

April - June 2016  
Volume 28, Number 2

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## SOUTHERN CA WALK INSPIRES

In a show of dedicated unity, a blue sea of over five hundred and twenty-five walkers surged through the Griffith Park WALK site to raise awareness of PWS. It truly was an awe-inspiring sight to behold; the support of family and friends coming together on April 24, the 16th anniversary of the *Waking for Prader-Willi Syndrome* events.

After sixteen years, the WALKs now represent much more than a “simple” fundraising vehicle – although this year Southern California supporters raised over \$30,000 to fund essential programs and services. The WALKS have grown into really fun events, and are now experienced as a reunion of sorts as people with PWS look forward to seeing their friends year after year. Our amazing DJ Extraordinaire, **Jimmy Rudon**, worked his energizing music to keep everyone – and especially our people with PWS – moving and dancing all day long. And boy, did we have some amazingly talented dancers at this year’s WALK! In addition to our Bounce House, relay games, table-top carnival games, and arts & crafts tables, this year’s WALK featured two face painters to help keep up with the high demand!

Deserving of special recognition and thanks, PWCF gratefully acknowledges the work and support of the following individuals and companies:

- The Southern CA WALK Planning Committee Members: **Julie Casey, Lisa Graziano, Petra Martinez-Ali, Renee Tarica, and Jennifer Wolkensdorfer**
- **Katherine Crawford** for designing this year’s T-shirt
- **Renee and Henry Tarica** for all of Renee’s planning work, printing of Footprint Signs, registration work
- **TJ and Cameron Graziano** for loading and unloading the van
- **Emily Dame** and **Gloria Burns** for their planning work, organization, and unloading the van
- **Kathleen O’Connell** for her help with water procurement and **Rick Swartwout and Pfizer Endocrine Care** for their generous donation of waters
- **Angela and Robert Lucero** for their help with the fruit and **Albertson’s** grocery stores for their generous donation of fruit
- **Lianne Noddle** and **Jeanine Milner** for help with registration
- **Jimmy Rudon** for sharing his DJ talents year after year
- **Balloon Factory** for donating the balloons for the Balloon Archway
- **Pamela**, owner of **Tarzana Subway**, for discounting our 550 sandwiches
- Our 50+ wonderful **Nursing Student Volunteers** from **Mount Saint Mary’s College of Nursing** and **West Coast College of Nursing**

PWCF extends our deepest gratitude to the top fundraisers who, along with each and every individual donor, raised over \$30,000 to support critical programs and services such as residential staff training, school training, advocacy services, two PWS Camps, three PWS Multidisciplinary Clinics, and so much more.

- **Trevor’s Treaders** honoring **Trevor Ryan**
- **Team Rosemarie Gujral** in memory of **Christopher Clarke**
- **Team Walking for Ryan** honoring **Ryan Casey**
- **Julianna’s Walking Warriors** honoring **Julianna Rodriguez**

Check out the photos of the Southern California WALK on page 12. Northern California’s WALK event is June 26. Watch next month’s newsletter for their update. And remember, it’s NEVER too late to support the WALK events. Donations to honor someone special are gratefully accepted all year long!

**Annual State Conference  
November 5, 2016**

DoubleTree Hilton Sacramento

**Prader-Willi Syndrome:  
Past, Present & Future**

*Featuring*

**Suzanne Cassidy, M.D.  
Jennifer Miller, M.D.  
Harold van Bosse, M.D.**

*Registration Flyer Enclosed*

**2016 Officers**

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**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, and their families and professionals with a state network of information, advocacy and support services.

**PWS SUPPORT GROUPS AND CONTACTS**

***Northern California***

SF Bay Area (young child)	Patti McRae	408-920-8003	<a href="mailto:pattimcrae@sbcglobal.net">pattimcrae@sbcglobal.net</a>
SF Bay Area (teen to adult)	Michelle Donaldson	415-290-6282	<a href="mailto:md@michelledonaldson.com">md@michelledonaldson.com</a>
Sacramento	Diane Kavrell	530-753-5928	<a href="mailto:diane.kavrell@gmail.com">diane.kavrell@gmail.com</a>

***Central California***

(Teens & Adults with PWS)	Paula Watney	559-299-8171	<a href="mailto:paulawatney@pwcf.org">paulawatney@pwcf.org</a>
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***Southern California***

Los Angeles County	Lisa Graziano	310-372-5053	<a href="mailto:LisaG@pwcf.org">LisaG@pwcf.org</a>
	Julie Casey	818-843-7321	<a href="mailto:julie.casey@att.net">julie.casey@att.net</a>
Orange County	Jenn Paige Casteel	949-735-0472	<a href="mailto:marchroses@hotmail.com">marchroses@hotmail.com</a>

***Inland Region Area***

San Bernardino County	Ester Del Real	909-213-5992	<a href="mailto:esterdelreal@ymail.com">esterdelreal@ymail.com</a>
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***Spanish Speaking***

Mercedes Gutierrez (Adults with PWS)	619-822-5742	<a href="mailto:mercedes.hernandez711@yahoo.com">mercedes.hernandez711@yahoo.com</a>
Kilma Bournigal (Infants/Children with PWS)	760-679-2300	<a href="mailto:kilmab@hotmail.com">kilmab@hotmail.com</a>
Veronica Garcia (Infants and Children with PWS)	760-357-8189	<a href="mailto:vbaez92@yahoo.com">vbaez92@yahoo.com</a>

***Online 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](http://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](http://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) Facebook Support Groups**

for Families of Children Ages Birth-3 Years  
for Families of Children Ages 3-5 Years  
for Families of Children Ages 6-12 Years  
for Families of Teens  
for Families of Adults

**International PWS Organization, IPWSO** offers information about PWS in other languages. Go to [www.ipwso.org](http://www.ipwso.org)

**PWS SHARE & SUPPORT GROUPS MEETING CALENDAR 2016**

***Southern California***

Beach Cities Health District  
514 N. Prospect Avenue, Redondo Beach CA  
0-5 Years: Redondo Room (Lower Level/Basement)  
6+ Years: Beach Cities Room (Lower Level/Basement)

**Sundays: Feb. 21, May 1 – Music Therapy**  
**Sept. 11, 2016**  
**Time: 2:00 p.m. – 4:30 p.m.**

*Childcare available ONLY for children under age 12 AND with RSVP. RSVP to PWCF at 310-372-5053*

***Northern California***

Support for Families of Children with Disabilities  
1663 Mission Street, 7th Floor  
San Francisco

**Saturdays: Jan. 23, April 30, Sept. 24**  
**Time: Check-in 10:15 a.m.**  
**Meeting: 10:30 a.m. - 1:30 p.m.**

*Childcare Available with RSVP. RSVP to SFCD 415-920-5040 x 135*

## PARENT TO PARENT

*Dear PWS Parents: “My older child has a very difficult time wiping her bottom after having a bowel movement. Seems like no matter how much we teach her, her bottom is never wiped thoroughly enough. This is especially difficult while she’s at school; either the school staff don’t want to help her wipe her bottom (and I don’t necessarily blame them for not wanting to help with this task!) or my child tries to hold it during the school day to avoid the situation entirely. Do other parents and providers have this same trouble and if so, how do you manage it?”*

Being a Special Ed teacher and a parent, my experience is this is a common problem with some [children and adults with] PWS. In an IEP meeting one of the participants suggested a “wand” that you can wrap toilet paper around and enables the student to reach in order to wipe. I believe it was ordered thru Amazon but a medical supply company should also carry them. It can be carried discreetly in a backpack and may even fold down. *Renee Lovern, parent of a 24 year old*

[Editor’s note: Self-wiping aide tools available include Freedomwand® Toilet Tissue Aid or Blue Bidet BB-20 Portable Bidet, both products available at [www.smile.amazon.com](http://www.smile.amazon.com) where you can choose to benefit PWCF]

Yes we have this issue. Our 14 yr old has difficulties with this. One thing we did that helped is we bought a toilet seat that is also a bidet. That helps clean things up – at home anyway. Our daughter once asked what I think is a question for the ages – “Why didn’t God give us longer arms?”

*George Anderson, parent of a 14 year old*

We have been dealing with this issue also for many years. I have taken three steps that have solved the problem so far.

- 1) At home we have installed a \$25 bidet that was purchased on Amazon. It’s working great!
- 2) I send disposable wipes with him to his programs.
- 3) He takes 1 tbs. Miralax daily which helps in texture and ease of movement.

Hope this helps!!!!

*Petra Martinez-Ali, parent of a 22 year old*

My son has the same issue. He tries to clean himself but rubs his skin too much and the area gets all red. I don’t know if it is due to weak motor skills. He knows how to do it but cannot clean properly. Sometimes he comes home with dirty underwear.

*Randeep Mehroke, parent of a 13 year old*

Get some rubber gloves and if that doesn’t work see if you can get respite from Regional Center to get a nurse to go to school with your child and help. My son is a digger and I can’t stop that. Good luck.

*Bobbie Annis, parent of a 27 year old*

Use baby wipes. We just kept them around and put in trash. Hope that helps.

*Laureen Adeniran, parent of a 14 year old*

I have the same problem with my 41 year old son with Prader Willi Syndrome. He is quite overweight and has a very large belly so he has trouble reaching. I do it for him when he will let me (baby wipes), but he wants so badly to be independent and is resistant to my help. He will allow me to do some things for him, but this is a hard one for him. HELP!!!

*Loni Hamilton, parent of a 41 year old*

We ran into the same problem with our son. It too was happening mostly at school where we were not available to supervise his wiping. Our son often complains that he had “pooped” his pants when in reality it was that he had not wiped entirely clean. We tried something and were happy with the results. It may be a bit gross but it worked. We taught our son to look at his soiled toilet paper after each wipe and to continue wiping and looking until there was nothing on the last wipe. We supervised this procedure at home. The other thing we did was have him wipe with a fresh flushable wet wipe when he was finished with the first procedure. This made him feel clean as he had preoccupation with feeling dirty down there. Hope this helps.

*Veronica Gonzalez, parent of a 9 year old*

Our 14 years old daughter has much the same trouble. She never wants to wipe her bottom or she just wipes very quickly. We help her when she’s at home but for years we received calls from the school to come with extra clothes, underwear, clean shoes for our daughter to change in to. There were times when she was quite messy with poo and we needed to take her home to get cleaned up. We suggest that parents might want to have a large plastic sheet to cover the car seat to avoid having to clean the car seat later. Our daughter never says she needs to go to the bathroom. When she was in elementary school, she was lucky to have a very understanding and caring teacher who reminded her to use the restroom after lunch. Our daughter recently had scoliosis surgery which has made the

*Parent to Parent continued on page 7*

### ***Our next Parent to Parent:***

“My brother is really sensitive to dental appliances, but his newest crown ‘feels different’ and has really been bothering him more than his other work. Is there anything that you’ve done that helps with mouth sensitivity issues after dental work?”

## FOOD TIP: OATMEGA

Submitted by Emily Dame

When I'm on the go and wanting a quick snack I often reach for a snack bar. My problem is that while many snack bars contain healthy ingredients, they often lack protein and have as many carbohydrates as a loaf of bread! I recently found Oatmega bars and I'm hooked. These bars contain EPA and DHA Omega 3's (300 mg of fish oil), hormone free grass-fed whey, they are non-GMO, and the cookies contain Chia seeds which are a popular 'super-food' because of their abundance of micronutrients. The company also donates their bars to local food banks. The bars are 190 calories, with 21 carbs and 7 grams of fat. They come in 8 flavors and there are also 3 flavors of cookies. I've tried 7 of the 8 flavors and they are all tasty! I've found these bars at Target, Whole Foods Market, and Sprouts Farmers Market. <http://givebar.com/>



## RECIPE CORNER

by Katherine Crawford

What do you do when you've got a craving for a rich and creamy soup, but don't want to have all of those extra calories that creamy soups have? I happen to have a brother with PWS who LOVES creamy soups, so I endeavored to find some recipes that would be kind both to his taste buds and also to his general health. I tried this recipe this past month and cannot WAIT to make it for him; imagine a rich, creamy soup with a smoky cheese-and-bacon flavor infused in it, and you'll be imagining this soup.

Why soup? Well, for one thing, it provides a king's serving of vegetables, and all cooked for ease of digestion - definitely a PWS issue! Another reason for soup is that it is a real make-ahead dish. You can make a large amount, then ladle it into containers to freeze for later evenings when you don't have the spare time to prep a full meal. (It's not leftovers when you plan ahead!)

But why make soup from scratch? This is a question that I answered for myself when I actually started cooking my own soup. The flavors from homemade soup just really POP. Another reason to make soup yourself is it gives you complete control over what goes into it. If you are aiming for low-sodium, it is easy to achieve. Don't like a particular ingredient? Don't add it. This type of tailoring makes it easy to take into account allergies and tastes of the whole family. It's really fun to experiment!

*Things to try with this recipe:* try different cheeses! Minced garlic is also tasty in this. Another variant you can try is using all cauliflower (omitting broccoli), and adding a cup and a half of shredded chicken for creamy chicken soup. The shredded chicken adds some protein to an otherwise high-veggie content soup. It also works great as a vegetarian soup with minor adjustments as noted in the recipe. Chopped onion tip: I use frozen pre-chopped onion, and it saves extra prep time.

## Creamy Broccoli and Cauliflower Soup

- 3/4 pounds chopped **broccoli**
- 3/4 pounds chopped **cauliflower**
- 1/3 cup chopped **onion**
- 1 1/2 cups **beef bouillon**
- 3 cups **skim milk** (or equivalent substitute)
- 1 tablespoon **cornstarch**
- 1/2 tsp **salt**
- 1/8 tsp **pepper**
- 1/3 cup **shredded asiago cheese**
- 2 slices crisp **bacon**, crumbled
- chopped **green onion**, for garnish

Cook **bacon** until crisp, set aside. Using same pan, brown cauliflower. Put **broccoli**, **cauliflower**, and **onion** in large pot to cook in **bouillon** until tender. Once tender, set aside to cool slightly. (*Vegetarian option: omit bacon, roast cauliflower instead*)

Pour into blender and puree. (Remember that not all of your soup will fit into your blender; you'll have to do a third to a half at a time. You can add some milk to the blender to help it puree.) Once you have blended your soup, you can return it to your pot. (*For chunkier soup, only blend half to two-thirds of the soup, then mix it back together with the unblended portion.*)

Mix **cornstarch** with 1/2 cup of the **milk**, then add this with all of the **remaining ingredients** to the soup. Ladle into bowls, garnish with chopped **green onion**.

Extras save *beautifully*. In fact, the flavors blend nicely when set aside as intentional leftovers. I use this soup often as a to-go lunch.

Happy cooking!

# EXECUTIVE DIRECTOR'S COLUMN

by Lisa Graziano, M. A.



## Person Centered Planning, Self Determination, Home & Community-Based Services (HCBS): Progressive Steps Forward or Life-Threatening Legislation for Persons with PWS?

If you haven't yet heard the terms "Person Centered Planning," "Self Determination," and "Home & Community-Based Services" you will soon. Regardless of the age of your child with PWS, it is essential to understand what these terms mean for the long-term health and welfare of your loved one. Let's take a brief look at each and focus on what we, as parents and care providers, need to do to keep our adult or soon-to-be-adult with PWS safe.

**Person-Centered Planning** is defined by California's Department of Developmental Services as "an approach to determining, planning for and working toward the preferred future of a person with developmental disabilities (a consumer) and her or his family. The preferred future is what the person and family want to do in the future based on their strengths, capabilities, preferences, lifestyle and cultural background. Person-centered planning is a framework for planning and making decisions." Through the Regional Center system, the Individual Program Plan (IPP) Team utilizes the person-centered planning process to develop the Individual Program Plan with the consumer, to help "the individual in developing a description that includes a preferred place to live, favorite people with whom to socialize, and preferred types of daily activities, including preferred jobs. Based on the individual's strengths, capabilities, preferences, lifestyle and cultural background, the planning team decides what needs to be done, by whom, when, and how.

**Self-Determination Program** is a federal program administered by the states. It is a "voluntary delivery system consisting of a defined and comprehensive mix of services and supports, selected and directed by a participant through person-centered planning, in order to meet the objectives in his or her IPP. Self-determination services and supports are designed to assist the participant to achieve personally defined outcomes in community settings that promote inclusion." Participation in Self-Determination is designed to give participants "greater control over decisions, resources, and needed and desired services and supports to implement their Individual Program Plan" and only funds "services and supports that the federal Centers for Medicare and Medicaid Services determines are eligible for federal financial participation." Self-Determination is designed for participants who have the *ability to* make well-thought out, judicious, realistic, and safe decisions about their health and welfare and future.

**Home and Community-Based Services (HCBS)** are new federal regulations, stealthily authorized in 2014 by the Centers for Medicaid and Medicare Services (CMS). These new regulations

define what types of residential, day program, and vocational settings or services are eligible to be funded by Medicaid and Medicare Services, mandating that all services or settings must be goal oriented, guided by the consumer's person-centered service plan and have the following characteristics: (1) integrated in and supporting full access to the greater community—both employment and community life to the same degree as individuals not receiving Medicaid HCBS, (2) giving individuals the right to select from among various setting options, (3) ensuring individuals' rights of privacy, dignity and other freedoms, (4) optimizing autonomy and independence in making life choices, and (5) making choices easier regarding services and supports.

Provider-owned or controlled HCBS settings must offer (1) a legally enforceable occupancy agreement, (2) privacy including lockable doors, roommate choice and freedom to furnish units, (3) individual's control of their own schedules, (4) freedom to have visitors, and (5) a physically accessible setting. Any modification must be supported by the Person-Centered Service Plan.

The intent of the new CMS regulations is to "deinstitutionalize" persons with developmental disabilities, get them living and working and wholly integrated into their community. **It all sounds great on paper, so what's the problem for persons with Prader-Willi syndrome?**

For people with PWS and others with substantial disabilities, the well-intended new regulations are **already having a negative effect on residential providers that serve persons with PWS both in the supported living setting and in group homes and will likely have a chilling effect on the development of new housing options that serve persons with PWS.** This at a time when the population of persons diagnosed with PWS is increasing and the demand for out-of-the-family-home placement will surely rise.

HCBS closes residential, day program, or sheltered work site settings that CMS considers too "congregate," defined as too many people with a developmental disability living or working in the same place. Closed too will be residential, day program or sheltered work site settings that are "insufficiently scattered," defined as being placed too close to each other. PWS group homes that have struggled financially to serve 5-6 residents may no longer serve more than four residents in the same home. Unknown is what will become of day programs and work sites that serve persons with PWS when the new HCBS regulations are fully implemented by March 2019. If a setting doesn't meet HCBS criteria, Medicaid/Medi-Cal won't fund it. If Medicaid/Medi-Cal won't fund it,

*Executive Director's Column continued on page 9*

# HEROES AND ANGELS



I wanted to let you all know that while we are still grieving our sweet Scarlett, we saw Lisa [Graziano's] post for a baby girl with Prader-Willi that needed a home and that baby (Josie) came to live with us this past Wednesday. She is such a wonderful joy to have here. I know that Scarlett had a hand in bringing her to us. It looks like we will once again be active in the Prader-Willi community. I have attached a few pictures.

[We] hope the Walk at Griffith Park is going well. We could not make it this year, since we're adjusting to accommodate Josie, but we expect to be doing the Long Beach 5K and doing the So Cal Walk next year.

Thank you all so much for your continued support. Because of your organization we know we can be good parents to this precious girl.

PWCF honors heroes, **Jennifer and James Meade**, who opened their hearts and home to their new baby, Josie.



## EDUCATION! EDUCATION! EDUCATION!

- There's nothing more true than Knowledge is Power and PWCF is here to help you stay both knowledgeable and powerful. Attend meetings and conferences and take advantage of all written and technological tools to stay informed. Register online at [www.pwcf.org](http://www.pwcf.org) or call the PWCF Office 310-372-5053

- **Eat Right, Future Bright! Learn Key Nutrition Strategies & Tips for Managing PWS**  
Featuring Jill Nowak-Przygodzki, R.D., CDE, Nutritional Consultant for PWCF  
**July 30** 9:00 am – 12:30 p.m. Children's Hospital Orange County

- **Learn How to Get What Your Child Needs from School**  
**IEP Parent Empowerment Training for Parents of the Child/Teen with PWS**  
Featuring Roger Goatcher, PWCF President, and Deputy Superintendent of Special Education  
**September 18** 10:00 a.m. – 2:00 p.m. PWCF Offices, Redondo Beach

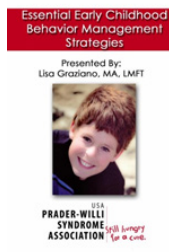
- **PWCF Annual State Conference - PWS: Past, Present and Future**  
Featuring **Suzanne Cassidy, M.D., Jennifer Miller, M.D., Harold van Bosse, M.D.**  
**November 5** 8:00 a.m. – 5:00 p.m. Double Tree Hilton Sacramento

- **NEW Behavior Management DVD - Essential Early Childhood Behavior Management Strategies**  
Lisa Graziano, MA, LMFT, recently presented a PWSA (USA) webinar entitled, Essential Early Childhood Behavior Management Strategies. Parents found it very helpful in understanding behavior strategies that work, and don't work, for our children. Many have asked to have this presentation available for future reference, to share with families, and to share with educators. One parent spoke to her child's school, and they will be using the webinar as an in-service training for their staff. As one parent stated: "Just wanted to let you know that the webinar was amazing. I've heard a lot of this behavior information before but the way Lisa explained it was better. (Or maybe the 5th time was the charm?!) She had the right speed for me and maybe because she was a parent who used it, it made more sense or I believed it more or something?! I don't know. But it was really good. This should be sent to every new family." Available from PWSA (USA) \$15

KNOWLEDGE  
IS  
POWER

### Additional Educational DVDs Available

- *Understanding the Student with PWS: Strategies for Success*
- *PWS Residential Staff Training*
- *Food, Behavior & Beyond*
- *PWS Behavior Management Strategies That Work: Especially for Parents, Extended Family, Babysitters & All Care Providers*



## ENDURING FRIENDSHIPS ARE PRICELESS

by Wanda Faivre



We had a great time at the 16th annual Southern California PWCF Walk in Griffith Park. My son, **Jesse**, with PWS, was such a trooper. He has a hip and knee condition which often limits his physical activity. With the encouragement of our friend Tara who joined us with her young son for the day, Jesse “slowly” walked the entire distance. It was very

heartwarming to me when two young men Jesse knew from PWCF Camp, **Ignacio** and **Jesus**, joined our small group as we were walking. The hot topic of discussion was the “Power Rangers!” Ignacio and Jesus purposely chose to slow down their pace to keep in step with Jesse. It was such a blessing to me to see their kindness and interest in connecting with him and to know that Jesse has budding friendship with others he has met at Camp.

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*Parent to Parent, continued from page 3*

job of cleaning her bottom even harder. We asked the classroom aide to remind her to use the restroom after the lunch but the aide said she cannot “force” anyone to use the restroom. It’s important to share information about PWS with the school, teachers, and at the IEP meetings to make sure that things like reminding to use the bathroom after lunch, etc. can be part of the IEP. We’ve gotten help from the Prader-Willi California Foundation since our daughter was 3 months old, and are grateful to Ms. Lisa Graziano and Ms. Emily Dame.

*With our warmest regards, Dave Nguyen, parent of a 14 year old*

We have (and have always had) this problem. Our son is now 9 and is just starting to get better at it! I’d say he’s 90-95% clean afterwards now. His ABA therapist started putting a small smear of peanut butter on a plastic plate. He has to fold & wipe until the plate and toilet paper come clean. The very last wipe is after the plate is clean, teaching him to wipe until you see nothing on the paper. After he mastered the paper plates, we moved to peanut butter on his arm, then leg, then lower back, all working up his muscles to reaching the right areas, and wiping with the correct firmness. Of course we still help him from time-to-time, and there IS supervision involved. School is always more difficult. Not sure I have any answers for those hours of the day. Hope that helps a little!

*Daniel Shea, parent of a 9 year old*

## Join Team PWCF!

Run, Jog, or Walk with us in the  
Aquarium of the Pacific 5K

Date: Saturday, October 8, 2016

Location: Aquarium of the Pacific, Long Beach

Registration Fee: \$30

## Need a bigger challenge?



Run the **JetBlue  
Long Beach  
Marathon  
or Half  
Marathon!**

Date: Saturday, October 9, 2016

Location: Start & Finish near Long Beach Arena

Registration Fee: Marathon \$90 / Half Marathon \$70

## Fundraising Goals

Aquarium of the Pacific 5K team members shall raise at least \$250 per person

JetBlue Long Beach Marathon & Half Marathon team members shall raise at least \$500 per person

If you raise \$500 or more (\$1,000 or more for the JetBlue Marathon, Half, or Bike Tour) we’ll reimburse your registration fee!

**The Team Member who  
raises the most money  
wins an iPad Mini 3!**

*88 cents out of every dollar PWCF receives  
directly supports families*

To join or support Team PWCF,  
visit [www.firstgiving.com/pwcf/team-pwcf-2016](http://www.firstgiving.com/pwcf/team-pwcf-2016)

contact PWCF at 310-372-5053 or [info@pwcf.org](mailto:info@pwcf.org)

## HAPPY MOTHER'S DAY I SEE YOU

*Submitted by Ruby Maestro, author unknown*



I see you running your child to therapy when your friends are running their kids to Little League or ballet.

I see you slipping out of the conversation when your friends are all chiming in about milestones

and test grades.

I see you constantly juggling appointments and meetings.

I see you sitting at your computer for hours researching what your child needs.

I see you cringe when people whine about what feels like petty things.

I see you spread thin but still going the extra mile for your family.

I see you digging for depths of strength you never dreamed you had.

I see you showing appreciation to the teachers, therapists and medical professionals who serve your child with you.

I see you rising early in the morning to do it all again after another chaotic night.

I see you when you're hanging on to the end of your rope for dear life.

I know you feel invisible, like nobody notices any of it. But I want you to know I notice you. I see you relentlessly pushing onward. I see you keep choosing to do everything in your power to give your child the best possible care at home, in school, at therapy and the doctor.

What you're doing matters. It's worth it.

On those days when you wonder if you can do it another minute, I want you to know I see you. I want you to know you're beautiful. I want you to know it's worth it. I want you to know you aren't alone. I want you to know love is what matters most, and you have that nailed.

And on those days when you have breakthroughs, those times when the hard work pays off and success is yours to cherish, I see you then too, and I am proud of you.

Whichever day today is, you're worthy, you're good and I see you.

## HAPPY FATHER'S DAY TO A SPECIAL NEEDS DAD

*by Karen Wang, a Friendship Circle parent*

My husband doesn't want me or the kids to acknowledge Father's Day – because he's a father every day.

My husband doesn't want me to announce that he works straight through breakfast and lunch without eating on most weekdays, comes home exhausted after a day of technical meetings, and then plays with our children and reads them stories until bedtime.

My husband doesn't want anyone to know about his anxiety over our disabled son's long-term care and quality of life. He won't admit to anyone except myself that he stays up late researching financial decisions, and that he lies awake in bed with his pulse racing over these decisions. His anxiety is the reason he works so hard all day.

But he did smile the time I told a family friend that my husband is the only reason we are able to do so much for our son: finding the right educational and recreational opportunities, getting extra therapy outside school, creating an enriched sensory environment at home, introducing him to new experiences in the world.

My husband was indignant when I suggested that the Kinect was really for him and not for the kids. He had learned about therapeutic uses for that type of video game system, and wanted to see how it worked for our son. I apologized.

My husband doesn't talk about the heartache of knowing that certain family members won't visit us and that we are unwelcome in a certain family member's home because of our older son's special needs.

My husband often talks to his manager at work about taking time off to attend school meetings and to stay home with the kids so that I can go to doctor's appointments.

My husband hates it when I tell friends that he becomes so consumed in playing with our kids that he forgets to take care of himself – even forgetting to eat or use the restroom.

My husband takes pride in not mowing our lawn for several consecutive weeks because he is too busy playing with the kids.

My husband never admits it when he desperately needs a nap on a Saturday or Sunday afternoon.

But he does admit that he sees himself sometimes when he looks at our sons' faces.

My husband doesn't understand why other parents don't just drop everything to help their children – after all, he didn't hesitate to jump at the idea of selling our house to pay for therapy.

*Fathers continued on page 9*

## PWSA (USA) ANNOUNCES NEW FACEBOOK JUST FOR DADS



PWSA (USA) recently unveiled a new Facebook group created especially for dads. As we all know, men and women often have different concerns and approaches when it comes to raising a child with special needs. It often helps to talk to someone in similar circumstances but dads can be less likely to reach out for that extra bit of support. So, PWSA (USA) created an awesome new resource for our wonderful and supportive but sometimes overlooked husbands and significant others. PWSA (USA) Dads is a sharing and support group for dads of kids with PWS of any age who are PWSA (USA) members. PWSA (USA) Dads provides a safe, secure place for learning, sharing and connecting with other dads of children with PWS, a place for asking questions, sharing experiences, and fostering friendships with fathers of kids the same age as yours... all in a hopeful, supportive environment sponsored and moderated by the PWSA (USA) staff. Go to [www.facebook.com/groups/PWSAUSA.Dads](http://www.facebook.com/groups/PWSAUSA.Dads) and join today!

If you're not already a member of PWSA (USA) go to [www.pwsausa.org/membership](http://www.pwsausa.org/membership) or call 800-926-4797 and complete your membership by phone.

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*Fathers continued from page 8*



My husband always keeps his cool at IEP meetings, so I'm the only person who knows how passionate he is about every detail that is discussed – and the details that are deliberately not discussed.

My husband grudgingly allows me to post pictures of him riding roller coasters with our disabled son on Facebook, but anyone who has ever visited us knows that our home is a shrine to Cedar Point.

My husband did not let a single tear fall on his birthday when I gave him a photo book titled “Boys Only,” filled with all the snapshots ever taken of him with our sons. He later said that he was overcome by emotion because it was the best gift he had ever received.

My husband is going to be really angry when he reads this.

Maybe you know someone like him.

Happy Father's Day.

*ED Column continued from page 5*

Regional Centers won't fund it. If Regional Centers don't fund it, it likely won't be an affordable option for someone with PWS. For those with PWS who need very specialized supports and services, HCBS has surely shrunk our options.

California's Developmental Centers, facilities that have served individuals including those with PWS who could not be served adequately in their community, have been closing over the past few years. Sonoma Developmental Center is slated to close in 2018 and the roughly 400 developmentally disabled people who live there will be “integrated” into the community, separated from people with whom they've lived and moved into their own home. Each will need some type of day program or employment, recreational services, and all new physician specialists. The two remaining centers, Fairview Developmental Center in Southern California and Porterville Developmental Center in the Central Valley, are slated to shut down by 2021 and each of *those* residents will need to be “integrated into the community.”

I liken the new HCBS regulations to Federal legislation passed in 1963 that mandated the deinstitutionalization of psychiatric patients and ordered the closure of psychiatric hospitals in order to get patients living and working and wholly integrated into their community. For those who were poorly treated or abused, it was a Godsend. For those who had no options for treatment, it was a sentence to homelessness, victimization, and premature death.

As parents and providers of care, we applaud HCBS's *goal* to “optimize individual initiative, autonomy, and independence in making life choices.” However, written into the regulations is some of the scariest verbiage for someone with PWS that I've ever seen: *a requirement that Provider-Owned or Controlled Residential Settings ensure that “individuals have freedom and support to control their schedules and activities and have access to food any time.”* Some supported living agency staff serving persons with PWS and some PWS-group home staff have already been instructed to remove the locks from all food sources in order to “comply” with the HCBS regulations! As we know, this will not only increase anxiety and unwanted behaviors, it is life threatening.

**What can we, as parents and care providers, do to protect our adult child with PWS?** First, keep informed and be cautious of the sources from which you receive information. On the surface HCBS and Self Determination sound idyllic. But when you peel back the layers and consider *how* these new regulations will impact *your* child with PWS in each and *every* setting, during each and *every* moment of the day *and* night, it becomes imperative to take action that will help protect your adult child's health and welfare:

- **Obtain conservatorship** so that you have the legal ability to protect your adult child's health and welfare
- **Avoid the voluntary Self-Determination Program**
- **Remember and use the words “health and welfare”** to justify and document your concerns or directions
- **Create a detailed, PWS-specific Person-Centered Service Plan (IPP).** Document and justify the reasons why specific

*ED Column continued on page 10*

## PWCF AWARDS FIRST PROMISING SCHOLAR TRAVEL SCHOLARSHIP FOR PWS RESEARCHERS



PWCF Professional Member, **Diobel Castner, M.S.**, received PWCF's first Promising Scholar Travel Scholarship for PWS Researchers. Dio presented a poster on PWS at the American College of Sports Medicine Annual Meeting in Boston in June. She received great feedback and will be going forward in drafting a paper with the results.

This scholarship was established in 2015 by PWCF's Board of Directors to fund promising scientists doing research related to Prader-Willi syndrome to attend a scientific meeting to present their research work. The scholarship is open to current students pursuing undergraduate or graduate studies or post-doctoral studies at an educational institution or hospital in the state of CA. Application criteria include academic achievement, good academic standing, being a presenter in a scientific session on the topic of PWS (abstract accepted or submitted for presentation), and showing potential for future work with people with PWS as a clinician and/or researcher.

PWCF is proud to congratulate Diobel Castner on a job well done!

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*ED Column continued from page 9*

modifications or changes must be written into the IPP to **protect your adult child's health and welfare**. Here are just a few suggested items to *specifically* document and justify in detail in your adult child's IPP:

- The refrigerator and food cupboards must *always* be locked;
- Access to all unauthorized foods and beverages must *always* be restricted;
- Your adult child cannot make sustained safe decisions about accessing his/her own food and that even just one food gorging episode can lead to death;
- Your adult child cannot make sustained safe decisions when they have access to his/her own money, be it cash, ATM, or credit card, because money equals food;
- Your adult child cannot make sustained safe decisions when taking public transportation, including private rides such as Uber or Lyft without supervision because riding "independently" brings him/her closer to access to food;
- Your adult child needs supervision 24/7/365;
- Your adult child requires structure and routine to reduce anxiety, reduce unwanted behaviors, reduce impulsive dangerous behavior such as running away, and reduce self-abusive behaviors

Know that PWCF and PWSA (USA) are your go-to organizations for the PWS-specific documents, articles, handouts, and resources you need. Our goal first and foremost is to support your loved one with PWS and your family.

## DING, DONG, THE MUSIC LIVES IN L.A.!

*FACT: One of the only activities that activates, stimulates, and uses the entire brain is MUSIC.*

Families who attended L.A. County's quarterly Support Group meeting in May were treated to the musical talents of Board Certified Music Therapist and current PWCF Board member, **Rodney Dong**.

Rodney brought a collection of instruments, including his own guitar, to demonstrate the power and benefits of Music Therapy. A dozen different drums, bongos, and bells were distributed



to a roomful of self-admitted non-musicians. Initially most of us beat timidly and haphazardly, but within minutes Rodney orchestrated a drum session that pulsed enthusiastically and expertly with energizing rhythm. Rodney shared that the primal healing and connecting powers of music live within each of us and can easily be harnessed to benefit our child's continuously developing brain. He shared that music activates neural pathways by releasing dopamine, one of the brain's "feel good" chemicals. Handouts highlighted the benefits of Music Therapy for the infant, child, or adult with PWS including reduced stress and anxiety, improved attention span, improved fine and gross motor skills, improved speech and language, improved impulse control, improved transition abilities, improved social skills, and enhanced learning, just to name a few.

Rodney and wife, **Gail's** 5 year old son, **Kiran**, is following in Dad's musical footsteps, already playing the violin! We look forward to bringing you more on Kiran's musical talents in the years ahead.



If you'd like to learn more about the benefits of Music Therapy or how to find a qualified Certified Music Therapist, give us a call at the PWCF Office and we'll connect you with Rodney who will be more than happy to share his wealth of information with you!

The next L.A. County Support Group meetings, one for families of a child Birth to 5 Years, and a separate meeting for families of a child or adult 6+ Years will be held on September 11 and will be a Share Session.

## OXYTOCIN PHASE 2 STUDY UPDATE

by Rob Lutz, Co-Chair, PWSA (USA) Research Committee

PWSA (USA)'s Research Committee Co-Chair, **Rob Lutz**, reports it has been nearly one year since we learned of the initial potential of oxytocin and PWSA (USA) began raising funds for the phase 2 clinical trial. This trial will provide us a greater understanding of the potential benefits, appropriate dosage needed, and additional vital information. The phase 1 study results were very positive and have been submitted for publication. We are amazed and gratified by the response of the PWS community for this project. Over \$600,000 has been raised to date which is sufficient to begin the phase 2 study.

While the fundraising campaign was underway, significant work was already underway to prepare for the clinical trial. This includes designing the protocol which determines how many patients should be enrolled, the dosages, and the criteria that will be measured.

One important consideration is what form of oxytocin to use. Not all oxytocin is the same. Each form of the drug might be made with different ingredients, a different purity, and different concentrations. Also, it is extremely important that whichever brand is selected is well positioned to be quickly moved forward after this next trial. Otherwise, there might be a longer delay before the drug is on the market for PWS.

PWSA (USA) and everyone involved in this effort wants to move as quickly as possible. We receive urgent calls almost every day from families that might benefit from oxytocin. But as stewards of the funds raised, we want to make sure monies are invested to maximize the information learned from the trial and speed future development. So please bear with us as we work to optimize the trial.

In the meantime, we continue to seek additional funds for the trial. While we could support the study with the funds raised to date, it would be beneficial to raise additional donations in order to allow

the researchers to enroll more patients and do more testing which could provide more definitive information regarding oxytocin.

To donate go to:

<http://www.firstgiving.com/pwsausa/oxytocin-study>

We also want to share one note of caution. We are aware that oxytocin is available today through the internet or compound pharmacies. Despite the potential of oxytocin, **we strongly encourage all families to resist trying any of these forms of oxytocin. Until oxytocin is properly studied in PWS, it could be dangerous or ineffective to give your loved one oxytocin.** As the father of a daughter who has PWS and might benefit from oxytocin, I want this drug vetted and approved as much as anyone. Working in the pharmaceutical industry, I am well aware of the precautions we need to take in order to move this drug forward so it can eventually be available to all of our children.

### PWCF SUPPORTS

### OXYTOCIN PHASE 2 RESEARCH STUDY WITH SECOND \$10,000 GRANT

In honor of PWS Awareness Month in May, PWCF issued our second challenge that we would match up to \$10,000 of all donations to support the Oxytocin Phase 2 Research Study. Wrote PWSA (USA)'s Development Director, Jack Hannings, "Thank you and PWCF for your generous \$10,000 match for the program. The May challenge grant was exceeded and your support made sure that we received generous donations during May." To date, PWCF has granted \$20,000 to support this exciting research.

We do live in exciting and hopeful times that a major breakthrough in the management of PWS' hyperphagia and anxiety symptoms is just around the corner!

## PWCF FAMILY FUN DAYS

Order your tickets today online at [www.PWCF.org](http://www.PWCF.org) or call the PWCF Office at 310-372-5053

### Cheer for the San Diego Padres!

**Saturday, August 20 5:40 p.m. Petco Park, San Diego**  
Field Pavilion level \$30 per ticket. PWCF attendees sit together!

Giveaway at the game - Fan's Choice:  
SD Lunch Bag or SD Bottle Holder!



### Oakland Athletics vs. Seattle Mariners!

**Saturday, Sept. 10 1 p.m. Game The Oakland Coliseum**  
Field Reserved Level tickets only \$35 per ticket.  
PWCF attendees sit together!

Oakland A's Mascot, Stomper,  
will visit between 1:30pm and 2:00pm!



# PHOTOS FROM THE SOUTHERN CALIFORNIA WALKING FOR PWS EVENT



## AMERICAN COLLEGE OF MEDICAL GENETICS CONFERENCE FEATURES SYMPOSIUM ON PWS

by Janalee Heinemann, M.S.W., Coordinator of Research and International Affairs, PWSA (USA),  
Vice President, IPWSO

PWSA (USA) had an awareness booth at the American College of Medical Genetics (ACMG) national meeting in Tampa Florida, March 8-12 2016. During this conference they had the first-ever symposium on a single syndrome - Prader-Willi syndrome - and had approximately 2,000 geneticists and genetic counselors attending. The symposium lasted 2 ½ hours with five speakers on PWS. What huge awareness! The moderators were **Jennifer Miller\***, M.D., and **Christian Schaaf**, M.D., PhD. It was a special time for us because **Suzanne Cassidy\***, M.D. also presented and received the Pruzansky Lecture award.

Dr. Cassidy provided an excellent overview and explained the importance of PWSA (USA) for education and support services. She recommended people stop by our booth and get the flash drive we were distributing free that had a tremendous amount of information on the syndrome - booklets, brochures, and articles. We heard very positive comments on the presentations at the symposium, and their amazement at the amount of services provided by our organization. One physician stated that PWSA (USA) should be the prototype for every rare disease organization. We were swamped at our booth and ran out of the flash drives, had more made quickly at the office, and ran out again! We also distributed other information, including the new Medical Alert booklet, and promised those who did not get a flash drive that we would send them the information. PWSA (USA) was mentioned 18 times in the program booklet - further great awareness.

**Carolyn Loker** helped me host the booth for the first time and told me that after all these years, she now truly understood the importance of doing these educational booths at major medical conferences. Although we are worn out by the end, the enthusiasm of interacting with hundreds of specialists who will ultimately make a difference in the care they give to our children thanks to

the information we distribute, keeps you on a high throughout the entire conference. Carolyn also got to experience how special it feels to help physicians from other nations that have little information on the syndrome.

PWSA (USA) recently had another major educational effort by mailing 1,041 packets of information on the syndrome to PWS clinics, geneticists and genetic counselors around the nation. A special thank you goes to Pfizer for funding this massive educational effort.

The above are just two more examples of how PWSA (USA) is saving and transforming lives - and why I am so proud to be a part of this wonderful organization.

*\*PWSA (USA) advisory board members*

## PWCF PRESENTS AT 5TH ANNUAL CHILDHOOD OBESITY BAY AREA CONFERENCE



PWCF was invited to present on Prader-Willi syndrome at the 5th Annual Childhood Obesity Bay Area Conference in April. PWCF's Education and Training Coordinator, **Emily Dame, M.Ed.**, presented a breakout session on *Prader-Willi Syndrome and Presenting Childhood Obesity in the Special Needs Community*.

## PWCF RAISES AWARENESS AT GLOBAL GENES DENIM DASH



On March 26 PWCF traveled to Citrus Community College in Glendora to spread awareness of Prader-Willi syndrome and other rare diseases at the 2016 Global Genes Denim Dash Virtual 5k Run/Walk for Rare Diseases.

Student leader **Alicia Beckley** and her organization the Phi Theta Kappa Honor Society Beta Nu Eta Chapter (PTK) chose to represent Prader-Willi syndrome at the event and invited PWCF to participate. The Denim Dash was created as a way to ensure that anyone, anywhere can participate and show their support and raise awareness for patients, family, and friends of the rare disease community. PTK students helped PWCF member **Beverly Ginyard**, PWCF Education and Training Coordinator **Emily Dame**, and PTK club sponsor **Olivia Canales** distribute PWS brochures, wristbands, and information on PWS to the crowd.

Call for  
research  
participants

PATIENTS NEEDED FOR PWS RESEARCH



**Parent-Led Physical Activity Program**

Study investigating a parent-led physical activity program for children ages 4 to 7 years old with and without PWS. A child ages 4-7 years with or without PWS and one parent per family are invited to participate.

We will train your family how to do a 12-week home-based program with activities and games that stimulate the development of motor skills. Your family will receive all play materials and our curriculum of games at no cost. The study will require three short visits at CSUF and two playdates (one at CSUF and one at a location of the parent’s choosing). During the visits at CSUF your child will have their height and weight measured and will complete movement-related tests. Parents will complete questionnaires and a recorded interview. Children and parents will also track their physical activity.

Your child will receive a bag of toys (\$10 value) following the first and last visits to CSUF. Parents/guardians will receive a \$20 gift card at the same visits. Parents will also be reimbursed for mileage (up to \$40 round trip) for the visits to CSUF and will be provided with free parking. . For non-local families interested in participating, arrangements for travel expenses may be available (please inquire with our study staff). Families may keep the all the materials when the program is over.

For information please visit our website at [pws.fullerton.edu](http://pws.fullerton.edu) or call or email us at:

- Dr. Daniela Rubin  
[drubin@fullerton.edu](mailto:drubin@fullerton.edu) 657-278-4704 Spanish/English
- Diobel Castner  
[dcastner@fullerton.edu](mailto:dcastner@fullerton.edu) 657-278-8737 English
- Research office  
[pwstudy@fullerton.edu](mailto:pwstudy@fullerton.edu) 657-278-3671 English



**RM-493 Medication Research Targeting Appetite in Patients with PWS at UC Irvine**

Recent scientific studies have implicated genetic variations in the MC4R cell signaling pathway, a key pathway in humans that controls energy expenditure and appetite—as an important root cause of obesity. Importantly, the MC4R cell signaling pathway is predicted to control appetite abnormalities such as hyperphagia (excessive hunger) often experienced by those with Prader-Willi Syndrome (PWS).

Rhythm is developing an investigative new treatment, Setmelanotide—also known as RM-493 that aims to treat people with PWS establishing weight and appetite control in people with PWS. Setmelanotide restores lost function to a portion of a metabolic pathway that is believed to be defective in PWS patients. Such an effect, if demonstrated in clinical trials, might provide those with PWS a significant improvement in quality of life and the potential to live more independently.

Rhythm seeks people between the ages of 16 and 65 years with confirmed diagnosis of PWS to participate in a medical research study examining the effects of this investigational drug for treating PWS. The study involves: 5-8 outpatient visits and up to 7 brief phone calls over a 14-week period

- Study participants may receive:
- The study drug at no cost
  - Study-related evaluations and laboratory tests
  - Paid travel expenses

To find out more, please contact Lead Researcher: Virginia Kimonis, MD at (949) 824-0571 or [vkimonis@uci.edu](mailto:vkimonis@uci.edu) or Claudia Shambaugh at (949) 824-0521 or [cshambau@uci.edu](mailto:cshambau@uci.edu) or Abhilasha Surampalli at [asurampa@uci.edu](mailto:asurampa@uci.edu)

**Diet and Behavior in Children with PWS**



Dr. Ann Scheimann, Pediatric Gastroenterologist at Johns Hopkins Children’s Center, Baltimore, MD is conducting a study regarding diet and behavior in children with PWS. She needs 10 children, between the ages

*Research continued on page 15*

## PATIENTS NEEDED FOR PWS RESEARCH

*Research continued from page 14*

of 6 - 12 years old, who are currently overweight to morbidly obese to follow a particular diet for 4 months and then off that diet for 4 months - monitoring behavior all along. There will be one observation visit in July and another in August to begin the study. Another visit will be required in December. In between visits there will be frequent contact with the office.

If you are interested in participating, please call 410-955-8769, then press 7 to speak to a nurse. Let them know that you're calling to be considered for Dr. Scheimann's study. Leave your child's age and your contact information. Dr. Scheimann will call you to discuss your participation and give you further information.

### *Swallow Study in Persons with PWS*



**The Children's  
Institute**

Roxann Diez Gross, Ph.D., is recruiting participants for a research study at The Children's Institute in Pittsburgh, PA. She is studying swallowing and esophageal transport of food in individuals

with PWS. This is an Institutional Review Board (IRB) approved study funded by PWSA (USA). The study will pay for most travel expenses if participants come from out of town.

This is a follow-up to the initial study sponsored by PWSA (USA) that gave insight into the fact that the high death rate from choking and pulmonary infection in children and adults with PWS cannot be solely attributed to eating behaviors. Although the combination of rapid eating and dysphagia (difficulty in swallowing) greatly increases the risk of aspiration and asphyxiation in persons with PWS, food impaction within the esophagus and/or unexpected regurgitation can also result in airway occlusion and/or aspiration. This study is examining ways to reduce the risk in our children and adults. For more information call the study coordinator, Ronit Gisser M.Sc. at 412-420-2249

### *Early Development of Children with PWS*



Purdue University is launching a new study on early development of children with Prader Willi syndrome. Purdue is recruiting families of children ages 3 years and

younger with PWS to participate in a longitudinal study about early development. Participation can be completed online and via phone, and families are provided \$15 gift card for each assessment. For more information contact [nddfamilylab@purdue.edu](mailto:nddfamilylab@purdue.edu).

### *Telehealth Intervention Research - Case Western Reserve University*



Research shows that imaginative play is related to important areas of development, such as social communication. Since many children with PWS have challenges with social-emotional skills, intervention targeting these skills through pretend play can improve quality of life and reduce problem behaviors. We are currently recruiting children 5-11 years of age with PWS and the parent/primary caregiver. For more information contact For more information, contact Anastasia Dimitropoulos and the PRETEND Research Team at [neurodevelopmentresearchlab@gmail.com](mailto:neurodevelopmentresearchlab@gmail.com) or 216-368-3471.

Or go to [www.pwsausa.org/telehealth-intervention-research-case-western-reserve-university](http://www.pwsausa.org/telehealth-intervention-research-case-western-reserve-university)

## PWCF SUPPORTS PWS CLINICS

As part of its ongoing commitment to bring high quality, PWS-informed medical care to families, PWCF helps fund three PWS Multidisciplinary Clinics in California: **Children's Hospital at Orange County**, under the directorship of Susan Clarke, M.D.; **Rady Children's Hospital at San Diego**, under the directorship of Lynne Bird, M.D., and the **PWS Adult Clinic at UC Irvine** under the directorship of June-Anne Gold, M.D.

While each PWS Clinic receives thousands of dollars of support each year from PWCF to fund various components of the clinics, the cost to patients is unfortunately not free of charge. Insurance co-payments are still required, dependent upon the family's policy. Research is often conducted with patients who attend each clinic, with the provision of medical care a primary directive.

California is fortunate to have a number of experienced physician specialists treat PWS patients in smaller clinic offices or private practice offices. For a list of all PWS Clinics and identified PWS physician specialists in California, go to our website or contact the PWCF office to request a copy of the referral list.

## BOARD CORNER

*Summary of Board of Directors Meeting on March 15, 2016*

*Submitted by Daniela Rubin, Ph.D*

Members present on the call: Whitney Bras, Roger Goatcher, Diane Kavrell, Jacki Lindstrom, Tom McRae, Nisha Mehta, Kimberlee Morgan, Daniela Rubin, Renee Tarica, and Jenny Wolkensdorfer  
Others present on the call: Lisa Graziano

Dear PWCF Members: Hope you are well. I am happy to report one more productive board meeting. Our meeting included planning for the our annual Walk events at Griffith Park, Los Angeles this past April 24 for Southern CA families, and the upcoming Walk on June 26th at Crissy Field, San Francisco for Northern CA families. We hope you noticed the presence of your Board members at our Walk and as we view this event as an opportunity to meet new families, catch up with friends and share a lovely time.

You probably received or will receive a phone call from one of us as well. This is part of our board member outreach efforts to know how our members are doing, see if we can be of help, or just remind you about the activities of PWCF. For example, grab your calendar as for this year we have planned these upcoming fun family events such as Los Angeles Angels Baseball games (June 25th), the Oakland A's baseball game (September 10th), San Diego Padres (August 20th).

As every year in March, we discussed the planning and organization

of our Annual State Conference. There is an excellent line up of speakers for this year's conference: **Suzanne Cassidy, M.D.**, **Jennifer Miller, M.D.**, and **Harold van Bosse, M.D.** Please mark your calendars for November 5. Both **Lisa Graziano** and **Diane Kravell** researched the best space for us to host the conference and this is the DoubleTree Sacramento hotel. While we considered different options such as San Jose, Sacramento, Oakland, it appears the most affordable and comfortable hotel site is the DoubleTree.

In terms of educational activities we have also planned an IEP parent empowerment conference to be held in Los Angeles on September 18th and we are still deciding on the date for a similar activity in Northern CA. We have offered the Behavior Management Parent Conference this past quarter in Southern CA and Lisa Graziano is looking into options for the Northern and Central California areas.

Our Fund development group discussed several topics including a potential Golf Tournament in Southern California. It was also mentioned the Tyrone Wells Benefit Concert organized by **Jessica and Christopher Patay**. The concert will be small and intimate, be hosted at the Patay's home in August, and is targeted to raise a minimum of \$10,000 in donations. The Patays have generously donated \$1,500 to help cover the cost of the artist performance fee. Additional donations to support this fundraiser are most welcome.

*Board Corner continued on page 17*

## UNCLE TOD'S LENDING LIBRARY

**Tod Holdorf**, beloved uncle of **Cameron Graziano**, donated back to PWCF all of the PWS DVDs and books he's purchased and learned from and no longer needs. With these and other materials, PWCF has created a new Lending Library!



Almost any item you see in our Website Store – and more – may be borrowed\*! Simply give us a call at the PWCF Office to start the process.

### **A sample of materials you can borrow includes:**

- The Brain and Behavior DVD featuring Janice Forster, M.D.
- Food, Behavior & Beyond DVD featuring Linda Gourash, M.D. and Janice Forster, M.D.
- Understanding the Student with PWS: Strategies for Success DVD
- PWS Behavior Management Strategies that Work: Especially for Parents, Extended Family, Babysitters DVD featuring Lisa Graziano, M.A.
- The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children book by Ross Greene, Ph.D.

\*All borrowed materials must be returned to PWCF by the agreed upon date or PWCF will charge your credit card on file for the cost of the materials borrowed.

# Board of Directors



## Do You Have What it Takes to Serve on PWCF's Board of Directors?

- ✓ Ability to listen, analyze, think clearly and creatively, work well with people individually and in a group
- ✓ Willingness to prepare for and attend Board meetings (3 in-person, teleconferences as needed), committee meetings, and other special events.
- ✓ Ability to ask questions, take responsibility and follow through on any given assignment, contribute personal and financial resources as generously as your personal circumstances allow
- ✓ Possess honesty, sensitivity to and tolerance of different views; a friendly, responsive, and patient approach; community-building skills; personal integrity; a developed sense of values; concern for the Foundation's development; a sense of humor
- ✓ Willingness to commit to serve a 3-year term

## What will you gain by participating on the Board?

- A sense of pride knowing you are working for the benefit of all persons impacted by PWS
- Input into decision-making that directly affects persons with PWS and their families
- Increased knowledge about Prader-Willi syndrome and its treatment and management strategies
- Increased knowledge about supports and services available in California
- Increased exposure to professionals who work with individuals with PWS

## What is expected of you from the PWCF Board?

- Three to four Saturdays per year to attend Board meetings (most held at PWCF office located in Redondo Beach. All reasonable travel expenses are reimbursed.)
- Time and energy spent on a committee, project or event
- Time to attend the annual General Education Meeting and an annual *Walk* event



## Nominate yourself or someone you believe has the skill set that will benefit PWCF.

Contact **Kim Morgan**, Chair, Nominating Committee at [info@pwcf.org](mailto:info@pwcf.org) or write to PWCF, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277.

The deadline to submit nominations for the 2017-2019 Board of Directors is **August 5, 2016**.

*Board Corner continued from page 16*

Look for the weblink to make donations in our PWCF webpage.

Last items but not least, we are reshaping our applications for future research scholars and also clinics to make the process more streamlined. If you are interested in research, consider joining our Research Committee.

Respectfully yours,

Daniela Rubin

## Volunteers are Priceless

- PWCF expresses our appreciation to:
- **Jessica Patay, Libby and Rob Fuller** for their help to mail the Walk brochures
- **Mike Matesevac** for distributing PWS brochures at an event in Georgia, at the suggestion of **D.L. Sweet**.
- **Kathleen O'Connell, Cameron Graziano, and TJ Graziano** for their help to haul waters for the Walk
- **Hilda Hernandez** for Spanish translation help
- **Beverly Ginyard** for her help with an awareness booth

## WE GET MAIL

**Dear PWCF:** First of all, we would like to take this opportunity to send you our sincere appreciation for all of your past, present and even future support to our family, especially for our daughter Christie Nguyen. While we are waiting for the feedback from school staff... we would like to let you know that we are so happy with the victory to gain the one-on-one for Christie.

We deeply understood that this victory, even we have been challenging for a long 2 years, that it must come from your knowledge, sharing experiences - and above all- your valuable time spending with us and all IEP meetings ... and so many occasions in the past years.

We definitely do not have enough words to express our appreciation for all of what you have done, supported, comforting us in all situations we have been through with the child having Prader-Willi syndrome.

I came to US for the past 28 years from a war torn country of Vietnam to start my life anew but I never had anyone, any organization giving myself, my family, my child such a loving and care hands as Prader-Willi California Foundation. I learnt so much from all of your supporting activities for my personal life.

Briefly to say, we believe that we owe Prader-Willi California Foundation and you, Lisa, and you, Emily a big time!!! Again, please allow myself, one more time, to say thank you so much Lisa and Emily. May God bless your hearts. *With our warmest regards, Dave Nguyen & Tracy Tran*

**Dear PWCF:** On behalf of People's Care, thank you so very much for taking the time to come out to our West Covina site to provide our staff (Community Services, Residential, Day Program) with the 2016 PWS In-Service Training. Everyone enjoyed your training - the PPT slides, your stories and the role playing! You are truly a great educator and trainer [Emily]! You did such a wonderful job! Thank you....thank you....thank you!!! Have a wonderful week and again, thank you. You were awesome!

*Best regards, Barbara Nguyen, Community Services Director, People's Care*

**Dear PWCF:** : My wife and I are grandparents to Miro Polaschek who turned 5 on May 15, 2016. Miro has 3 older sisters and 1 younger sister living at home aged 17,15,13 and 3. We are respite carers for Miro and spend 3 days a week staying with the family to give our daughter and son in law time out to put time into their other children with their schooling, sports and other activities. Miro is starting school at a special needs school when the education department and his specialists have sorted his needs and acquired the best services available at the school and privately. We follow you on Facebook and appreciate your stories on care, studies done to assist in better care and personal notes from families and people with PWS. Keep up the good work and please add us to your email list. *Thanking you kindly, John and Barbara Mutlow, New Zealand*

**Dear PWCF:** [In response to PWS Camp enrollment assistance:] We appreciate all your and the rest of PWCF's support. You all truly make a difference in the lives of all of us.  
*Thank you again, Janice Hubberth*

**Dear PWCF:** Thank you so much for your email and answers. I greatly appreciate it. Apologies for the delay on my reply, I was at my cousins wedding at the weekend. An Irish wedding is usually a three day event. Your answers provide so much wanted information, Thank you. In regards to your questions [about how I became interested in PWS] I attend the Institute of Technology Sligo [Ireland]. It is a state-funded third-level educational institution and I am currently in my fourth year studying BA (Hons) Social Care Practice. As part of my course I must do 800 hours of placement, split over two years. As part of my second year placement, I went to an organization called Western Care for adults with intellectual disabilities. Here I met a 20 year old boy whom has PWS. He lived about 20minutes from me. I had known him a bit as every St. Patrick's Day the 6 Pipe Bands of the island would meet up and play together for the tourists and locals and this lad

*Mail continued on page 19*

# MEMBER ACTIVITY



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.

New and renewing Extended Family, Family Friends, and Professional Members are listed.

## New Auxiliary Members

Stephanie Giacchetti, Mira Costa High School  
Dr. Lianyee Liwanpo, St. Jude Heritage Medical Group  
David Powers, DDS  
Sara Snyder, Tesoro High School  
David Ward, M.D., Loma Linda University Health System

## New Individual Members

Catherine Ho

## New Family Members

Amie Adams & Jake Lile  
Trish and Brian Busby  
Jennifer Howell  
Shannon & Stephen Hunt  
Erika Mireles  
Melissa & Adam Phan

## New Professional Members

Cambrian Homecare

## Renewed Auxiliary Members

Jeremy Freund, M.D.  
Linda Smith

## Renewed Extended Family Members

Dolores Albaugh  
Susan Alexander  
Lisa Ann Bonk  
Sylvia Boyle  
Terri Canales  
Carina Chaij  
Darren Clarke  
Sally & Chet Collom  
Mary Culver  
Polly Edgerton  
Laura & Ray Esau  
Molly Fuller  
Martha & Gary Girdaukas  
Wendy & Bob Graziano  
Jo Swanda & Paul Graziano

Patricia Grey  
Sandra Hansen  
Jo & Floyd Hatcher  
Mary Lee & Ron Higgins  
Cassie & Tod Holdorf  
Kelly Jaeger  
Sharri & George Marich  
Linda McGee  
Carolyn Meyer  
Kathleen Minor  
Lynn & Chuck Morrow  
Tammie Nance  
Lianne & David Noddle  
Kathy & Ralph Paige  
Stephen Patay  
Mark Savit  
Judy Schlafer  
Frances & Dave Sim  
Catherine Soden  
Margaret & Bill Spinelli  
Pat & Ron Vogrin  
Celeste & Tom Von Der Ahe  
Carol Williams  
Mary & Pat Williams

## Renewed Family Friend Members

Dolores Horn & Mel Goldberg  
Jan & Steve Grogan  
Gloria & Henry Maranon  
Stacy Mason  
Tyna & Ray Triggs

## Renewed Professional Members

Mario Alvarez, United in the West  
The Arc of San Diego  
Lynne Bird, M.D., Children's Hospital San Diego  
Mary Lane Carlson, EdD, MPH, RD, CDE  
Vicki Cox, M.S., LCGC, UCSF Pediatrics/Medical Genetics

Jack Darakjian, Modern Support Services, LLC  
Larry Landauer, Regional Center of Orange County  
Marjan Homes, Lulu & Oscar Cachuela  
Ashley Phelps-Leak, Lee Street Homes  
Lynn DeFreece, North Valley Services  
Gayle Palmer, Pukett Residential Services, Inc.

Sterling Ross, Esq., Robb & Ross, Special Needs Trust & Conservatorships  
Julie Seguin, Ph.D.  
Melanie Silverman, MS, RD, IBCLC  
People's Care at Orangecrest Villa  
People's Care at Tradewinds

*Mail continued from page 18*

would always be here. He loved music and I used to let him play my drum for a while and my boyfriend would show him a few notes on the pipes. He absolutely loved Patrick's day and music; I think it was because his name is Patrick :) I worked with him and shadowed another worker over the 13 week placement and just found it so interesting. There are only 100 cases [of PWS] in Ireland and it is not really a [known] disability. As I found it so intriguing and felt there was not a lot of information here about it, I decided to do my dissertation on the topic to try and promote it, or at least give some knowledge to my classmate. I currently have been volunteering in the organization for almost two and half years, as I loved working there so much. Once I finish I hope to apply to Western Care. Thank you again. *Kind regards, Caitriona*

## FUTURE SLP ONE OF OUR OWN

PWCF is proud of our graphic designer, **Katherine Crawford**, for her acceptance into University of Colorado, Boulder. Katherine will be pursuing her Master's degree in Speech and Language Pathology. She plans to continue her work with PWCF during the program in the meantime. We look forward to Katherine treating patients with PWS soon!

**We live in a world in which we need to share responsibility. It's easy to say, 'It's not my child, not my community, not my world, not my problem.' Then there are those who see the need and respond. I consider those people my heroes.**

**- Fred Rogers "Mr. Rogers"**

**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@pwcw.org

## DONATIONS

April - June 2016

### Shining Star Donations

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

Suzanne Privette in honor of Samantha Morgan (monthly donation)

Linda and Mark Ryan "In tribute to you, Trevor, for all the hard work you do to make us proud. We love you."

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

Julie & Dan Casey in honor of Ryan Casey

Linda and Mark Ryan in loving memory of Phil and Marilyn's son, Chris

### General Donations

Kyra Allen

Adobe (Tom McRae's monthly payroll match)

Dolores Albaugh

Anonymous Donor in honor of Nolan Bonk

Dr. Lynne Bird

Lorraine Bizal in honor of Ryan Patay

Sylvia Boyle

Carol & John Braunschweiger

California Vocations, Inc. (Bob Irvine)

Olivia Canales

Molly Carter

Chaya & Samuel Chazanow

Darren Clarke

Comcast Corporation in honor of Michael

DeNatale

Comcast Corporation in honor of Michael Moore

Maritza Cruz & Bridget Cruz Brown

Mary Culver

Ida Dacus

Ester Del Real

Michelle & Kevin Donaldson

Gayle L. Dunn in memory of William Byrne Ritt

Laura & Ray Esau

Eric Elliott in honor of Melinda Morrow "Happy Birthday, Moms. Love, Lee, Eric & Kalyan"

Mattie & Mary Gannon

Martha & Gary Girdaukas

Roxanna Goin

Lisa & TJ Graziano

Wendy & Bob Graziano

Eileen & Michael Groom

Nancy Guerrera

Mary Lee & Ron Higgins

Jean & Lowell Hobrock

Cassie & Tod Holdorf

Home Shopping Network, LLC awarded PWCF

\$1,000 thanks to nomination from Donna Franco

Janice & Neil Hubberth

Phyllis & Jake Hurse

Kelly Jaeger

Lucy Jao & Bie Chuan Ong

Esther Sleeth-Keppler "Freya, You are a lucky little girl. Your family loves you so much. Keep growing and learning. Lots of love, Esther"

Lana Kidd

Kroger

Margot & Gerry Lawrence

Stephanie Lawson

Miriam Liberman in memory of Sandy Kovacs

Hope May-Liddiard

Jacki & Jeffrey Lindstrom

Jacki Lindstrom of J.P. Lindstrom, Inc.

Judy & Sidney Loewen

Georgene & Ralph Lowe

Alison & Carlos Luis

Sharri & George Marich

Patti & Tom McRae (monthly donation)

Sean Malloy

Erika Mireles

Gail Morgan

Lynn & Chuck Morrow

Fran Nicholson

Anthony Nowak-Przygodzki

Patricia Olivarez via Local Independent Charities of America

Jessica & Chris Patay

Plegeling Foundation on behalf of Tom McRae

Michelle & Mike Raleigh

Ida Rehfeld in honor of Betty Cox

Teresa Rehfeld in honor of Betty Cox

Mark Savit

Julie Seguin, Ph.D.

Doris Semadeni

Janice & John Shimmin

Catherine Soden

Laura & Michael Tomelloso

Liang Yu Tai & John Cheng

Renee & Henry Tarica in memory of Sandford Kovacs

& Mr. & Mrs. Edelman's grandson, Sam

Celeste & Tom Von Der Ahe

Tracy Tran

Tyna & Ray Triggs

Mary & Pat Williams

Suzanne Windus in honor of Emily Reynoso "Emily

is a beautiful child of God. She is blessed with

beautiful sweet parents"

Debby Yashar

### Donations to Support PWS Camp

Barbara & David Gow

Suzanne Privette in honor of Samantha

Morgan (monthly donation)

Kerry Reis

### Generous Donations to Support

#### Walking for PWS Events

Albertson's Grocery Stores

Chad Arifuku

Maria Barraza in honor of Andrea Barraza

Julie & Dan Casey in honor of Ryan Casey

Darren Clarke in memory of Christopher

Clarke-Gujral

Wanda & Steve Faivre in honor of Jesse Faivre

Linda & Mark Ryan in honor of Trevor Ryan

Minette Gaitan in honor of Julianna Rodriguez

Cherisse & Sydney in honor of Brooke Gilchrist

Ashok Gujral in memory of Christopher

Clarke-Gujral

Robert Harrison in honor of Samantha Morgan

Sue Haskell in memory of Yvette Tarica

Leo Hassey in honor of Del Luis

Hilary Hoffman in honor of Ryan Casey

Dolores Horn & Mel Goldberg in memory of

Yvette Tarica

Charles Hunt in honor of Del Luis

Jacqueline & Rigo Jimenez & in honor of

Giovanni Jimenez

Anna Kanauka in honor of Cameron Graziano

Virginia Kimonis, M.D. and UC Irvine in honor

of everyone with PWS

Phillip Lee, M.D. in honor of Cameron Graziano

Marieclaire Leon in honor of Ryan Casey

Miriam Liberman in memory of Yvette Tarica

Angela & Robert Lucero in honor of RJ Lucero

Michele Maher in honor of GiGi Greskovic

Candelaria & Ignacio Martinez in honor of

Ignacio Martinez

Nisha & Minesh Mehta in honor of Siena Mehta

Jeanine Milner in memory of Yvette Tarica

Bob Morgan in honor of Samantha Morgan

Lianne & David Noddle in memory of Yvette

Tarica

Pamela Prudhomme in honor of Brooke

Gilchrist

Pfier Endocrine Care

Brian Rhodes in honor of Trevor Ryan

Marybeth Rotheim in honor of Trevor Ryan

Daniela Rubin, Ph.D. and CSU Fullerton in

honor of everyone with PWS

SAILS Organization

Lori & Adam Saitman in memory of Yvette

Tarica

Denise & CJ Sawicz in honor of Veronica Bosse

DL Sweet in honor of everyone with PWS

Tarzana Subway and owner Pamela

Adam Taylor in honor of Austin Williams

True Compass in memory of Christopher

Clarke-Gujral

Chris Welker in honor of Samantha Morgan

Amy & Paul Wissmann in honor of Amanda

Wissmann

**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)

# 2016 Annual State Conference Prader-Willi Syndrome: Past, Present, and Future

Friday November 4 - Meet & Greet

Saturday November 5 - Conference

DoubleTree by Hilton Sacramento, CA

PWCF Rate \$99/Nite 916-929-8855



**Prader-Willi  
California Foundation**

*Supporting People with Prader-Willi Syndrome*

## Featuring



**Suzanne Cassidy, M.D.**  
Keynote Speaker



**Jennifer Miller, M.D.**  
PWS Endocrine Specialist



**Harold van Bosse, M.D.**  
PWS Orthopedic Specialist

Hear some of the nation's top leaders in PWS address critical PWS Concerns. You'll go home with new symptom management strategies, renewed energy and hope, and connections to last a lifetime.

**Meet & Greet Friday Night | Breakout Share Sessions | Youth & Adult Conference**

**Questions? Contact PWCF 310-372-5053 info@pwcf.org www.PWCF.org**

## **PWCF 2016 Annual State Conference Registration Form**

Online [www.pwcf.org](http://www.pwcf.org) | Mail 514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277 | Fax 310-372-4329

### Conference Registration

PWCF Member: \$85 / \$150 per couple

Non-PWCF Member: \$100

PWCF Professional: \$100

Non-Member Professional: \$125

**Register by 9/3 and deduct \$10!**

*Fees May Be Reduced or Waived Upon Request*

### Youth & Adult Program Registration

PWCF Member: \$30/child or adult

-or- \$25/child for multiple children

Non-Member: \$40/child or adult

*Fees May Be Reduced or Waived Upon Request*

Siblings Welcome!

Names of Conference Registrants \_\_\_\_\_ Vegetarian Lunches requested: \_\_\_\_\_  
 Name & Age of Person Enrolling in Youth & Adult Program \_\_\_\_\_ ( ) \_\_\_\_\_ ( ) \_\_\_\_\_ ( ) \_\_\_\_\_ ( )  
 Mailing Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
 Email \_\_\_\_\_ Phone \_\_\_\_\_

Total Amount Due for Conference Registration: \$ \_\_\_\_\_

Total Amount Due for Youth & Adult Program: \$ \_\_\_\_\_

Total Tax Deductible Donation Amount: \$ \_\_\_\_\_

Total Amount Enclosed: \$ \_\_\_\_\_

I have enclosed my check made payable to "PWCF"

Please charge my credit card

Name as it appears on card \_\_\_\_\_

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

Expiration \_\_\_\_\_ Security Code \_\_\_\_\_

Billing Address \_\_\_\_\_ Signature \_\_\_\_\_

*(if different from mailing address above)*



# Eat Right, Future Bright!

## Learn Key Nutrition Strategies & Tips for Managing PWS



**Saturday, July 30, 2016**  
**9:00 a.m.—12:30 p.m.**

**Children's Hospital Orange County**  
1201 West La Veta Avenue, Orange, CA 92868  
Wade Education Center, 2nd Floor Specialty Clinics Building

**Managing the diet of children and adults with PWS can be challenging. PWCF is here to help!**

This parent conference will teach you about:

- Calories, protein, fats & carbs
- Meal Planning
- Portion Sizes
- Meal Schedules & Timing
- The Principles of Food Security
- How to Read Food Labels
- Fad Diets
- Red Yellow Green System of Weight Management

**Presented by Jill Nowak-Przygodzki, R.D., CDE, Nutritional Consultant for PWCF**



Jill is a registered dietitian who has been working with patients at CHOC since 2004. She is a member of the Department of Endocrinology and Diabetes multidisciplinary team and provides nutrition education to patients including meal planning, weight management and behavior modification for a variety of disorders including Prader-Willi syndrome, type 1 and type 2 diabetes, celiac disease, cardiovascular disease, and hypertension. She is a Certified Diabetes Educator and holds a Certificate of Training in Childhood and Adolescent Weight Management. Jill is a long-time, invaluable member of the PWS Clinic at CHOC where she provides nutritional consultation guidance and services to families.



For more information contact PWCF  
Phone: 310-372-5053  
E-mail: [info@pwcf.org](mailto:info@pwcf.org)



### Eat Right! Future Bright! Parent Nutrition Conference | July 30, 2016

PWCF Members \$40 | Non-Members \$50 | Childcare \$10 | Regional Center Vendor #PH1837

☎ 310-372-5053 🌐 [www.pwcf.org](http://www.pwcf.org) 📠 Fax 310-372-4329 ✉ Mail to PWCF 514 N. Prospect Ave., #110-LL, Redondo Beach, CA 90277

Name(s) \_\_\_\_\_ Phone \_\_\_\_\_ Number Attending \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ Zip \_\_\_\_\_

Email \_\_\_\_\_ Childcare Name(s) \_\_\_\_\_ Age(s) \_\_\_\_\_

I have enclosed my check made payable to "PWCF"  Please charge my credit card \$ \_\_\_\_\_

Name on Card \_\_\_\_\_ Signature \_\_\_\_\_

Card No. \_\_\_\_\_ Expiration Date \_\_\_\_\_ Security Code \_\_\_\_\_

Billing Address \_\_\_\_\_

*if different from address above*

# Let's Play Ball, San Diego!

## San Diego Padres v. Arizona Diamondbacks

Saturday, August 20, 2016

5:40 p.m. at Petco Park

Field Pavilion level \$30 per ticket

PWCF attendees sit together!



Every ticket sold benefits PWCF!

Giveaway at the game!  
Fan's Choice: SD Lunch Bag  
or SD Bottle Holder



### Family Fun Day with the San Diego Padres Ticket Order Form



Mail or Fax Order Form with payment to PWCF at 514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277 | Fax 310-372-4329

Name \_\_\_\_\_ Email \_\_\_\_\_ Phone \_\_\_\_\_

Shipping Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Please send me \_\_\_\_\_ tickets at \$30/ticket.

I have enclosed my check made payable to "PWCF"  Please charge \$ \_\_\_\_\_ to my credit card

Name as it appears on card \_\_\_\_\_ Card No. \_\_\_\_\_ Expiration \_\_\_\_\_ Security Code \_\_\_\_\_  
(on back of card)

Billing Address \_\_\_\_\_ Signature \_\_\_\_\_  
(if different from shipping address above)

Questions? Contact PWCF at [info@pwcf.org](mailto:info@pwcf.org) 310-372-5053 | 800-400-9994 toll-free in California

# *PWCF Wants to Take You Out to the Ball Game!*

It's time for our **Fourth Annual PWCF Family Day** at the **Oakland Coliseum**  
*Field Reserved Level tickets only \$35 per ticket, with \$5 from every ticket sold benefiting PWCF*  
*PWCF attendees sit together! Oakland A's Mascot, Stomper, will visit between 1:30pm and 2:00pm!*



## *Oakland Athletics vs. Seattle Mariners*



**Saturday, September 10 ■ The Oakland Coliseum ■ 1 pm Game**



**Family Fun Day with the Oakland A's**

**Mail or Fax Order Form to PWCF at 514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277 Fax 310-372-4329**

Name \_\_\_\_\_ Email \_\_\_\_\_ Telephone \_\_\_\_\_

Shipping Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

**Please send me \_\_\_\_\_ tickets at \$35/ticket.**  I have enclosed my check made payable to "PWCF"  Please charge \$ \_\_\_\_\_ to my  Visa  MasterCard  Amer Express

Name as it appears on card \_\_\_\_\_ Card No. \_\_\_\_\_ Expiration \_\_\_\_\_ Security Code \_\_\_\_\_  
(on back of card)

Billing Address \_\_\_\_\_ Signature \_\_\_\_\_  
(if different from shipping address above)

# Join Team PWCF!



**We're proud to be an official charity with the 2016 JetBlue Long Beach Marathon**

Run, Jog, or Walk with us in the Aquarium of the Pacific 5K Run/Walk

## 5K Run/Walk

Date: Saturday, **October 8, 2016**

Location: Aquarium of the Pacific, Long Beach

Registration Fee: \$30



## **Need a bigger challenge?**

## Run the JetBlue Long Beach Marathon or Half Marathon

Date: Sunday, **October 9, 2016**

Location: Long Beach – Start & Finish near Long Beach Arena

Registration Fee: Marathon - \$90 / Half Marathon - \$70

## Fundraising Goals

- Aquarium of the Pacific 5K team members shall raise *at least* \$250 per person
- JetBlue Long Beach Marathon & Half Marathon team members shall raise *at least* \$500 per person

If you raise \$500 or more (\$1,000 or more for the JetBlue Marathon, Half, or Bike Tour) we'll reimburse your registration fee!

**Team Member who raises the most money wins an iPad Mini 3!**

**Fundraising you can feel good about:  
88 cents out of every dollar directly  
supports families**

**Space is limited so join Team PWCF today!  
For more information and to register for  
Team PWCF visit:  
[www.firstgiving.com/pwcf/team-pwcf-2016](http://www.firstgiving.com/pwcf/team-pwcf-2016)**

**Experience the thrill of a lifetime as you cross the finish line  
knowing you're supporting families affected by  
Prader-Willi syndrome**

For more information about the 2016 JetBlue Long Beach Marathon or Aquarium of the Pacific 5K Fun Run/Walk  
Visit the official website at [www.runlongbeach.com](http://www.runlongbeach.com)

## **Learn more about Prader-Willi syndrome:**

[www.pwcf.org](http://www.pwcf.org) • [info@pwcf.org](mailto:info@pwcf.org)  
310-372-5053 • 800-400-9994 (within CA)  
[www.facebook.com/PWCF1](https://www.facebook.com/PWCF1) • Twitter: @PWCF1