

January - March 2015  
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## PWCF Members Run the ASICS LA Marathon & LA Big 5K



Team PWCF 5K Participants

A small and mighty group of amazing people comprised this year's Team PWCF. Three ran 26 miles in the ASICS LA Marathon and 23 walked or ran 3.1 miles in the LA Big 5K. Together they raised over \$15,000 to fund critical services provided by PWCF.

**PWCF Marathon Team:** Our elite Marathon runners, **Kim Morgan** (PWCF's Vice President), **Julia Rutledge**, and **Estavan Policarpo**, really are awesome. Without glory or fame or even a photo to commemorate their Team,

they pushed themselves to their limits for the love of the cause (and, ok, maybe too for the love of running!). Kim ran for her daughter, **Samantha**; Julia ran for her son **Maddox**; and Estavan ran for his nephew **Juan Gutierrez**. Marathon Day was expected to reach record-breaking temperatures and so the Marathon moved up the runners' start time almost a full hour so that runners could beat the heat as they ran from Dodger Stadium to Santa Monica. Even running in the heat with an hour less sleep, Kim achieved her goal to run the LA Marathon in 3 hours 45 minutes.

**PWCF Marathon Cheer Squad:** Estavan's niece, **Molly**, came *thiiiiis* close to running in the Marathon for her brother until the Marathon Committee learned she's only 16 and not eligible. But that didn't stop her from participating. Nope! Instead, Molly rounded up her whole family – mom, dad, and brother **Juan** who has PWS – and all participated in PWCF's Cheer Squad. **Petra Ali-Martinez**, director of this year's Cheer Squad, brought her entire family as well and tasked her husband **Munawwar** to help set up PWCF's booth. She tasked their son, **Aiden** who has PWS, with distributing hundreds of PWCF brochures and wristbands.



Aiden and Erin



The Policarpo Family

A true ambassador for PWS, Aiden singlehandedly raised public awareness of PWS with enthusiastic, determined focus. **Erin Phillips** was an *awesome* addition to this year's Cheer Squad as she generously donated her time away from her family to add her own special brand of enthusiasm and gusto. The entire Squad poured their heart, soul (and sweat 'cause it was a *really* hot day!) into creating an exciting, encouraging atmosphere for *all* of the Marathon runners.


**PWCF 5K Team:** Though few of our 5K participants would call themselves athletes, each is a true champion. The excitement began as the Team gathered at PWCF's Booth in the 5K at Dodger Stadium. Everyone encouraged each other, helped each other pin on their bibs, and posed for photos. No one took themselves too seriously; all knew we were running – ok, walking – for a great cause, each for a loved one or dear friend. The LA Big 5K route is a beautiful and peaceful one, despite the thousands of participants. Whether one found it easy to raise the minimum \$250 in sponsor donations, or whether it was simply easier to donate it, there was absolute consensus that participating on Team PWCF in the LA Big 5K was absolutely a worthwhile experience.



Julie Casey and Renee Tarica

*Marathon continued on page 12*

**Support PWCF's 15th Annual**



**WALKING FOR PRADER-WILLI SYNDROME**

[www.PWCF.org/WalkingForPWS](http://www.PWCF.org/WalkingForPWS)

**PRADER-WILLI  
CALIFORNIA FOUNDATION**  
*A Full Life Without Limits*

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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:pmcrae@sbcglobal.net">pmcrae@sbcglobal.net</a>
SF Bay Area (teen to adult)	Michelle Donaldson	415-759-8740	<a href="mailto:michelle.sf@comcast.net">michelle.sf@comcast.net</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 [paulawatney@pwcf.org](mailto:paulawatney@pwcf.org)

**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 [esterdelreal@ymail.com](mailto:esterdelreal@ymail.com)

**Spanish Speaking**

Mercedes Hernandez (Adults with PWS)	619-822-5742	<a href="mailto:mercedes.hernandez711@yahoo.com">mercedes.hernandez711@yahoo.com</a>
Kilma Carillo (Infants/Children with PWS)	760-427-1100	<a href="mailto:kilmab@excite.com">kilmab@excite.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) Online eSupport Groups** [www.pwsausa.org](http://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 Organization, IPWSO** offers information about PWS in other languages. Go to [www.ipwso.org](http://www.ipwso.org)

**PWS SHARE & SUPPORT GROUPS MEETING CALENDAR 2015**

**Southern California**

Beach Cities Health District  
514 N. Prospect Avenue  
Redondo Room (Lower Level/Bottom Floor)  
Redondo Beach

**Sunday, January 11**  
**Sunday, April 12**  
**Sunday, July 26**  
**Sunday, October 25**

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

**Northern California**

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

**May 2, September 19**  
**Time: Check-in 10:15 a.m.**  
**Meeting 10:30 a.m. - 1:30 p.m.**  
Childcare Available.

RSVP to SFCD 415-920-5040 x 135

## PARENT TO PARENT

*“Some of my extended family do not respect my decisions about food portions for my child with PWS. What can I do to help them understand that my child’s needs are different?”*

I normally educate them what Prader-Willi is and how proper dieting affect[s] the mortality of their lives. Hope this helps.  
*William Go, father of Janelle, age 27*

If you hand them one of the PWCF’s brochures that explains all about PWS, it may help. Most of my relatives don’t understand until I explain the various issues related to PWS, and there are many! Then, they just begin to have a vague idea what it’s like! And if they still don’t understand, ask them to look it up on the internet! After that, I don’t worry any further about them....My daughter’s own father never really understood and always blamed me and that’s when I decided I don’t owe anyone an explanation.  
*Renee Lovern, mother of Kimberly, age 23*

I have also had some difficulties with some family members. I actually bring his dish or bowl with me to their homes -- which is much smaller than their plates, and I insist on serving him. He’s 28 so I have had many years of this. Now they serve much healthier dishes and know I will serve him. It took a long time and it also took me telling them we wouldn’t come over if they served food he couldn’t eat and if they commented on my serving his portions. It got better.  
*Molly Carter, mother of Danny*

Whether it be family, extended family, care givers or even strangers, gaining respect from others will be a constant challenge due to the lack of understanding of your child’s needs. The primary source of respect must come from yourself. If you respect the decisions you have made and believe they are the best for your child then you do not need the respect of others in this regard. Know that you know your child best and that you are doing the best you can to keep them healthy and happy. If others really are concerned about the portions you are giving your child then direct them to the [PWCF]

web site so they can educate themselves about the dietary needs of a [child or adult with] PWS. If they do this then they will respect you for respecting the needs of your child. If others are not willing to do this then you can only go so far to attempt to explain that the metabolism of [children and adults with] PWS is much lower than most kids and more food than what your child needs will send the wrong signal of anticipation, causing more problems in the near and long terms. For some people, you may never be able to say enough for them to understand and this is why you need to rely on the respect of yourself and the decisions you make for your child.  
*Mark L. Ojeda, father of Eric, age 31*

Wow! Great topic. This is such a huge issue in my family as well. They see my son, Trevin, is skinny or normal weight so [they believe] we are mean, too extreme, and out of line to have him on a diet and they continue to give food and candy. No concern for our wishes or Trevin’s needs. It is so hard for others to see when your own family does not understand. We have invited them to events and PWS medical clinics but no luck. I think this is one of the hardest parts of PWS. They do not understand we as parents are doing 100 percent all we can to make sure our children live life to the fullest and longest. They cannot let go of small town traditions around food. Schools and church has been hard too as they are not willing to change or adapt as it is “how they have always done it”. It is even harder yet when it keeps getting put on us that they shouldn’t have to punish the other kids in school or church or even our own nieces and nephews with getting rid of candy and crap food. We should adjust. So I would love ideas and suggestions. So far we don’t fight it and cut calories at meals, which is not right but easier than the constant battle. We also avoid some activities since it is easier too. Can’t wait to read this part. Thanks for all you do.  
*Crystal Redner, mother of Trevin, age 6*

### *Next Parent to Parent Question:*

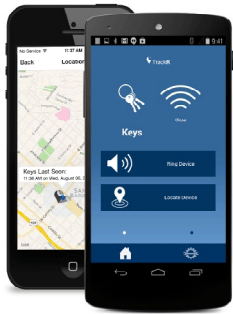
*“How do you carve out time and what do you do, either for yourself or for you and your spouse, to feel rejuvenated, refreshed, re-energized and ready to react calmly to the next day’s stressors?”*

**VOLUNTEERS**  
are **Priceless**

PWCF thanks **Brittany Burns, Bill Spinelli, Kimberly Storr, and Elizabeth Greskovics** for their help to prepare the 2014 Member Give Back program items for mailing

## GADGET TIP: TRACKR

*Submitted by Dolores Kirchner*



A parent I met with let me know about this device...It's a small tracking device so you can locate missing items—or persons—using your smart phone and a specific application. I'm sharing this since I know sometimes families would feel better with this type of security—especially if their child may be a wanderer.

TrackR has an app for both iPhone and your Android smartphone. There are various styles and types of TrackR's. One style has an extra durable metal key loop that that hooks onto not just keys, but backpacks, purses, and more. TrackR Bravo is water proof. Keep track of things at the water park, by the pool, at the beach, or at the lake. There's even a Distance Indicator that displays the distance between you and your item—or person—letting you know how far away they are. Cost of one TrackR is \$24. Discounts for multiple devices. For more information or to order your Tracker, go to <http://www.thetrackr.com/>



## FOOD TIP: SAME RICE, LOWER CALORIES

*Submitted by Katherine Crawford*

Rice is a great food staple - it goes with just about anything, it is easy to prepare, and it's inexpensive... except for one thing. Just a single cup of cooked white rice is around 200 calories! This starchy food is quickly converted to sugar, and then to fat. But what if there was a way to have the same exact rice, but lower the calories?

An undergraduate and his mentor from the College of Chemical Sciences in Sri Lanka discovered that you can reduce the calories of a serving of rice by taking advantage of chemistry. "What we did is cook the rice as you normally do, but when the water is boiling, before adding the raw rice, we added coconut oil—about 3 percent of the weight of the rice you're going to cook," said Sudhair James, the undergraduate who presented this research. "After it was ready, we let it cool in the refrigerator for about 12 hours. That's it." This simple method reduced the calories between 10-15% in standard white rice (from 200 calories to 170-180 calories), with the potential of more calorie reduction in healthier types of rice—anywhere from 50-60%.

But how does it work? Not all starches are equal. Some starches are easily digestible, and others are not. By cooking the rice with a lipid such as coconut oil and letting it sit to cool overnight, the easily-digestible starches are converted into "good" starches that are harder for your body to break down into sugars. This conversion remains true even if you heat it up afterwards, which gives you lower-calorie rice, hot or cold.

## WE GOT TALENT

*Submitted by Patti McRae*



Sixteen year old **Duncan McRae** is an actor who performs with Angels on Stage. In 2014 Duncan was awarded the Gypsy Robe for his commitment and spirit in the Angels on Stage production of the Little Mermaid. This year he is flying in the role of Grandpa Joe in the 2015 production of Willy Wonka Junior. Great job, Duncan!

Programs and performances for Angels on Stage are in Sunnyvale. For more information contact them at [info@angelsonstage.org](mailto:info@angelsonstage.org) or (888) 871-3331. [www.angelsonstage.org](http://www.angelsonstage.org)



# EXECUTIVE DIRECTOR'S COLUMN:

by Lisa Graziano, M. A.



Civilizations around the world have been making resolutions at the start of the new year for over four thousand years.

Babylonians promised their gods at the start of each year that they would return borrowed objects and pay their debts. Gotta love a returned object and a paid off debt!

Ancient Romans began each year by giving gifts and making promises to their god Janus. An interesting god, Janus had two faces – one looking back on the past and the other looking forward toward the future. The Romans made resolutions to Janus in hopes he would look back on their prior year's wrongdoings and forgive them, and bless them in the year ahead. Who doesn't love forgiveness?

In the Medieval era, Knights took a vow each year to re-affirm their commitment to chivalry, the code of conduct to which they aspired. Ahhh, just the thought of good manners, graciousness, courtesy, and gallantry makes me quiver.

Today, the concept of the New Year's Resolution is universal: to reflect upon the prior year and resolve to make improvements. What are the most popular top 10 New Year's resolutions you ask? Wikipedia lists them as:

1. Improve physical well-being: eat healthier, lose weight, exercise more, eat better, drink less alcohol, quit smoking, stop biting nails, get rid of bad habits
2. Improve mental well-being: think positively, laugh more often, enjoy life
3. Improve finances: get out of debt, save money, make small investments
4. Improve career: perform better at current job, get a better job, establish own business
5. Improve education: improve grades, get a better education, learn something new (such as a foreign language or music), study more, read more books, improve talents
6. Improve self: become better organized, reduce stress, be less grumpy, manage time better, be more independent, watch less television, play fewer sitting-down video games
7. Take a trip
8. **Volunteer to help others, practice life skills, give to charity, volunteer to work part-time for a charity organization**
9. Get along better with people, improve social skills, enhance social intelligence
10. Make new friends

A 2007 study by Richard Wiseman, PhD showed that a whopping 88% of all New Year's resolutions fail. Why? Because, he reported, goals are either too vague or not made "public" enough. If you haven't yet publicly announced *your* specific New Year's resolution, PWCF would like to help. Simply choose as your own, Resolution #8 above, commit to supporting *your* charity – PWCF – and as you will see as you read this edition of *PWCF News*, you will actually be accomplishing *ten* New Year's resolutions this year!

1. Improve physical well-being: PWCF resolves to continue to **share with members what we learn** from PWS specialist clinicians and researchers about critical health issues that affect persons with PWS. This issue contains critical information about issues affecting elimination of the bowel.
2. Improve mental well-being: PWCF resolves to provide families with even **more opportunities to connect, play, and laugh together**. This year there are three Family Fun Days, one with the Oakland A's, one with the Anaheim Angels, and a third with the Los Angeles Galaxy!
3. Improve finances: PWCF resolves to **identify and pursue new funding sources so that we may continue to provide the critical supports and services that our families and professionals need**. PWCF shall continue to manage members' money judiciously, invest wisely, and spend sensibly.
4. Improve career: PWCF resolves to **attract and retain highly qualified, bright, compassionate, enthusiastic Board members, staff, consultants, and volunteers**.
5. Improve education: PWCF resolves to **provide members with opportunities to learn even more** by sharing information about the management of medical and therapeutic issues, and hosting seminars and training sessions on PWS behavior management and school advocacy strategies.
6. Improve self: PWCF resolves to never be grumpy with members, and to be **even more proactive and organized**. We will **continue to support and promote current PWS research, encourage new research**, and work to **identify potential new researchers**.
7. Take a trip: PWCF resolves to **reach even wider areas of the state** to provide training to schools, residential settings, and even in family homes.
8. Volunteer to help others: PWCF resolves that our Directors, Officers, staff, and volunteers will **always be available to assist family and professional members** and always ready to learn how we may provide even better support and services.

*Executive Director's Column continued on page 7*

# PWSA (USA) ISSUES MEDICAL ALERT: CONSTIPATION IN INDIVIDUALS WITH PRADER-WILLI SYNDROME

*James Loker, M.D., Pediatric Cardiologist, Ann Scheimann, M.D., MBA, Gastroenterologist*

*PWSA (USA) Clinical Advisory Board Members*

Constipation is a common problem in individuals with Prader-Willi syndrome (PWS). It takes longer for food to move through the GI system in Prader-Willi syndrome.\* This slower passage of food can lead to serious issues similar to the ones seen related to the stomach (see MEDICAL ALERT BOOKLET under “Severe Gastric Distress and Gastroparesis”).

Outpatient methods used to clear constipation in non-PWS patients may be ineffective due to poor fluid intake and hypotonia. Inpatient regimens frequently use large volumes of fluid which may cause problems. Reliance on these methods may lead to life-threatening conditions such as necrosis and perforation of the colon and subsequent sepsis. Due to decreased muscle tone and altered pain response, individuals with PWS may not have the same clinical exam that a non PWS patient would have. A heavier reliance on imaging may be necessary. Individuals with PWS may be at higher

risk for impaction. Rectal examination and enema may be required in addition to oral cleanout regimen. This may also be problematic in some leading to rectal picking.

Patients with PWS having constipation and receiving repeated regimens of oral PEG (polyethylene glycol) solutions for bowel cleansing should be monitored closely for abdominal distention and retention. **Failure of standard constipation protocols to clear the stool in a timely manner, especially in the face of increasing abdominal distension, vomiting, decreased appetite, stoppage of food consumption and/or abdominal pain warrants surgical or GI consultation. Emergent surgical or colonoscopic intervention may be necessary.**

\*Kuhlmann, et al (2014) A descriptive study of colorectal function in adults with Prader-Willi Syndrome: high prevalence of constipation, BMC Gastroenterology, Apr 4; Vol 14: page 63

## USE OF MIRALAX (PEG) IN CHILDREN WITH PWS

*Ann Scheimann, MD, MBA, Professor of Pediatrics, Division of Pediatric Gastroenterology & Nutrition at Johns Hopkins Hospital, PWSA(USA) Clinical Advisory Board Member*

*Janalee Heinemann, MSW, PWSA (USA) Coordinator of Research & International Affairs*



You may have read that the FDA has formally questioned the long term use of PEG (polyethylene glycol) in children. MiraLAX is a polyethylene glycol-containing drug. They do not know how much of PEG gets absorbed and what long term side effects it may have. This laxative has become the centerpiece for management of constipation in pediatrics, especially in children with chronic disorders including Prader-Willi syndrome.

There is potential for side effects with every medication. Mineral oil, lactulose, phosphate enemas, milk of magnesia -- all have potential side effects. Presumably, these medications are only used when they are needed and when the physician believes that the potential benefit outweighs the potential harm. The use of medications off-label and for prolonged periods of time is indispensable in pediatrics. Premature discontinuation of laxative use in children is often associated with symptom relapse and in the long term may be more harmful than prolonged use of laxatives.

PEG is one of the most studied medications ever in pediatric gastroenterology. We do not know of a molecule that has been studied so much to show efficacy in chronic constipation, has been studied in comparative studies, has been studied in fecal disimpaction, has been studied at very high doses as prep for colonoscopy, has been studied in different ages.

There are Cochrane reviews (Cochrane Review: Osmotic and stimulant laxatives for the management of childhood constipation. Gordon M, Naidoo K, Akobeng AK, Thomas AG. Evid Based Child Health. 2013 Jan;8(1):57-109) and **the official position statement from the North American Society for Pediatric Gastroenterology released in January suggesting that there is justification to use PEG as first line treatment for childhood constipation and that this agent is deemed more effective than other agents and as safe as other agents.**

The FDA should be applauded for awarding a study to evaluate in even more detail the safety and potential side effects of PEG, but until the results of the study are concluded, **current advice for treatment of constipation in PWS remains the same – use MiraLAX to manage constipation.**

## NEW PWS CLINIC TO SERVE ADULTS WITH PWS



**June-Anne Gold, M.D.** from the Division of Genetic and Genomic Medicine at UC Irvine is in the process of initiating a new clinic that will focus on providing genetic evaluation and management for adults with Prader-Willi syndrome. It is anticipated that the clinic will be held approximately four times per year.

Dr. Gold has a long-standing interest in rare diseases and their natural history, and for many years she has had a passion for individuals with PWS and the challenges they and their families face. Dr. Gold is a member of the Board of Directors of both the Prader-Willi California Foundation and the International Prader-Willi Syndrome Organisation. She is involved in much PWS-related research and brings a wealth of information and care to her patients with PWS.



To learn more or be referred to the new PWS Clinic serving adults with PWS please call UCI's Division of Genetics and Genomic Medicine at 714-456-5791.

## EXECUTIVE DIRECTOR'S COLUMN, CONTINUED

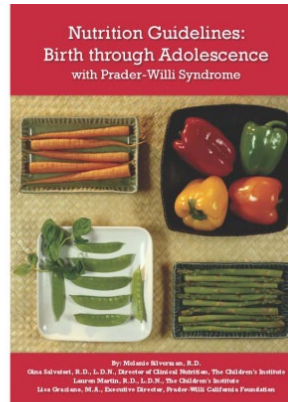
*Executive Director's Column continued from page 5*

9. Get along better with people: PWCF resolves to **reach out to other organizations to develop alliances**, and expand our advocacy and awareness-raising capabilities.
10. Make new friends: PWCF resolves to **welcome newly identified families and newly identified professionals** and help them feel valued and appreciated.

On behalf of PWCF's Officers, Board of Directors, Consultants, and Staff, I wish you the healthiest and happiest of new years.

## PWSA PUBLISHES UPDATED NUTRITION BOOK

PWCF announces an updated booklet, *Nutrition Guidelines: Birth Through Adolescence*.



This 16 page publication, which includes sections on calorie needs, what and how to feed your child, special events, and much more, is produced thanks to the volunteer efforts of PWCF Professional Member **Melanie Silverman, M.S., RD, IBCIC**, **Gina Salvatori, RD, LDN** (Director of Clinical Nutrition at The Children's Institute), **Lauren Martin, RD, LDN** (also with The Children's Institute) and **Lisa Graziano, M.A.** (PWCF's Executive Director).

This booklet can be purchased from PWSA (USA) for \$7.50 online at [www.pwsausa.org/shop/publications](http://www.pwsausa.org/shop/publications) or by calling 800-926-4797.

This same team is putting the finishing touches on an updated book, *Nutrition Guidelines: Adolescence-Adult with PWS*. It is anticipated that it will be available for purchase in the next couple of months.



# ENAMEL EROSION AND SEVERE TOOTH WEAR IN CHILDREN AND ADULTS WITH PRADER-WILLI SYNDROME

by Barbara Dorn RN and Dr. Kimberly Wachter, DDS, with edits by Lisa Graziano

For years, it has been that individuals with Prader-Willi syndrome (PWS) have problems with saliva production resulting in dental caries/cavities, loss of enamel and severe tooth wear. Studies on “Salivary Flow and Oral Abnormalities in Prader-Willi Syndrome” as well as the study on “Severe Tooth Wear in Prader-Willi Syndrome: A Case-control Study” done by Saeves, Nordgarden, Espelid and Storhaug (2010 and 2012) from Olso, Norway support and validate these findings. The challenge now facing those with PWS is what to do to prevent and/or manage these problems. The following resource provides an overview of these dental problems along with some possible approaches.

**ENAMEL EROSION** is the wearing down of the protective coating (enamel) of the teeth. When enamel wears down, microscopic channels in the tooth open up and become exposed. Most people with this problem complain of discomfort and pain. However, since many persons with PWS have an altered pain response they may not experience this sensation.

## COMMON CAUSES

- Abnormal salivation
- Diet high in sugars and acid (*Soft drinks, sport drinks, fruit drinks, lemonade, coffee, tomatoes, strawberries. Citric acid, phosphoric acid, ascorbic acid are a few ingredients to watch for in foods.*)
- Grinding of the surfaces of teeth
- Health conditions including gastric reflux
- Medications (aspirin, antihistamines and some vitamins)

## PREVENTION

- Drink water. Limit soft drinks, sport drinks, juices and coffee in moderation. Dilute juices with water.
- Brush with Biotene dry mouth toothpaste to improve saliva. Biotene also contains fluoride, which is essential to dental health.
- Minimize swallowing toothpaste (*too* much fluoride can cause problems like enamel fluorosis. This condition can occur in children and causes defects in the enamel of the teeth. Ingesting large amounts of fluoride can be toxic and cause nausea, stomach pain and/or vomiting. It may not be quickly detected in person with PWS).
- Swish your mouth out with water or brush your teeth after drinking or eating items high in acid.
- Don't sip on beverages for extended periods of time.
- Do not drink or eat high acid beverages/food in the evening after supper.
- Use a straw to keep acids away from teeth.
- Get regular dental checkups and cleanings (at least once every 6 months).
- Talk to your dentist about daily fluoride mouthwash if there is a history of cavities (use as a rinse; do not swallow). If needed to prevent swallowing, apply mouthwash with a Q-tip.

- Ask the dentist if sealants may be helpful in preventing enamel erosion and tooth decay.

## TREATMENT

Once lost, enamel **cannot** be replaced. Treatment of tooth enamel loss depends on the underlying problem.

If a person with PWS is found to have a sudden loss of tooth enamel, testing should be done to determine if a medical condition is present. (May require special diet and medical intervention).

## **Signs of Enamel Erosion:**

- **Translucency** of the enamel
- **Darkening or discoloration** of the teeth
- **Pain or cold sensitivity** (may not always be reported in persons with PWS)

**SEVERE TOOTH WEAR/GRINDING** (also called bruxism) occurs most commonly at night. When teeth grinding occurs on a regular basis, teeth can be damaged and other oral complications can arise. Often seen in both children and adults with PWS.

## CAUSES

The exact causes are unknown, but it is often associated with stress and/or an abnormal bite.

## TREATMENT

- Mouth bite guard - best if individually fitted by a dentist. Used most commonly while the person sleeps. May require incentive program for compliance.
- Avoid or cut back on foods and drinks that contain caffeine, such as colas, chocolate and coffee.
- Avoid alcohol. Grinding tends to intensify after alcohol consumption.
- Discourage chewing on pencils or pens or anything that is not food. Minimize chewing gum. It allows jaw muscles to get used to clenching and makes it more likely to grind teeth.
- Work with person with PWS to learn not to clench or grind his/her teeth. Have him/her practice relaxing jaw muscles.
- Try holding a warm washcloth against the cheek in front of the earlobe.
- Include plenty of water. Dehydration may be linked to teeth grinding.

# PWCF WELCOMES PWS SPECIALIST DAVID A. STEVENSON, M.D. TO CALIFORNIA



PWCF is proud to introduce California's newest Pediatrician and Medical Geneticist, **David A. Stevenson, M.D.**

Dr. Stevenson completed his residency in Pediatrics at the University of New Mexico and a 3 year fellowship in medical genetics at the University of Utah. He has been on faculty at the University of Utah for the past 10 years, and worked closely with the PWSA of Utah to establish their

PWS Clinic. Dr. Stevenson moved to California this year and is currently an Associate Professor in the Division of Medical Genetics at Stanford University.

As a medical geneticist, Dr. Stevenson is interested in genetic disorders and has an active medical genetics clinic at Stanford

where he sees patients. He has a specific interest in Prader-Willi syndrome and has been active in clinical research.

He has worked for many years with the Prader-Willi Syndrome Association (USA) primarily investigating the causes of morbidity. He is currently a member of the PWSA (USA) Scientific Advisory Board.

Dr. Stevenson is excited about his relocation to California and looks forward to seeing individuals with PWS in his clinic and getting to know members of the Prader-Willi California Foundation.

To learn more or to schedule an appointment with Dr. Stevenson at Stanford University, Lucile Packard Children's Hospital call 650-723-6858.



## WHEREVER YOU ARE PWCF HAS A FAMILY FUN DAY FOR YOU!



### Family Fun at the Oakland A's!

A's Battle Defending AL Champion Kansas City Royals

**Sunday, June 28 at 1:00 p.m. at the Oakland Coliseum**

Field Level \$28/ticket

Pre-Game Visit with Stomper!

### Family Fun at the Anaheim Angels!

Angels v. Texas Rangers

**Saturday, July 25 at 6:00 p.m. at Angels Stadium, Anaheim**

Club Loge Behind Third Base \$28/ticket

Post Game Fireworks!



### Family Fun at the LA Galaxy!

Galaxy v. Portland

**Sunday, October 18 at 4:00 p.m. at the StubHub Center, Carson**

Upper Preferred Seating \$29/ticket

Exciting Last Game of the Season!

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

Call for  
research  
participants

## PATIENTS NEEDED FOR RESEARCH STUDIES TARGETING HYPERPHAGIA

### [Beloranib Study](#)

This important phase 3 clinical trial sponsored by Zafgen, **bestPWS**, will help determine the effectiveness of a novel treatment for PWS called beloranib. In a phase 2 clinical trial completed earlier this year, beloranib showed a reduction of body fat and hyperphagia-related behaviors (the drive to eat) in a small group of PWS patients.

**Participants:** Adolescents and adults (12-65 years) with PWS, obese with a BMI of greater than or equal to 30, and, less than or equal to 60 kg/m<sup>2</sup> (or greater than or equal to 95th percentile for ages 12-17). The study will enroll people with PWS living in a family home environment or group home less than half time with a consistent primary caregiver.

Study participants will be randomly assigned to receive beloranib or placebo. Study participation will involve twice weekly injections administered by visiting nurses at the participant's home and approximately 8 visits to the study site over 7 months. Patients who complete the study will be eligible to enroll in an optional study extension where all patients will receive beloranib for another 6 months. Travel expenses for visits to the study site will be covered.

**To learn more go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and type in "Zafgen Prader Willi" on the search bar.**

To participate in the study contact the site closest to you:

**Northern CA: UC Davis in Sacramento**

Contact: Majid Mirmiran, MD, PhD  
916-734-4790  
[majid.mirmiran@ucdmc.ucdavis.edu](mailto:majid.mirmiran@ucdmc.ucdavis.edu)

**Southern CA: UC San Diego,**

**Rady Children's Hospital**  
Principal Investigator: Lynne Bird, MD  
Contact: Rachel Winograd  
858-966-8453  
[rwinograd@rchsd.org](mailto:rwinograd@rchsd.org)

### [Prader-Willi Oxytocin Study](#)

The purpose of this study is to investigate if intranasal oxytocin will improve hyperphagia, social skills, and behaviors in subjects with PWS. Individuals with PWS have been found to have a deficit of oxytocin-producing neurons and decreased oxytocin receptor gene function, so this study will determine if oxytocin administration will improve some of the aspects of PWS that are particularly troublesome for children and their families (the insatiable appetite and social behaviors).

**Participants:** Children (ages 5-11 years) with a confirmed diagnosis of PWS, in nutritional phase 2b or 3, as determined by Dr. Kimonis, currently on growth hormone treatment and have been receiving growth hormone treatment for at least one year prior to screening date.

**Study Location:** University of California, Irvine Institute for Clinical and Translational Science. After a screening visit to qualify for the study, patients will be given either oxytocin or placebo and then after a 2-4 week wash-out period, will return for treatment with the alternative treatment.

Each treatment period will consist of 7-8 clinic visits. Measurement of sleep quality will be recorded from direct observation and questionnaires. There may be therapeutic effects for PWS by decreasing symptoms. There are potential side effects associated with this drug that will be discussed in detail with you before beginning the study. Compensation is \$200 total.

### [Contact:](#)

**Virginia Kimonis, M.D.**, Lead Researcher, Division of Genetics and Metabolism, Professor of Pediatrics, UCI.  
949-824-0571  
[vkimonis@uci.edu](mailto:vkimonis@uci.edu)

or **Claudia Shambaugh**, Study Coordinator  
949-824-0521  
[cshambau@uci.edu](mailto:cshambau@uci.edu)

See page 12 for a parent's  
experiences in this study



UCI IRVINE

## PATIENTS NEEDED FOR RESEARCH STUDIES ON MOVEMENT AND ENERGY USE IN PWS

Call for  
research  
participants

### *Motor Proficiency, Movement Planning, and Sensory Integration in PWS*

Participants: Children ages 4 to 7 years who are diagnosed with PWS.

Participants will be asked to make three visits. Visit 1 will last 1-2 hours and Visit 2 and 3 will last 3-4 hours. Testing will take place in the Movement Enhancement Laboratory in the Ruby Gerontology Center at CSUF.

Measurements include: a health screening, an intelligence test, and movement assessments. Participants will be given a package of toys worth \$20 following each visit to CSUF. Parents/guardians will be reimbursed for mileage for the visits to CSUF and will be provided with free parking. **For more information or to participate** call or email [pws.fullerton.edu](mailto:pws.fullerton.edu) or contact:

Dr. Daniela Rubin 657-278-4707 [drubin@fullerton.edu](mailto:drubin@fullerton.edu) or the Research Office 657-278-8737 [pwstudy@fullerton.edu](mailto:pwstudy@fullerton.edu)

Languages: English/Spanish

### *Energy Expenditure in Children with PWS While Walking on a Treadmill*

Participants: Children with and without PWS ages 7-12 years old. Must be able to walk continuously for 5 minutes.

Complete 1 site visit at CSU Fullerton lasting 2.5 hours. Children will receive a \$20 gift card for their participation

For more information or to participate call or email Frank at [frank.chavoya@csu.fullerton.edu](mailto:frank.chavoya@csu.fullerton.edu) or Dr. Daniela Rubin at [drubin@fullerton.edu](mailto:drubin@fullerton.edu) or the Research Office at 657-278-3671

Languages: English/Spanish



CALIFORNIA STATE UNIVERSITY  
**FULLERTON**

## MENU CONSULTATION SERVICES FOR RESIDENTIAL SERVICE PROVIDERS



The Center for Prader-Willi Syndrome at The Children's Institute of Pittsburgh recently announced its new Menu

Consultation Services specially designed for care providers.

Writes The Center, "The dietitians at The Children's Institute can help residential providers implement a formalized version of the Red, Yellow, Green (RYG) System for Weight Control. This diet, along with the structure of planned menus and visually appealing meals, has been proven to promote successful weight loss and management in patients who have gone through their PWS program. In fact:

- An average of 66% of families continue to follow the RYG diet 3 months post-discharge

- Patients following this diet lose an average of 74% more weight
- Patients on the RYG diet are four times more likely to lose weight than those following other diets

"The Center for Prader-Willi Syndrome offers three levels of consultation services which are described in the attached brochure. They are confident that their program will benefit organizations that serve individuals with PWS, and can make a positive difference in the lives of individuals with PWS and their families."

Please contact TCI's The Center for Prader-Willi Syndrome directly to learn more about their Menu Consultation Services. Feel free to contact directly Gina Salvatori, RD, LDN, Director of Clinical Nutrition at The Children's Institute, at 412-420-2159.

# MY EXPERIENCE WITH THE PWS BELORANIB STUDY

by Victoria Stover, Fallbrook, CA



We are enrolled in San Diego with Rachel and Dr. Lynne Bird. If anyone wants to know what it is like, it's amazing!! They classified us as the guinea pigs, since we were first to start and willing to let them, figure things out and how they best can work with scheduling, breaks for eating snacks, etc. Going with the flow is easy with them.

Rachel is so attentive to our needs, works always to make sure we are feeling comfortable, and talks to you about everything going on, and just casual conversations. She only leaves our sides on our breaks for breakfast and lunch so she can continue to do the paperwork and blood spinning, etc. She helps Meagan stay calm

“Rachel is so attentive to our needs, works always to make sure we are feeling comfortable, and talks to you about everything going on”

during blood draws, and we always have the same amazing guy, John, draw her blood (minus his one vacation day=small crying spell and nervousness) who greets her with a smile, calls her his buddy, and always jokes and laughs with her.

EKGs are done every visit, pre- and post dose, vitals, fasting and urine voided weights in same gowns every time, fasting blood work, and injection. We had a DEXA scan (bone density) first

visit, so that visit was a little bit longer than the rest so far.

We just started week #4. Some things make us think she is on it, and some make us think maybe not, but we know in week #7 we will definitely be on it.

The home health nurse, Susan, just the same: so caring and always making sure Meagan knows she is in charge and can freely discuss anything with her. She comes twice a week, and they have their time, laugh and joke. She has to come on holidays and does it with a huge smile on her face. Another perfect fit for PWS clinicals, as she has a distant family member who has PWS so she understands our lifestyle and always wants to know what worked for us so that she can help educate others about PWS.

We have a log pad that is simple to use, it alarms you if you need to do something, and you carry it with you to all study-related appointments and your home health nurse inputs as well as at her visits.

“The time seems long on the day of the appointment but in the grand scheme of things, it's so little compared to the life time of hunger pains.”

Compensation is a benefit as we have been in non-compensated studies, so I was shocked at the amount they are willing to give, for our time and energy, and driving the hour to the hospital.

I highly recommend if you can make it fit your schedule to be willing to partake in this study; this one is a much higher quality one than some of the ones we have done.

Our prayer now is that this will be a benefit to Meagan and all people with PWS. The time seems long on the day of the appointment but in the grand scheme of things, it's so little compared to the life time of hunger pains.

Hope this helps any families that are on the fence about joining a study.



# HIGH PROTEIN DIETS AND THE PALEOLITHIC DIET: COMMENTARY

by Daniela Rubin, Ph.D. and Jill Nowak Przygod R.D., CDE



In the last two decades, a great deal of interest has been placed on diets that provide a high percentage of caloric intake through protein. High protein diets are those that provide more than 3 g of protein per kg of body weight per day or about 30% of the total calories. In comparison, current dietary guidelines for Americans recommend 0.8 g/kg/day or about 15% of total calories for protein intake. The benefits of these high protein diets include increased satiety, increased calories spent processing the food, and positive protein balance which is helpful for maintaining muscle mass in situations in which there is caloric deficiency.<sup>1</sup>

Recommendations suggest that protein consumption should be no more than 35% of total daily calories. At this moment there are no studies that have evaluated whether too much protein can be harmful in the long run to the kidneys except when people have pre-existing conditions in their kidneys.<sup>2</sup> However, two common issues associated with high protein diets are dehydration and the high fat intake that is associated with these diets. Specifically, the large weight loss induced at the beginning when adopting a high protein diet is water loss.

The Paleolithic diet is included in this category of high protein diets. The key message this diet advertises is to restrict refined carbohydrates and dairy products and emphasize vegetables and lean proteins. There are also specific limitations as to which foods to consume and which not to. While the idea sounds interesting, there is no solid evidence that these diets should be recommended.

The small amount of research on this diet has been short-term (3 weeks to 3 months) clinical interventions in at-risk adult populations such as people with diabetes and/or the metabolic syndrome. The results of these studies suggest that this type of diet leads to reduction in fat mass and improvement of cholesterol and glucose levels. One study had 20 people enrolled to begin with and only 14 completed the diet during 3 weeks with results evaluated in only 6 participants.<sup>3</sup> This study had no comparison group.<sup>3</sup>

A second study was done in 13 patients with diabetes during three months.<sup>4</sup> In the latest published study, 14 adults in their mid fifties and with two of any of these conditions (high lipids, high sugar, high blood pressure, obesity) were enrolled in the Paleolithic diet during two weeks and compared to a control group.<sup>5</sup> The poor design of such studies (very few people who did the diet, no comparison group, short duration) begs the question as to how

really helpful is this diet. One key reason why these trials are so short is the fact that it is very hard for people to adopt this diet strictly for a long time. One other concern is that trials testing this diet have been done in adults at risk for disease or with disease and we do not know how this diet works for growing children and adolescents.

Therefore, based on the limited amount of research evaluating the Paleolithic diet it seems premature to recommend that the Paleo diet should be adopted in people with Prader-Willi syndrome. Moreover, concerns regarding the nutrients provided by this diet lie on the limitation of dairy consumption, which can cause poor intake for calcium and vitamin D (both nutrients needed for bone health). Also, there is a limitation on the consumption of whole grains and legumes, thus limiting the intake of dietary fiber, B vitamins and iron. Also, compliance may be an issue because of the limitation of foods and perhaps cost.

However, most certainly the indications of a reduced intake of refined carbohydrates (sugary drinks, sweets, cookies, pastries, etc.) and increased intake of vegetables align well with healthy dietary practices for PWS as well as for the general population.

## References:

1. Jeukendrup, A., & Gleeson, M. (2010). Sport Nutrition: An Introduction to Energy Production and Performance. Champaign, IL: Human Kinetics.
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3. Osterdhal, Kocturk, Koocheck et al. (2008) Effects of a short-term intervention with a paleolithic diet in healthy volunteers. *Eur J Clin Nutr* ;62(5):682-5.
4. Jönsson, Grandfelt, Ahrén et al. (2009). Beneficial effects of a Paleolithic diet on cardiovascular risk factors in type 2 diabetes: a randomized cross-over pilot study. *Cardiovasc Diabetol*. 16;8:35.
5. Boers, Muskiet, Berkeelar et al. (2014) Favourable effects of consuming a Palaeolithic-type diet on characteristics of the metabolic syndrome: a randomized controlled pilot-study. *Lipids Health Dis*;13:160.

“based on the limited amount of research evaluating the Paleolithic diet it seems premature to recommend that the Paleo diet should be adopted in people with Prader-Willi syndrome”

# ASICS LA MARATHON AND LA BIG 5K DONORS!

PWCF expresses its profound appreciation to each and every one of our participants and to each and every one of our donors. Your contributions will directly assist and support someone with Prader-Willi syndrome. A sincere thank you to everyone who participated!

## ASICS LA Marathon Runners & Supporters

### **Kim Morgan** and her donors running in honor of **Samantha Morgan**

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Ashley Heath

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Gregory Williams (Honda North America) • Warren K. Zahler

*Marathon/5K Donors continued on page 15*

# PWCF EVENTS CALENDAR 2015

Date	Day	Event	Location
January 11	Sunday	LA County Support Group Meeting	Redondo Beach, PWCF Office
January 23-25	Fri - Sun	Board Meeting	Desert Springs Resort
March 10	Tuesday	Board Meeting	Evening - Phone Meeting
March 14	Saturday	LA Big 5K	Dodger Stadium
March 15	Sunday	ASICS LA Marathon	Los Angeles
April 11	Saturday	Northern CA Walk	San Francisco
April 12	Sunday	LA County Support Group Meeting	Redondo Beach, PWCF Office
April 18	Saturday	Central CA Walk	Dry Creek Park
April 26	Sunday	Southern CA Walk	Griffith Park
May 2	Saturday	Northern CA Support Group Meeting	San Francisco
May 14	Thursday	Behavior Management Training	Redondo Beach, PWCF Office
May 16	Saturday	Board Meeting	Redondo Beach, PWCF Office
June 18-23	Thu - Tues	PWS Camp	Camp Harmon
June 28	Sunday	Family Day at the Oakland A's	Oakland Coliseum
July 14	Tuesday	Board Meeting	Evening - Phone Meeting
July 25	Saturday	Family Day at the Anaheim Angels	Anaheim
July 26	Sunday	LA County Support Group Meeting	Redondo Beach, PWCF Office
August 1	Saturday	IEP Advocacy Training	Redondo Beach, PWCF Office
September 12	Saturday	Board Meeting	Redondo Beach, PWCF Office
September 19	Saturday	Northern CA Support Group Meeting	San Francisco
October 3	Saturday	Behavior Management Training	Redondo Beach, PWCF Office
October 4	Sunday	Brass Golf Tournament	Black Gold Golf Club, Yorba Linda
October 18	Sunday	Family Day at the LA Galaxy	StubHub Center
October 25	Sunday	LA County Support Group Meeting	Redondo Beach, PWCF Office
November 1-7	Sun-Sat	Obesity Week	Los Angeles
November 3-7	Tues-Sat	PWSA Meetings/Conference	Orlando, FL
November 13	Friday	Board Meeting	So. CA Hotel
November 14	Saturday	PWCF Annual State Conference	So. CA Hotel

**Renee Tarica & Lianne Noddle** and their donors  
running in memory of **Yvette Tarica**

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running in honor of **Lindsey Wang**  
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Krysta • Anonymous • Susan Requa

**Chris Welker** running in honor of **Samantha Morgan**

**Melissa Williams** raised funds in honor of **Ryan Ramirez**  
Ruth Ann Williams • Melissa Williams

## BOARD CORNER

*Summary of Board of Directors Meeting on January 24-25, 2015*

*Submitted by Diane Kavrell*

The Board met from Saturday January 24th through 26th at the Desert Princess Hotel in Palm Springs. Members in attendance were Julie Casey, Tom McRae, Whitney Bras, Roger Goatcher, Daniela Rubin, Ph.D., Diane Kavrell, Renee Tarica and Nisha Mehta. Also present were Lisa Graziano (Executive Director), Gloria Burns (Office Manager), Sheila Umeda (Social Worker Consultant) and Jill Nowak (Dietician Consultant).

The following reports were presented and reviewed prior to the meeting and were approved into the record at the meeting: Executive Committee Report, Executive Director's Report, Finance Committee Report, Social Media Report, Public Awareness Committee Report, Program Committee Report, and the minutes from the November meeting.

### Highlights of the meeting include:

- Although we are currently financially secure we are always looking for future donations to ensure our position and increase services to our members either through grants or Corporate Sponsorships. The Board discussed researching the feasibility of hiring a Fund Development Manager whose sole purpose would be to identify and plan future revenue sources. Also discussed was the feasibility of hiring a public relations consulting firm to help us raise awareness of PWS.
- The Board began discussing ideas for the 2015 Member Give Back program, and also re-confirmed the desire to continue

the Member Outreach program by calling members in March.

- Working on various member activities: Oakland A's event, Anaheim Angels, and LA Galaxy; dates to be finalized soon. Also another fun event both being held in Northern and Southern California will be an afternoon at "We Rock the Spectrum". It's a very cool indoor play area that has something for everyone from ages 1 and up. Watch the newsletter, our website, Facebook & Twitter for details on all of these events as they are finalized.
- Annual GEM (General Education Meeting) has been renamed to Annual State Conference.
- We will again host IEP and Behavior workshops; one of each to be held in both Northern and Southern California.
- Two consultants Sheila Umeda (Social Worker) and Kim Nowak (Dietician) both told us about the help they are giving to our families. Sheila is especially helpful with insurance issues.
- Voting to grant IPWSO \$500 toward the development of their Prader-Willi Syndrome mobile app for the iPhone (currently only available for android platforms) contingent on the app actually being developed.
- The Board also spent significant time discussing the budget and finalizing the strategic plan.

### *We Remember Richard Sadaichi Sakurai*

*September 30, 1966 – December 7, 2014*

Richard Sakurai, known to all who loved him as "Ricky," loved life. He loved his friends, and he absolutely loved his family.



He and his mother, Rose, loved to travel. They traveled to Japan a number of times, and often took Ricky's nephews and other family members with them on their adventures.

Family was very important to Ricky. Also important were his friends.

Ricky enjoyed spending time at the New Day Program in Montebello where he was a valued member of their group.

Ricky passed away in the loving embrace of his mother who was devoted to her son. He will be missed by many and loved forever by all who knew him.



# TRIBUTE TO SCARLETT LEIGH MEADE

by Jennifer Meade



Our beautiful Scarlett was born on January 24, 2014. She provided many surprises through her short life including the day she was born. My 39th birthday was the day before. I was 7 months pregnant. At 10PM that night my

water unexpectedly broke and Scarlett was born 3 hours later. With the premature birth, Scarlett was whisked off to the NICU for immediate treatment.

Almost immediately, the doctors expressed concern that Scarlett was very sleepy and hypotonic. I thought she was just traumatized from being born 2 months early. Scarlett was tested for a slew of potential disorders and a few weeks later, Scarlett was diagnosed with the UPD version of Prader-Willi syndrome. Her father and I were devastated. What we read on the Internet regarding Prader-Willi was horrifying. Luckily we found the Prader-Willi national organization and ordered the Package of Hope. As we became more educated on the disorder we felt more confident that we could handle it. Scarlett didn't seem like a "special needs" baby, she was just Scarlett.

We did everything we could to make sure Scarlett had all the early intervention tools that she needed. We organized all of her specialist referrals through her pediatrician. She was set up for regular appointments with a physical therapist, occupational therapist, ophthalmologist, gastroenterologist and endocrinologist. Scarlett was making great strides in her development. She got off her feeding tube at 5 months. She started growth hormones at 7 months. She was an incredibly easy going baby who hardly ever cried. Keeping up with all of the intervention therapies was a lot of work for her father and me, but it became a new normal for us. We were in love with our baby Scarlett and everything we did for her was worth it.

Scarlett was never sick until she was about 9 months old. It started with 2 weeks of diarrhea, which the doctors initially thought was from a type of baby food that was introduced. Then she got what seemed to be a cold but turned into something more when she became feverish and just wanted to sleep all day. We took Scarlett to the emergency room and she was diagnosed with Para influenza Type IV. She recovered a week later and we took her home.

Unfortunately a few days later we had to take her back since she became sick again. This time the diagnosis was worse – ALL T-Cell Leukemia. Scarlett had to go on chemotherapy immediately in the hopes of eradicating the cancer. Just like with having Prader-Willi, we were fully prepared to work with Scarlett to get through this

crisis, which we thought would just be a temporary setback. We reached out through PWSA(USA) and PWCF to connect Prader-Willi experts with Scarlett's oncology team. Scarlett took the chemotherapy treatments in stride. She never complained and was still a happy baby for the first few weeks. Unfortunately, she contracted another respiratory virus that her little body could not fight off because the chemotherapy and Leukemia wiped out her immune system. Scarlett had to go on a respirator in order to get enough oxygen to her infected lungs.

The doctors did not think Scarlett was going to make it on Christmas Eve, but she continued to hold on for an additional three days. Because she was such a fighter, her big sister was able to have a Christmas morning opening gifts from Santa. We had the love and support of family and friends who stepped up and offered help in our time of need. So many people prayed for her. Unfortunately we did not get our miracle. On December 27th, Scarlett's little body shut down and she died peacefully in our arms.

We had 11 months and 3 days as Scarlett's parents. While we are grateful for that time with her, we are also sad for all the things we will miss from not seeing her grow up. We were ready to deal with all of the difficulties that Prader-Willi would bring later on. We had ideas about diet plans, teaching her yoga for exercise, starting speech therapy, going to a regular school, and the list goes on.

Scarlett's life was full of only love and goodness. We did not see her as special needs. To us she was just special. We will miss her every single day for the rest of our lives. We are grateful for the support we received from the Prader-Willi community throughout Scarlett's short life.

*After battling leukemia, Scarlett passed peacefully on December 27 in the arms of her parents. Her memorial service was held on January 9 at All Souls Mortuary Chapel. To send the family a message, go to [www.allsoulsmortuary.com](http://www.allsoulsmortuary.com) or email PWCF at [info@pwcf.org](mailto:info@pwcf.org).*

*Jennifer and James ran on Team PWCF in memory of Scarlett at the LA Big 5K on March 14. Their determination raised awareness of PWS, their generosity raised funds for PWCF, and their courage inspires all who have the honor to know them.*



## WE GET MAIL

Dear PWCF: Thanks for your past information and support. Big win today for our IEP meeting... got 1:1 [aide support] till she is in 2nd grade...presently in Kindergarten. I was coached by all your “lingo” and all the info from PWCF. Our hearts are thankful. We stood our ground and won today. Yeah for the Home Team. I will help others in the future to achieve as well. Great New Year! *Love, Rhonda Faust of Angela PWS, turning 6 on March 14. Always Thankful!!!*



Dear PWCF: Thank you for the Healthy Life materials I just received from your organization. How clever and how useful! Up here at Far Northern we are working on a number of small projects to increase the health status of those we serve. Your materials are very useful for everyone as well as the population you focus on. Thank you so much for the resources.

One of the projects we are working on are small food banks for people in supported and independent living. For a small amount a money (\$10.00) a month, a bag of food is delivered either weekly or bi-weekly to your home with recipes and instructions on how to cook the food. It also creates jobs for our clients who work the food bank. I would like to share this material with the food banks and would like to know if we could have permission to copy the two brochures for the purpose of helping people understand nutrition facts labels and nutrition and physical activity guidelines. Thank you again for the gifts. *Laura Larson, Executive Director, Far Northern Regional Center*

Dear PWCF: I saved part of my allowance money since 6<sup>th</sup> grade (I am in 8<sup>th</sup> grade) to help support you. There was a boy in my classes K-5 who had Prader-Willi. *Olivia Maturama*

Dear PWCF: ...I'm excited about all of the new experiments they are doing with the “new” drug. I'm so thankful for the CA Association [PWCF] as they have been so into getting PWS out into the news and information that was not available 30 years ago! Keep up the great work!! *Thanks and kind regards, Pat Noland*

## THANKS TO OUR SHINING STARS!



Thanks to our Shining Star donors, we have raised over **\$35,000** towards PWCF's mission as we begin 2015! This support helps families all across the state of California. We're working together to improve the lives of those affected by PWS. Your tax-deductible donations will help us do even more.

**Since 1979 PWCF has been the *only* organization in California to solely focus on serving persons with PWS, their families, and the professionals who serve them.**

PWCF provides caring support to newly diagnosed parents; provides critical advocacy services to families; brings invaluable education and training to families and professionals including residential providers, teachers, and Regional Center staff; funds PWS Multidisciplinary Clinics; raises the public's awareness of PWS; and helps researchers progress PWS research.

Now, we begin 2015 with all the hope and promise that a new year brings. Thanks to everyone who supports PWCF!

# 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.

*Your support keeps PWCF strong so that we may provide vitally needed programs and services to persons with PWS, families, and the professionals who serve them.*

*Renew your membership today!*

## Renewed Family Friend Members

Patrick Maxon  
Janice Nakagawa & Steve Grogan  
Nancy & John Jenkins  
Ronnie Raffaniello  
Tyna & Ray Triggs

## Renewed Professional Members

Mary Lane Carlson, Ed.D, MPH, RD, CDE  
Jowella Chico  
Jowella Chico Care Home  
Janet Foos  
Redwood Coast Regional Center  
Larry Landauer  
Executive Director, Regional Center of Orange County  
Ellen Lewis  
Southern CA Integrated Health & Living Project  
Paul Jorgenson  
Ashbury Images  
Santi J. Rogers  
Executive Director, Department of Developmental Services  
Daniela Rubin, Ph.D.  
CSU Fullerton  
James Shorter  
Executive Director, Golden Gate Regional Center  
Melanie Silverman, MS, RD, IBCLC  
Melinda Sullivan  
Executive Director, Frank D. Lanterman Regional Center

## Renewed Auxiliary Members

Lynnette Collins  
Laura Cornish

## Renewed Extended Family Members

Dolores Albaugh  
Lisa Ann Bonk  
Terri Canales  
Carina Chaij  
Sally & Chet Collom  
Mary Culver  
Laura & Ray Esau  
Molly Fuller  
Wendy & Bob Graziano  
Pat Grey  
Sandra Hansen  
Jo & Floyd Hatcher  
Anna Maria Kanauka  
Sharri & George Marich  
Betty McBroome  
Linda McGee  
Kathleen Minor  
Lynn & Chuck Morrow  
Lianne & David Noddle  
Kathy & Ralph Paige  
Judy Schlafer  
Margaret & Bill Spinelli  
Villy Vitro  
Ron & Pat Vogrin  
Celeste & Tom Von Der Ahe  
Mary & Pat Williams

## WE GOOFED!



### Corrected Date of Southern California's Walking for Prader-Willi Syndrome event

Last issue listed the Southern California WALK event incorrectly.

The **correct date** for this year's So CAL event is **Sunday, April 26.**

**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@pwc.org

## DONATIONS

January - March 2015

### **Shining Star Donations**

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

Stephen Coffey  
Mark & Susan Lewis  
Dennis Martino in honor of Lilli Moore  
The Nararo Foundation  
Jacqueline Smalley  
Gabriel Snodgrass in loving memory of Julianna  
Michelle Snodgrass  
in honor of Veronica Renee Bosse

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

Bonnie Gowing in honor of Trevor Ryan  
Ash Gujral in memory of Christopher Clarke  
Tim & Karen Jobe  
Suzanne Privette in honor of Samantha Morgan  
(monthly donation)

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

Rudy & Catherine Alvarez  
in memory of Daniel John Alvarez  
Anonymous  
Mary Culver in honor of Allison Mahan  
Candelaria & Ignacio Garcia  
in honor of Ignacio Martinez, Jr.  
Phillip Lee, M.D. in honor of Cameron Graziano  
Judy & Bob Morgan in honor of Samantha Morgan  
Ivette Ramos in honor of Victor Ramos  
Mark & Linda Ryan in honor of Trevor Ryan  
Rose M. Sakurai in memory of Richard Sakurai

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

Lisa Ann Bonk in honor of Nolan Carl Bonk  
Michele Boucher & Scott Rosenthal  
in honor of Trevor Ryan  
Rima & Robert Buch in honor of Elle Martiniak  
Lorraine & Marvin Buhai  
in honor of Amanda Wissmann  
Ida Dacus in memory of Curt Martens  
Molly Carter in honor of Dan Carter  
Gayle Dax-Conroy  
Kathleen Dignan in honor of Timothy Dignan  
Easter Seals Central California  
in honor of PWS Camp at Camp Harmon  
Wanda & Steve Faivre  
Lisa & T.J. Graziano in honor of Cameron Graziano  
Gitta Meyer-Green & Lawrence Green  
in honor of Cameron Graziano  
The Greskovics Family  
Brian P. Hughes in honor of Ryan Casey

Kelly & Hurt Jaeger in honor of Brooke Marich  
The Kairey Family in honor of Amanda Wissmann  
John Koerber in honor of Alison M. Koerber  
Elias & Miriam Liberman in memory of Yvette Tarica  
Kathleen & Ralph Paige in honor of Nicolas Paige  
Catherine Soden in honor of Lillian Moore  
Kathy & Kristina Swesey in honor of Emily Varni  
Liang Yu Tai  
Michael Tomelloso

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

Kyra Allen in honor of Faith Allen  
Arstein-Kerslake Family  
Marilyn & John Bintz in memory of Page Bintz  
Ira Bloom  
Michelle Bosse  
Bev & Bud Bush  
Terri Canales in honor of Taylor Skye Canales  
Thelma & Thomas Davidson in honor of Ian Davidson  
Ira Fennessy  
Barbara & Larry Gunter in honor of Brandi Sherman  
Linda Hamilton  
Susan Hill  
Alex Huck  
Maria & Ken Knox in honor of Jamilet Knox  
Linda McGee  
Lucy Jao Ong & Bie Chuan in honor of Audrey Ong  
Karen Reynolds in honor of Ryan Olson Ramirez  
Dana Rottici & Family in honor of Julia Lindstrom  
Leanna Russell in honor of Teresa Sharpen  
Judy Schlafer in honor of Timothy Schlafer  
Renee & Henry Tarica  
Plonneke & Martin Thoolen

### **Magnanimous General Donations**

Amy & Paul Wissmann  
Mari O'Neill in honor of Olive Baach

### **General Donations**

Adobe matching donations  
received from Tom & Patti McRae  
Dolores Albaugh  
Kyra Allen  
Catherine and Rudy Alvarez  
Benevity Community Impact Fund  
Daos Boonma in honor Ryan Casey  
on Dan Casey's birthday  
BP Fabric of America Fund  
Mary & Holger Bracht  
Terri Canales  
Molly Carter

Liang Yu Tai & John Cheng  
Chevron Matching Employee Funds  
Comcast Corporation at the request of  
Michael Denatale  
Ann Cave  
Michelle & Kevin Donaldson  
Eric Elliott  
Laura & Ray Esau  
Fidelity Charitable Gift Fund  
Stacy Garden  
Lisa & T.J. Graziano  
Pat Grey  
Robin Grey  
Kroger Grocery  
Barbara & Larry Gunter  
Loni & Steve Hamilton in honor of  
Michael Hamilton's 40<sup>th</sup> birthday  
Susan & Daniel Hedstrom  
Trudy & Randy Hermans  
Heather Hessel  
Olivia Maturana in honor of Oscar Hill  
Jean & Lowell Hobrock  
Kelly Jaeger  
Nancy & John Jenkins  
Anna Maria Kanauka  
Mary & Alan Kisaka  
Margot & Gerry Lawrence  
Hope May-Liddiard  
Jacki Lindstrom  
Patti & Tom McRae (monthly donation)  
Kathleen Minor  
Randeep & Kulvir Mehroke  
Gail Morgan  
Michael Morgan  
Melinda Morrow  
Christa Murphy  
Masani & Hanif Nassor-Covington  
Fran Nicholson  
Betty Olson  
Linda & Mark Ryan  
Margaret O'Sullivan  
Kathy & Ralph Paige  
Amanda A. Schriever  
Janice & John Shimmin  
Renee & Henry Tarica in honor of  
Lorraine Kushynski's 60<sup>th</sup> birthday  
Laura & Michael Tomelloso  
Kristen Van Kouwenberg  
Billy Vitro

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

Suzanne Privette in honor of Samantha Morgan  
(monthly donation)

**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)

# PWCF wants to

# Take You Out to the Ball Game!

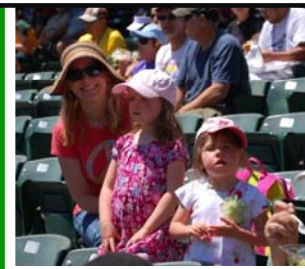
It's time for our third annual PWCF Family Day  
 at the Oakland Coliseum on Sunday, June 28<sup>th</sup> to watch the  
 Oakland A's battle the defending AL Champion Kansas City Royals!

*Field level tickets only \$28 per ticket, with \$5 from every ticket sold benefitting PWCF. PWCF attendees sit together and enjoy a Pre-Game visit from the Oakland A's Mascot, Stomper!*



## Oakland Athletics vs. KC Royals

Sunday, June 28<sup>th</sup>, 1 pm at The Oakland Coliseum



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

Mail Order Form with payment to PWCF at 514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277

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

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

Please send me \_\_\_\_\_ tickets at \$28/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)

# Family Fun with the Anaheim Angels!

Angels v. Texas Rangers

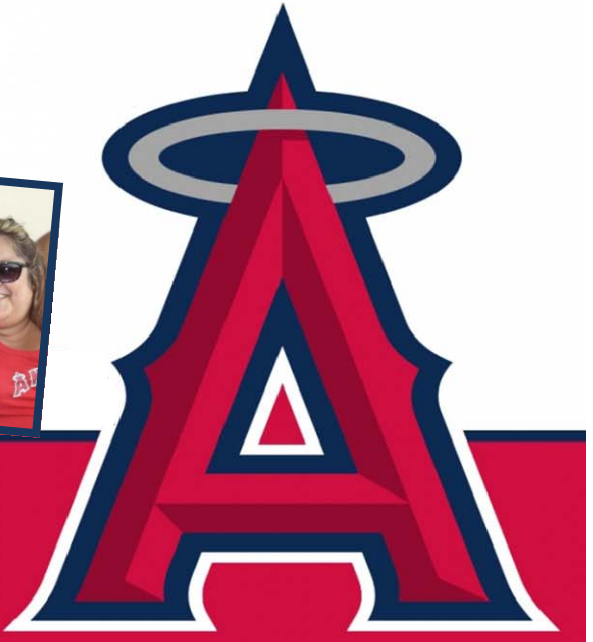
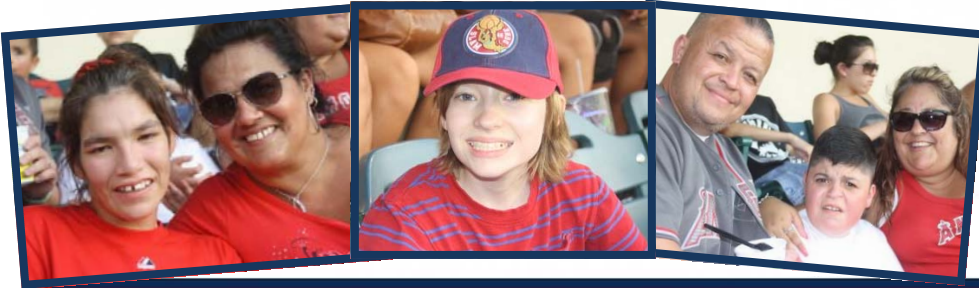
Saturday, July 25 at 6:00 p.m. at Angels Stadium, Anaheim

Club Loge Behind Third Base • \$28/ticket

Post Game Fireworks!

Every ticket sold benefits PWCF

Thank you for your support!



**Family Fun Day with the Anaheim Angels  
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 \$28/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)



Presented by  HERBALIFE.

# CHAMPIONS



## Prader-Willi California Foundation Family Fun Night



VS



Presented by  HERBALIFE.

### OCTOBER 18<sup>th</sup> AT 4:00 PM

### TICKETS ARE \$29

Please join us as your 2014 MLS Cup Champions battle their rivals and help raise money for a great cause.

To order your tickets please contact the Prader-Willi California Foundation 310.372/5053 [info@pwcf.org](mailto:info@pwcf.org)

1.877.3GALAXY



**Prader-Willi**  
California Foundation

*Supporting People with Prader-Willi Syndrome*

**STUBHUB! CENTER**

 @LAGALAXY

# Prader-Willi California Foundation



## Family Fun Night with the LA Galaxy!

### Ticket Order Form

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

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

Please send me \_\_\_\_\_ tickets at \$29/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)

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

**A portion of each ticket sold benefits PWCF**  
**Thank you for your support!**

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

