafer in honor of Timothy A. Schlafer  
Ann Sharpan in honor of Teresa Ann Sharpan  
Margaret & Bill Spinelli in honor of Cameron Graziano  
Gabriel Valenzuela in honor of Miss Cropper  
Linda Williams in honor of Duncan McRae  
Mary Williams in memory of William Graziano

##### **Magnanimous General Donations**

The Nararo Foundation  
Matched from Paul Wissmann donation by KPMG

##### **General Donations**

Anonymous donor in honor of Nolan Bonk  
Julie & Dan Casey in honor of Ryan Casey and in honor of Richard Willis'  
October 28<sup>th</sup> Birthday; in honor of Craig  
Michael DeNatale via Comcast  
Jann's November 16<sup>th</sup> Birthday; in honor of April Bennett's November 27<sup>th</sup>  
Birthday; and in honor of June Reifeiss' December 9<sup>th</sup> Birthday  
Ann Farry in honor of Julia Lindstrom  
Marie Claire Leon via Razoo Foundation in honor of Ryan Casey  
Patti & Tom McRae in honor of Duncan McRae  
Michael Moore via Comcast  
Masani & Hanif Nassor-Covington  
Arthur & Sylvia Perez  
Grady Robbins via Enterprise Rent-A-Car via United Way  
Sharon Seidenstein in honor of Emma Fluhr-Resendes

##### **Donations to Support PWS Camp**

Suzanne Privette in honor of Samantha Morgan

**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).

# Use PWS Thank You Cards and Raise Awareness of Prader-Willi Syndrome

Each of these cards features beautiful artwork created by a child with PWS. Colorful and expressive, there is a card for every occasion from "Happy Birthday" to "Thank You." Each set contains 8 cards. Interior left blank for your message. Back includes artist and PWS info.

Mail 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 over the phone

**\$10 per set // Two sets for \$18 Add \$3 shipping & handling**

Yes! Please send me \_\_\_\_\_ sets of the \_\_\_\_\_ Series.

Name: \_\_\_\_\_

Shipping Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

Phone \_\_\_\_\_

I've enclosed my check made for \$ \_\_\_\_\_  
Made payable to Prader-Willi California Foundation

Please charge \$ \_\_\_\_\_ to my  Visa  MC  AMX

Card No.: \_\_\_\_\_

Exp. Date: \_\_\_\_\_ Security Code: \_\_\_\_\_

Name on Card: \_\_\_\_\_

Email: \_\_\_\_\_

Billing Address (if different from above): \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

## Cameron Series



## Kai Series

## Duncan Series

## Madison Series

