

July - Sept, 2014
Volume 26, Number 3

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**ANNUAL
GENERAL
EDUCATION
MEETING**
SANTA CLARA MARRIOTT
Nov. 8, 2014

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PWCF Held 4th Annual PWS Camp June 19-24, 2014



Fifty-six lucky campers participated in PWCF's six day camp at Easter Seals Camp Harmon located in the beautiful Boulder Creek mountains. **Linda Ryan, Lisa Graziano, and Katherine Crawford** trained all staff before the start of camp, and both Lisa and Katherine remained at camp throughout the week to provide oversight and behavioral intervention.

Campers enjoyed a great campfire experience, singing, dancing, swimming, gardening, tending to farm animals, and making fun stuff in arts and crafts like "flubber" and tie-dyed shirts. Camp Harmon's new chef prepared great tasting, healthy meals that campers loved!

New friendships forged during the week are a testament to the power of PWS Camp. At times groups of kids and adults huddled so tightly it looked like they couldn't get close enough to each other! Writes one parent, "Carlos develops new friendships and gains "real life" responsibilities at Harmon camp. [He] also gets very excited about all the activities they have, especially when they dance. He enjoys interacting with all the counselors and shows motivation to keep going the following years." Richie attended his first PWS Camp and "had a wonderful camp experience... He praised his counselors, loved the social aspects of meeting new friends with PWS and was more upbeat after attending camp."

Campers were delighted by the new animals at camp. Ducks, chickens, rabbits, pigs, and even a little goat had new homes at camp this year. Campers could visit the animals with their counselors during the rest hour after lunch. The goat loved the attention and was eager to play with the campers.

The daily rest hour also provided time for campers to catch up with friends in other cabins, hunt for feathers and guess what bird the feathers belonged to, or meet up for a group session about PWS topics. One participant shared that it was the first time he got to spend time with other people with PWS, and it made him feel less alone as he worked through the struggles of having the syndrome. Other topics included friendships and what things we do with friends, what hobbies we enjoy, and what accomplishments we are

most proud of. The topic sessions were moderated by Lisa Graziano and Katherine Crawford.

While the campers got to enjoy some independence from their families and making friends, their families had a week of respite from their day-to-day caretaking responsibilities. Knowing their child was well cared for, parents could kick back and relax. Some families chose to vacation nearby the camp near scenic coastal towns like Santa Cruz. Writes one parent, "As parents we always feel happy when [our son] is happy. So often he tends to be negative, so when he raved about Camp we were thrilled. He praised the staff, the counselors, the food security and quality of food, the nurses, and overall experience (especially meeting new friends). He looks forward to returning next year, which means he *really* did love it. We enjoyed a little respite as well."

Stay tuned for next year's PWCF Camp dates, to be released mid-January 2015!

**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

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

Central California

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

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

Inland Region Area

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

Spanish Speaking

Mercedes Hernandez (Adults with PWS)	619-822-5742	mercedes.hernandez711@yahoo.com
Maria Knox (Adolescents with PWS)	909-421-9821	teachknox@aol.com
Kilma Carillo (Infants/Children with PWS)	760-427-1100	kilmab@excite.com
Veronica Baez (Infants and Children with PWS)	760-357-8189	vbaz92@yahoo.com

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. In the search box under the heading "Join a Group" enter PWCFmembers. When the PWCFmembers group name appears, click and follow instructions to join.

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

PWSA (USA) Online eSupport Groups www.pwsausa.org Click Enter. Click "Support" for Families of Children Ages Birth-5 Years for Spanish-Speaking Families for Families of Children Ages 6-12 Years for Military Families for Families of Teens for PWS + Autistic Symptoms for Families of Adults for Persons with PWS for Siblings for Grandparents

International PWS Organization

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

PWS SHARE & SUPPORT GROUPS MEETING CALENDAR 2014

Southern California

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

2:00 p.m. - 4:30 p.m.

Sunday, October 26

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

Northern California

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

10:30 a.m. - 1:30 p.m.

Saturday, November 15

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

PARENT TO PARENT

“How do you make exercise fun?”

I'm not a parent but as a brother active in this I have found some ways that help. Patience and energy, I know with Lauren it takes me portraying the exercise as fun or just having a huge amount of energy and using that to stimulate her into thinking that her work out is just merely a game. Creating a competitive style exercise has helped getting my sister motivated enough to want to participate and actually do the exercise. I can't stress enough how much energy one needs to have and also taking that energy and finding a way to channel it and make it contagious so you can make it possible for the exercise to be fun. Hope this helps, *Kevin Amarasekera, brother of Lauren, age 26*

My suggestion is to add some friendly competition to the exercise, either with a similarly able child, or with themselves by 1) charting the overall minutes of exercise (for beginners), or 2) charting the time that it takes to walk a specific distance. (Lower time = greater effort!) The objective is for the child to beat their best time! Charting helps them see their progress. Best, *Janice Forster, M.D., The Pittsburgh Partnership*

Treadmill: With a flat screen monitor balanced on the console and a little platform rigged to support the keyboard and mouse, I can be working on the computer (or playing computer games if one prefers) while getting in my workout. I can walk 3.5 miles per hour and still do some types of work. You can find a used (gym quality) treadmill on Craig's list for about 1/4 - 1/5 of the retail price. *Lynne Bird, M.D., Director, PWS Clinic, Rady Children's Hospital*



One of the things I did for Hailey was get her one of those adult trikes. It has a basket on the front and she has trained her little dog to sit in the basket. We have neon lights in her wheels for night rides. She will ride and ride. *Evan Postal, dad of Hailey, age 11*

We've found that our 24 year old daughter LOVES her YMCA membership. She set up an appointment with the personal trainer, and loves to tell me how many pounds she lifted at the end of a day. She likes having a personal program to follow, and seeing her progress. She also likes to swim laps in the pool (and relax in the hot tub and sauna afterward). Unfortunately now that school has started again she has less time to spend at the YMCA. She also likes to go on long walks (4-6 miles) with her support staff – we remind them to wear good walking shoes when they come! Walking and talking seems to allow her both physical exercise and

time to get everything off her mind – a nice extra benefit. *Michelle Donaldson, mom of Cerridwyn, age 24*

For fun we swim. She's like a fish or as she calls herself a Mermaid. Can't get her out of the water. *Julie Miller mother of Kelly Ann Mitchell, age 26*

Here are a few ideas...

1. Dance to your favorite music
2. Scavenger hunt around the yard or inside the house (when too hot or cold outside)
3. Play a ball game or relay races with your family at the park. *Jill Nowak, RD,CDE, Endocrine Pediatric Dietitian, Children's Hospital Orange County*

1. Do it with your child if possible.
2. Make it a guessing game – e.g., How many steps to the corner? How many trees do you think we will pass?
3. Incorporate exercise as part of helping around the house. Putting clothes in the washer, have them bend down to the floor level to get the clothes and put them in one by one, guessing how many of each color and telling you whose clothes they are.
4. Sweeping leaves outside, count the brush strokes to get a pile.

Something about counting keeps the brain engaged and takes the mind off the physical aspect. I use it for my child and for myself. Other suggestions are to use headphones with lively music and a nice pair of sneakers dedicated to when they exercise, make it a special treat. *Angela Garcia, mom of Ashley, age 27*

My little brother, Dalton, hates to exercise so I got creative with him. We live on a ranch so every time it rains, I would make him go with me to find arrowheads. He enjoyed it so much that now he goes out all the time looking for flint. He will spend hours out in the desert, always within eye site, picking up flint. He now has bags and bags of it in his room and won't let us throw it away. 99% of it is flint chippings but they are his treasures. He likes to get his bags out and show us his finding which we all enjoy because he is really into it. We're now trying to figure out what to do with all the flint! So, I suggest hunting for arrowheads. It's not a lot of strenuous work but it gets him off the couch and he really enjoys it. *Betsy Whipple, sister of Dalton, age 30*

We are very fortunate that our daughter has learned how good it feels to exercise so she is self-motivated. Part of that has probably come from it being a lifestyle for all of our family. I would suggest role modeling for your kids (and you will benefit too – great way to de-stress!). If it isn't something everyone in the family does, but something one person alone has to do, that takes all of the fun out

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Next Parent to Parent Question:

“How do you support your other children/teens with their feelings about having a sibling with PWS?”

GADGET TIP: BRUSH BUDDIES

Submitted by Angela Garcia of San Jose



Studies have shown that on average people brush their teeth for less than a minute when dentists recommend you brush your teeth for 2 minutes. Think about it, did you spend a full two minutes brushing your teeth this morning? Brush Buddies recognized this was a huge problem so they surveyed kids, parents and dentists and found that they could increase brushing time if they made brushing fun.

Brush Buddies makes brushing fun with an adorable group of character-based toothbrushes, “bling” brushes, and singing tooth brushes.

Use Biotene dry mouth toothpaste on your Brush Buddy Brush Beatz and your child or adult with PWS – or the whole family! – will have fun keeping their teeth clean and healthy!

Brush Buddies are available at Walgreens, CVS, Rite Aid, and online. For more information go to www.brushbuddies.com



FOOD TIP: AK-MAK CRACKERS

Submitted by Lisa Graziano of Redondo Beach



One of my son’s favorite late afternoon or after school snacks is crackers and cheese. I found a cracker that’s not only tasty but healthy too. Ak-mak crackers are made with organically grown whole wheat flour. Five crackers are 110 calories, 20 carbs, 2 grams fat, and 5 grams of protein.

I like to pair the crackers with a light string cheese which is about 50 calories, 2.5 grams fat, 0 carbs, and 7 grams of protein.

Paired together, one healthy, delicious snack is only of 72 calories. Enjoy!

WE GOT TALENT

Submitted by Rhonda and Andy Faust of Antioch

Our little **Angela**, age 5, has really grown up in the last two years while attending her special day preschool class. She started the preschool at age 3 because we pushed for the school district to do something...our daughter could hardly speak. After attending a couple of PWS meetings in San Francisco and being a part of the online PWS parent group, we quickly learned the lingo. Today Angela graduates from preschool speaking full sentences and can say her ABC’s!



EXECUTIVE DIRECTOR'S COLUMN

by Lisa Graziano, M. A.

As parents we work tirelessly to create an environment in which our child, regardless of age, may explore their world and practice new skills all the while being safe. As they push their limits, proudly commanding us to “Watch me!” they demonstrate they are changing, growing.

When my son was almost three he was invited to an elaborate birthday party that featured, among other fantastical things, a huge backyard bouncer, with a ladder of sorts on the inside that led waaaaay up high to a slide. While the other three year olds effortlessly zipped up the ladder and down the slide, my son struggled to pull himself up on the first step. And just as he'd make it, his strength would give out and he'd slip back down. Undeterred, he continued his efforts, ascending two steps, falling back three. Exhausted as he was, he was absolutely bound and determined to climb that ladder and slide down that slide.

I cheered him on, feeling fiercely proud of his determination and tenacity. I wanted with all my heart to see him overcome that obstacle and experience the thrill of the slide and the joy of his triumph. And then, looking ridiculously over-protective as I pushed myself farther inside that kiddie bouncer than it would allow my adult-sized body, I began to fear: What if he pulls himself higher, loses his grip and falls straight backward? Or what if he actually gets to the top of the slide but tumbles face-down and breaks his neck? What is his body realistically capable of and is his possible success worth the potential consequences if he fails? Should I force him now to abandon this endeavor that seems destined to fail, or do I wait until he decides to stop? Is it better for him to experience defeat or be ‘rescued’ from it? Is ‘defeat’ defined as not reaching the goal, or is defeat giving up too soon?

I couldn't know it then, but I know it now: There are no correct answers to these questions, I will likely always ask the same questions in some form or another, and just when I figure out the right answers for this situation, something will change and I'll have to start questioning all over again.

Every day I speak with some parent who expresses concern about how much autonomy their child should have in any particular situation, whether it be at school, work, or a home setting. Most often this is prompted by a “professional” encouraging a greater level of independence than the parent believes is safe for their child. Like the principles of California's new Self-Determination Program* (legislation that, quite frankly, makes me very nervous, but that's an article for another day), of *course* we want our child

to achieve his greatest potential. Of *course* we'd like our adult child to be independent, out on his own, making his own decisions in the world. And yet, more than *any* professional, we know the limitations that PWS imposes on our child and the potential risk of “failure” that too much independence can bring.

PWCF's vision is that persons with PWS will live a full life without limits, and every day science moves us closer to the medical breakthroughs that will manage the hyperphagia food drive and enable our children to live free from the limits imposed upon them by this syndrome. Meanwhile our challenge is to help people with PWS live the fullest life possible in the safest environment possible and, with the support of PWCF, educate the “professionals” in their universe of the need to balance their “independence” with necessary life-saving limits.

My son did eventually climb all the way to the top of the ladder that day, and then smoothly whizzed down the slide. If I live to be a 103 (and I do plan to), I will never see a more glorious smile! At almost three years old he learned something important about himself that day, something that profoundly changed him: he has the ability to reach deep within himself and harness great internal strength. Or maybe it was just me who was profoundly changed as I witnessed his strength of character triumph over his syndrome and my hope for a freer life was renewed.



Like you, I will never stop trying to give my son a bigger world in which to live, and I'll never stop working to keep him safe. And if I appear ridiculously overprotective in the process, then so be it.

*http://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?lawCode=WIC§ionNum=4685.8.#content_anchor

We could all take a lesson from the weather. It pays no attention to criticism.

~Anonymous



NOT A **RUNNER?** NOT A **PROBLEM!**

Team PWCF has open spaces for our **SECOND ANNUAL** charity participation in the **LA Big 5K!** Experience the thrill of a lifetime running with thousands of other people who, like us, are supporting important charities. This year we had **TWO** runners with PWS (and more in push-strollers), and this upcoming year we're looking to include even more!

If you walk the 5K, it takes around an hour. Join our Team PWCF 5K Walkers if you want a workout goal without the worry.

Want a bigger challenge? Sign up for Team PWCF in the **ASICS LA Marathon!**

Space is limited so join Team PWCF today!

For more information and to register for Team PWCF visit:

www.firstgiving.com/pwcf/2015-team-pwcf

LA Big 5K

Saturday, March 14, 2015

Registration Fee: \$30

Fundraising Minimum: \$250

Raise over \$500 for your 5K fundraising and you are eligible for PWCF to reimburse your registration fee!

ASICS LA Marathon

Sunday, March 15, 2015

Registration Fee: \$150

Fundraising Minimum: \$500

Raise over \$1,000 for your Marathon fundraising and you are eligible for PWCF to reimburse your registration fee!

CONTAINERS AND THINGS

by Lisa Peters of Massachusetts



Nicholas loves containers.

All kinds of containers.

He loves boxes, backpacks, pouches, suitcases and duffel bags.

In fact, if you happen to possess a container that has some Velcro, a zipper, a latch or a key hole, I expect if you show it to Nicholas you will probably never see it again.

He is fascinated with the secret power of something closed.

To him, it is a priceless treasure just waiting to be discovered; an endless opportunity to find something valuable, like Muffy's lost knotted leash or a collection of wrapperless crayons.

Nicholas will spend much of his free time zipping and unzipping his modest collection of bags. He enjoys listening to the sound of metal meshing with metal or the scratching sound of Velcro tearing apart and stubbornly revealing the innermost contents of a secret compartment.

For Nick, it's all about the simple things.

Eventually many of these containers end up discarded on our living room floor.

Parent to Parent, continued from page 3

of it. We schedule exercise into our day just as we do homework time or chores – it is part of your self-care. How to make it fun? Find what YOU enjoy. That is what will motivate you. Be it a walk (change the scenery, take a new route, find a trail) or a swim or a bike ride (we use a tandem). If the “exercise” is something our daughter cannot do, we make “accommodations”. While everyone is surfing, GiGi will take a sand run then swim with us and hang out on the surfboards in the water with us. If we are “peppering” volleyball, GiGi will catch the ball and throw it back on her turn rather than bumping it. If we are playing a game, she will usually fall asleep on the beach. But, she makes a plan to get to the gym before that or take a run on the beach. Eventually, part of the “fun” comes from the rewards – losing weight, feeling better all-around and lowering your stress. And, that is a motivator!
Elizabeth Greskovics, mom of GiGi, age 14

Exercise for my son, Ian, was always a challenge until I found the egg timer, shaped like a ladybug. What I found out was once a challenge of time came into the picture the game was on. A

I have stubbed my toe on many bags I *thought* were empty. As I open the bag, box or backpack I am surprised to see that there is usually another bag hidden inside. I smile and open the next bag which usually holds another, and another and another until finally the last zippered bag will hold one of Nick's most treasured items.

I have found things like a Dora sandwich box, my tattered copy of Dr Spock's Child and Baby Care book and even the instruction booklet for our microwave oven.

Nick's “hide the object in backpack” game is usually a lot of fun that is until we are late for school and I notice that I can't find my keys. We have spent many mornings on the living room floor unzipping layers upon layers of backpack packaging, where more often than not, we do not find my car keys.

Yes, it is a known fact that in the Peters' household prized possessions must be hidden well out of sight from our little “backpack man.”

Or you will find yourself having a conversation that goes something like this:

“Niiiiiiiiiiiiick,” Weston shouts annoyingly.

“Have you seen the charger for my ipod?”

“Oh, O” Nick says quietly.

He puts his head down and walks quickly into the living room to begin a new search.

simple challenge like, “I bet you cannot walk around the block in 20 minutes”; “I bet you can't walk a quarter mile in 15 minutes on the tread mill.” I always made sure he could accomplish his goals. Set the minutes higher and then start lowering the time so he has victory. Good luck! PS: This worked for a lot of things like showers and cleaning his room, too. *Tom Davidson, dad of Ian, age 38*

We do lots of Wii dance a-thons with neighbors' kids and friends from school. *Victoria Stover, mom of Meagan, age 15*

Talk about things they like to talk about when you're on a walk with them, talk about maybe playing a game with them after you come back from your walk/exercise. Sometimes [people with] PWS don't mind doing the exercise as long as they enjoy the person they are doing it with! The motivation



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GROWTH HORMONE REPLACEMENT THERAPY IN BODY COMPOSITION AND EXERCISE CAPACITY IN ADULTS WITH PWS

Submitted by Daniela Rubin, Ph.D., PWCF Board of Directors

Growth hormone is currently part of the treatment of individuals with Prader-Willi syndrome when the person is a candidate for it and there are no contraindications. For the past ten years several studies have demonstrated that growth hormone replacement therapy (GHRT) increases lean mass (muscle) and reduces fat mass in adults with PWS. Lafortuna and colleagues evaluated whether two years of growth hormone replacement therapy was effective at improving body composition and exercise capacity in adults with PWS. They also investigated if treatment led to increases in muscle strength. The changes pre- and post treatment were evaluated in 15 obese adults ages 19 to 35 years old. Only 40% of the adults presented with growth hormone deficiency.

Despite no change in body weight, the GHRT resulted in increased lean mass and decreased fat mass. There were no adverse changes in metabolic parameter such as blood sugar and lipids. In contrast, participants showed a decrease in inflammation markers linked to obesity (c-reacting protein). In terms of the changes in muscle, there was an increase in muscle size 5-10% in the lumbar and thigh areas (where measurements were taken) and this increase in

size was accompanied with gains in strength. What this means is that GHRT was effective at increasing lean mass, muscle size and the capacity to develop force (strength). Last, but not least, after GHRT people were able to sustain physical work (like walking on a treadmill at different speeds and incline) at a much faster speed and higher incline and exerted themselves less than before when walking uphill at moderate pace.

Although the study did not evaluate the following, practical applications of the findings in this study include the possibility of increased energy expenditure and its contribution to maintain body weight because of the increased muscle mass. The increase in muscle strength and exercise capacity can translate into more stamina, more energy and increased potential to participate in activities with a physical component such as dancing, exercise, sports, walking or whatever the person with PWS likes to do.

References: Lafortuna C et al. (2014) Skeletal muscle characteristics and motor performance after two years of growth hormone treatment in adults with Prader-Willi syndrome. J Clin Endocrinol Metab 99: 1816-1824

Parent to Parent, continued from page 7

definitely gets harder as they get older however. *Karen Benedikt, sister of Barbara Olson, age 48*

I make exercise fun by working out with my son and finding something that he likes. I do a lot of working out at home (TurboFire) is a good at home workout routine that incorporates high energy, dance moves and great music. My son LOVES music. Usually when I'm doing my working out at home, he sees how much fun I'm having and joins in. It is important to be each other's cheerleader during this time. Another good way to make exercise fun is to sign up your kid in a workout class specifically with their age group. For example, I signed my son up for Tiny Tots Yoga, swimming and basketball. He enjoys being with his peers and the instructors are so good at making the activities fun that the kids don't even realize how hard they are working out. These classes are usually offered through a community center in your city. Hope this helps! *Kim Cain, mom of Xavier Morris (son 4yrs)*

I'm Elli mother of Mariela, we live in Buenos Aires - Argentina. We met [Lisa Graziano] when I was Vice President of the International Prader-Willi Syndrome Organization during the period that Pam Eisen was President. We were lucky to have an early diagnosis and we planned the exercise for her. She loved to swim and ride horses. But the most important was and is to walk every day at least one hour - mostly three. When she was younger it took long to make 2000 meters, now she walks real fast. Of course you have to have the right shoes with those small feet. But we started to count the trees, then the cars, then the colour of the cars, and when she was 8 she was already proud of how long she can walk and is happy to

go for a walk. I get older and have not so much time, so she has a personal trainer that picks her every afternoon from school and has three hours of walking and exercises. Someone else [exercises with her on] Saturday and Sunday. Regards and in our Association we say, "No te preocupes, ocupate." [which loosely translates to "No worries"] *Un abrazo Elli Silberstein, mom of Mariela*

Top three ways to make exercise fun:

- 1) Find a video you enjoy and do it at home. Search for free exercise videos online (www.jessicasmithtv.com) or look at Amazon. There are a ton of them right there ready to be bought.
 - 2) Take advantage of the outdoors. www.localhikes.com puts you in touch with hikes in your area that help you enjoy the scenery while exercising.
 - 3) Exercising as a family or with friends makes it more fun.
- Hope this helps! *Melanie Silverman, MS, RD, IBCLC, Feeding Philosophies*

Put on some music and dance. Being that he doesn't walk without help, we stand him up, put on the music and dance with him, he loves it. He loves music so even when he's on the treadmill we have music on. *Angela Lucero, mom of RJ, age 13*

My name is Susie and I am mom to Emily who is 9 with PWS (UPD). I am a single parent and work full time so there are never enough hours in the day. I pick Emily up from daycare at 6:30 p.m. every night which only gives us about 2 hours to do homework, eat dinner, take a bath and somehow fit in some exercise for Emily. My secret is a treadmill in my bedroom in front of a television. If Emily wants to watch any television (and she loooves Disney, *continued on page 9*

NEW INVESTIGATIONAL DRUG FOR HYPERPHAGIA

Call for Research Subjects

Essentialis, in collaboration with the University of California, Irvine, has initiated a clinical trial of **diazoxide choline controlled-release tablets** (DCCR) in patients with PWS. DCCR is a new once-per-day tablet formulation of diazoxide. Diazoxide has been approved in the US for nearly 40 years for the treatment of rare hypoglycemic conditions in neonates, children, and adults. Many of these patients are treated with the drug for years. Essentialis has already tested DCCR at many different dose levels in 200 patients for periods as long as 16 weeks.

DCCR may benefit PWS patients in a number of ways. DCCR works on a part of the brain called the hypothalamus, which regulates appetite and energy expenditure, restoring a more normal balance of food intake and energy expenditure. DCCR also works on adipose (fat tissue) causing a shift from storing fat to burning fat for energy, reducing fat mass. In the liver, DCCR works to reduce the production and secretion of triglyceride (fat) and cholesterol.

In animal models of hyperphagia (consuming too much food), diazoxide treatment reduced how much food they ate, reduced how much excess weight they gained, increased their energy expenditure, caused a shift to burning fat as fuel and lowered their triglycerides. Diazoxide treatment reduced both the numbers of meals these animals ate as well as the size of meals they ate. **In clinical studies in obese patients, both DCCR and diazoxide have been shown to reduce appetite, induce weight loss and improve triglyceride levels.**

In a condition called hypothalamic obesity, that is similar to PWS, diazoxide treatment of adolescents reduced their rate of weight gain from about 21 pounds in 6 months to 2.6 pounds in 6 months.

This Clinical study is designed to evaluate the safety and efficacy of multiple dose levels of DCCR in PWS patients. **To be enrolled in the study, patients must be between 10 and 20 years old, obese and have a genetic confirmation of PWS.** They can be male or female and of any race or ethnic background. They can be receiving or not receiving growth hormone. They should be generally healthy. They cannot be diabetic.

Parent to Parent, continued from page 8

Jr. and Sprout), she has to walk on the treadmill. Once she gets going, she'll walk for 30-45 minutes. She gets so distracted by her favorite shows that she doesn't even realize she's walked a mile or so. As a bonus, while she's on the treadmill, I can get some chores done :) *Susie, mother of Emily, age 9.*

Ways to make exercise fun: 1) bring along a friend or pet; 2) use the Striv app on your smart phone (it counts steps and you can set goals); 3) earn tokens for completed exercise; dress up in your favorite exercise clothes; 5) walk to a destination spot like the movie theatre, park, mall; 6) keep a log of time you exercise and

After screening, which will involve an interview, medical history, a hyperphagia questionnaire, physical exam and blood draw, patients will return for 7 more visits over 14 weeks. During the first 10 weeks of the study, patients will receive DCCR and will have their dose increased up to 4 times. At the end of 10 weeks, patients who responded to DCCR with reductions in hyperphagia, or an increase in energy expenditure will be eligible to participate in a 4 week extension to the study. During the extension, half of the patients will be randomized to continue on DCCR and half will be randomized to placebo.

Every visit will involve a physical exam, measurement of blood pressure and heart rate, measurement of weight, blood draw, and an assessment of how well the patient is tolerating the drug. Most visits will also include a measurement of resting energy expenditure and completion of a hyperphagia questionnaire. A few visits will involve more extensive assessment including measurement of body fat content by DEXA. Patients will be compensated for their participation in the study.

The most common adverse effects of DCCR and diazoxide include the potential for fluid retention and peripheral edema (swelling of ankles, feet, or hands) and the potential for increases in blood sugar.

By participating in this clinical study, patients will help deepen the understanding of the safety and efficacy of this new investigational drug for PWS. Based on the results from this study, Essentialis will be able to design larger, more extensive studies of this drug in PWS patients, and will be positioned to have a constructive discussion of the further development and approval of this drug with the FDA and their counterparts in Europe and Asia.

Those who are interested in finding out more about the clinical study can go to www.clinicaltrials.gov and search for NCT02034071. For more information or to enroll in the study, contact Virginia Kimonis, M.D., principal investigator, at 714-456-5791 or 949-824-0571 or email vkimonis@uci.edu. You can also contact Marie Wencel, research coordinator at 949-824-0521 or email mwencel@uci.edu.

use stickers. *Jackie Lindstrom, mom of Julia, age 29*

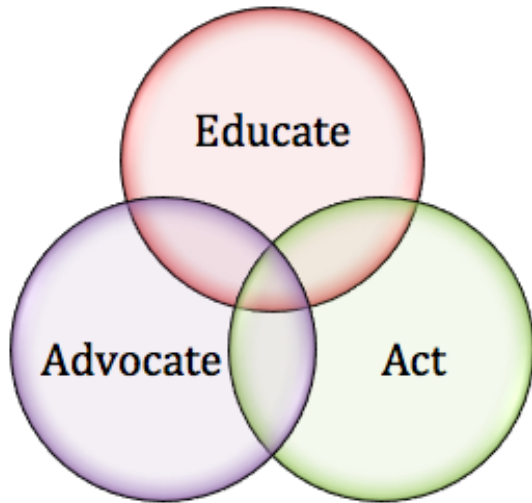
My daughter Kim (23) with PWS has a 3 wheeled adult trike and loves it! Kim's balance has never been good for riding a two wheeled bike. She and I take bike rides and enjoy seeing the neighborhood together! So, for those who have trouble balancing, the 3 wheeled bikes are the answer. Wal Mart has the best price and most stores will assemble for free. Besides swimming, and walking the dog, bike riding is her best way of exercising.

Renee Lovern

ASSERTIVENESS AND EFFECTIVE PARENT ADVOCACY

by Marie Sherrett

Reprinted from *Wrights Law* | www.wrightslaw.com



I find that parents of children with special education needs come in several categories:

- Pacifists or those who gets things done
- Clinging vines or parent advocates
- Silent victims or fighters
- Dreamers or crusaders
- Waiters or initiators
- Bombshells or assertive parents
- Appeasing compromisers or action heroes

Which are you?

Parents are not assertive if they:

- Beat around the bush
- Fail to describe problems
- Feel guilty or are afraid to be vocal
- Agree with professionals to keep peace
- Ignore the right to services
- Leave everything to others
- Accept excuses for inappropriate or inadequate services
- Beg for what the law says a child should have
- Abdicate to others the right to advocate for a child
- Depend on others to advocate
- Give up because of red tape
- Are too hasty to act
- Fail to act
- Accept the status quo
- Give in to defeat
- Are uncomfortable with accomplishments
- Discourage your child from having hope of success

What do you do?

Assertive parents:

- Express themselves clearly, directly and without guilt
- Are not intimidated
- Prepare for meetings
- Stay together
- Are informed
- Keep records
- Collaborate
- Effectively communicate
- Demonstrate self-confidence
- Advocate effectively
- Are self-reliant and independent
- Persist
- Analyze problems
- Organize to effect change
- Are positive and strong
- Have pride
- Encourage others and hold people accountable

Does this describe you?

Advocacy helps you get services for all special education children in the least restrictive environment. Then you can participate, plan for educational programs, and get legislation passed.

Advocacy opens new doors so children may become part of the community. Advocacy knocks down barriers and prepares children for independence.

To meet others, you can

- Publish a letter or article for your local papers
- Pass out flyers at school
- Organize public meetings
- Encourage volunteers
- Plan
- Have goals and objectives
- Talk to the media (I love to do this!)

None of this is easy but the rewards can be fantastic!

Remember: Parents put together Public Law 94-142. Parents who vote urged Congress to pass the law that became the Individuals with Disabilities Education Act.

You can make things better for the next generation without filing for due process. How? You must learn the art of persuasion, advocacy-style! There is both safety and strength in numbers.

If you can go over a hill and change a classroom, you can go over a mountain and change a state's respite care services, early infant and toddler program, inclusive educational situations and training

continued on page 14

**PWCF's ANNUAL
GENERAL EDUCATION MEETING
Saturday, November 8, 2014**

Cynthia Tobias

For over 25 years, best-selling author and speaker Cynthia Tobias has been sharing her philosophy on how to succeed in life with a strong-willed child. Her message is meant for people of all ages... the mind of a strong-willed child looks different at every age – young or old.

Janalee Heinemann, M.S.

*Director of Research and Medical Affairs
Prader-Willi Syndrome Association (USA)*
Janalee Heinemann will bring us up-to-date on the world's research related to PWS.

Ann Scheimann, M.D., MBA

*Gastroenterology and Nutrition
Inflammatory Bowel Disease Center
Johns Hopkins Children's Center*
Dr. Scheimann is a specialist in GI issues that affect persons with PWS. She will share the latest GI management and treatment strategies.

**Marriott Santa Clara
Saturday, November 8**

2700 Mission College Boulevard
Santa Clara, CA 95054
Registration 8:00 a.m.
Conference 9:00 a.m. – 5:00 p.m.
Youth & Adult Program 9:00 am – 5:00 pm

Meet & Greet

Friday, November 7 at 7:00 p.m.
Marriott Lobby & Bar

Reserve your hotel room by **October 21** for a reduced room rate of only \$109 (plus taxes). For hotel reservations call 408-988-1500 and request the PWCF room rate.

Contact PWCF by **October 21** for a Spanish Interpreter.
Ponte en contacto PWCF antes del 21 de Octubre por un intérprete Español.

PWCF 2014 GEM Registration Form

Use this form or register online at www.PWCF.org

Early Bird Discount: Register by 10/14 and deduct \$10

PWCF Member: \$60 / \$90 per couple
Non-PWCF Member: \$75

*Your Regional Center may be able to help cover your fees
Fees may be reduced or waived upon request*

I am not a PWCF member. Please send me membership information

Please Print:

Name(s) of All Persons Registering for General Education Meeting

Mailing Address

City State Zip

Telephone Email

Number of Vegetarian Lunches Requested: _____

Youth & Adult Program Registration

PWCF Members \$10/child or adult
Non-PWCF Members \$15/child or adult

Fees may be reduced or waived upon request

Names & Ages of Persons Enrolling in Youth & Adult Program

Name: _____ Age: _____ PWS? Yes/No

Name: _____ Age: _____ PWS? Yes/No

Name: _____ Age: _____ PWS? Yes/No

Name: _____ Age: _____ PWS? Yes/No

Fee Calculation

Total Enclosed for General Education Meeting: \$ _____

Total Enclosed for Youth & Adult Program: \$ _____

Total Tax-Deductible Donation Enclosed: \$ _____

Total Amount Enclosed: \$ _____

Check payable to PWCF enclosed Charge my credit card

Name on Card: _____

Credit Card No: _____

Expiration: _____ Security Code: _____

Email: _____

Signature: _____

Return Registration Form to PWCF:

Fax: 310.372.4329 514 N. Prospect Ave., Suite 110-Lower Level
Redondo Beach, CA 90277

ATTENTION PARENTS OF LITTLE BOYS

Undescended Testicle Repair Surgery - Orchiopexy

Adapted from Children's Hospital of Pittsburgh of UPMC

What Is An Undescended Testicle Repair?

In the mother's womb, a baby boy's testicles develop inside his abdomen. Shortly before birth, they move down into the scrotum. In about 4 percent of infant boys and in almost all infant boys with PWS, this movement does not occur. If the testicles do not move down into the scrotum by age 1, the pediatrician and parents must discuss whether or not to use surgery, called an orchiopexy (OR-kee-o-PEK-see), to bring the testicles down into the scrotum.

Undescended testicles may not cause pain, but they may cause swelling or a lump in the groin area (the place where the lower abdomen meets the inner thigh). If not corrected surgically, the undescended testicles may cause infertility and other medical problems later in life, including the development of tumors or hernias. The area is also more vulnerable to injury if not corrected.

The surgery to move the undescended testicle into the scrotum is done under general anesthesia. General anesthesia makes your child's whole body go to sleep and is needed for the surgery so that his reflexes will be completely relaxed. General anesthesia makes the surgery easier and safer to do because your child will not feel any pain or have any memory of it.

Caudal anesthesia is given with general anesthesia to block pain in the low back, tummy and lower trunk area and provides up to 4 hours of pain relief in that area after the surgery. Caudal anesthesia is usually more successful in younger children. The surgeon may give your child a local anesthetic injection if a caudal injection is unsuccessful or unnecessary.

Facts About Undescended Testicle Repair Surgery

- This surgery is done to move a young boy's testicles from his abdomen, or tummy, into the scrotum, the sac of skin that holds the testicles on the outside of the body.
- Orchiopexy is most often an outpatient surgery
- Your child's surgery will be done under general anesthesia, which means that he will be asleep during the surgery.
- When general anesthesia is needed, there are special rules for eating and drinking that must be followed in the hours before surgery.
- During the surgery, your child will be given a numbing medication—either an injection in the low back called a caudal or directly into the incision, or cut—to relieve discomfort after the surgery.
- The surgery takes about 45 minutes, but recovery from the anesthesia might take several hours.

Before Surgery

It is important to notify your child's surgeon in advance that your child has Prader-Willi syndrome because there are specific precautions regarding the use of anesthesia. Provide your doctor with the **PWS Medical Alerts** booklet available from PWCF and PWSA (USA), as well as the document **Guidelines for Postoperative Monitoring of Pediatric Patients with Prader-Willi Syndrome** available from both PWCF and PWSA (USA). According to PWS specialists Merlin Butler, M.D., PHD, FACMG and Janalee Heinemann of PWSA (USA), these special precautions include high pain threshold, thermos instability (hyper and hypothermia), hypotonia, rumination (aspiration), food seeking (which may lead to undetected eating prior to surgery), IV access problems, skin picking on any surgical site (post surgery), hypothyroidism, growth hormone deficiency (unless on growth hormone therapy).

The Surgery

A pediatric anesthesiologist—a doctor who specializes in anesthesia for children—will give the medications that will make your child sleep during the surgery. At this time, you will be able to ask any questions about the surgery. Once your questions are answered and the operating room is prepared, your child will be taken into the operating room and given an anesthetic to make him go to sleep. When your child is asleep, the surgery will begin.

During the procedure, the surgeon will make a small incision (cut) in the groin and locate the testicle. He or she will examine the testicle to make sure it is healthy. Commonly, there is a hernia sac (a pouch containing tissue that is "pushed out" from the abdomen) in this area that has to be repaired first.

Next, he or she will make a second incision in the scrotum to make a "pocket" under the scrotal skin and place the testicle into the scrotum. Once the procedure is complete, the surgeon will close both incisions with dissolvable sutures (SOO-chers) or stitches that will dissolve on their own.

Waking Up

After surgery, your child will be moved to the recovery room. You will be called so that you can be there as he wakes up.

Children coming out of anesthesia react in different ways. Your child might cry, be fussy or confused, feel sick to his or her stomach, or vomit. These reactions are normal and will go away as the anesthesia wears off. While your child is in recovery, your surgeon will talk to you about the surgery. That is a good time to ask questions about pain medications, diet and activity.

When your child is awake enough, he might be given a Popsicle® or "slushy" to drink in the recovery room. Once the anesthesiologist sees that your child can hold down the drink and his pain is controlled, you may go home. That usually takes about 1 hour.

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MIRALAX CAN HELP

Fighting the Challenges of Slow-Emptying Bowel in PWS



As we learn more about the fact that a symptom of PWS is a slow emptying stomach, called gastroparesis, we are also learning that the bowel intestinal tract seems to empty too slowly. This means that digested food that the body turns into waste product and must eliminate from the body as feces/stool is not entirely eliminated, leaving too much stool in the intestinal tract. MiraLAX can help.

to how to handle the needed surgery. Prior to this extensive workup, her incontinence had been blamed on behavior and depression. I believe it is important to alert all experts to this information when dealing with incontinence.”

Many parents and care providers believe that because their child or adult has a bowel movement every day this means they don't have a slow emptying bowel. This is not necessarily true. Even with a regular daily bowel movement the intestinal tract may not empty appropriately. As the colon becomes more backed up with retained stool, the ability to evacuate stool is less effective. Over a long period of time, continuous, constant hard pushing has resulted in some people with PWS to experience rectal prolapse. The feeling of constant fullness and pressure on the anus or itching of the skin from irritation from bile acids present in the stool may contribute to reasons why some people with PWS insert their fingers into their anus or pick at it.

Shares one mother, “I was very interested in the article about stomach and bowel emptying printed in the [PWCF News, January – March, 2013 issue). I thought I would share my daughter's issues so I could spread the word about this potential area of concern. **“My daughter had been a rectal picker, but it stopped thanks to MiraLAX.”**

She continues, “Despite the cessation of picking, my daughter had to have surgery for a prolapsed rectum, uterus, and bladder. She was having several medical issues including incontinence. They did an MRI topography and said her entire peritoneal floor had very low tone. Fortunately she was seen at [a prominent hospital] where they have a dysmotility guru. Several experts met to decide

Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely Liquid

It is recommended to check your child's/adult's stool against the Bristol Stool Chart, below.

Normal stools should be **Bristol Class 4**. If you are concerned, consult your physician and assess for stool buildup (e.g., palpation, x-ray). Discuss the use of over-the-counter medications such as MiraLAX (polyethylene glycol 3350) to improve stool elimination and over-the-counter probiotics to help regulate the balance of helpful organisms (microflora) in the intestines.

We will keep you updated as we learn more about how to treat a slow emptying bowel and stomach.

.....
Orchiopexy, continued from page 12

A Parent's/Guardian's Role During the Surgery

The most important role of a parent or guardian is to help your child stay calm and relaxed before the surgery. Talk to your child or hold his hand before the surgery, while sleep medication is given and while in recovery. You may bring along a “comfort” item, such as a favorite stuffed animal, for your child to hold

At Home After the Surgery

After your child is discharged and goes home, he might still be groggy and should take it easy for the day. Once your child is home, his diet should be restricted to clear liquids, such as water, Popsicles® or Kool-aid® for a couple of hours to ensure his

stomach is settled after the surgery and the car ride home. If your child does well with these liquids, after a couple hours, he may try a light diet of soft foods like applesauce, soup, toast, bananas, rice or hot cereal. Just as you should every day, avoid greasy foods that stay in the stomach for a long time, such as pizza and fast food. Your child may resume his normal diet the next day.

The incision should not be soaked for about 5 days. If your child is in diapers, he will need “wash cloth” baths for 4 to 5 days. If your child is toilet trained, he will need washcloth baths for 4 to 5 days, but may take a quick shower after 2 days. If the cotton dressing gets wet, you may remove it and replace it with a band-aid.

COMMUNITY PARTNERS PROGRAMS

Three Easy Ways to Support PWCF



If you search the web (and who doesn't?) you can use www.goodsearch.com instead of Google or Yahoo and every time you click search it's a penny earned for PWCF. To get started go to goodsearch.com and click on "sign up" in the upper right hand corner and follow the directions to get started.



Help Ralph's support PWCF by registering your Ralph's Reward Card online in the Community Contribution Program. Once you register, every time you shop for groceries with our Ralph's Reward Card, a donation will automatically be made to PWCF at no additional cost to you! You must re-register every year; the new year starts on September 1st, so even if you registered before you need to re-sign up each year:

- 1) Go to www.ralphs.com
- 2) Click on "services" along the top red bar then select "Community Contributions"
- 3) At the bottom of the page click on "enroll"
- 4) Follow the directions to establish your online account or sign-in to your existing account
- 5) Designate Prader-Willi California Foundation – Organization #93694 – then whenever you use your Rewards Card a portion of your purchases will be donated to PWCF



Sign up for eScrip which encompasses three ways to support PWCF. You can register your rewards cards, credit cards, or debit cards so that whenever you shop at a participating merchant a portion of the proceeds go back to PWCF. You can also shop the eScrip online mall and participate in eScrip Dining.

1) Sign-up and register your reward cards, credit cards and debit cards then whenever you shop at participating merchants a portion of your purchase amount will be given to PWCF

- Visit www.escrip.com to sign up
- Click on "about the program" along the top then click on "sign-up"
- Search for Prader-Willi California Foundation or enter group ID# 500042750
- Once our name appears you can select it and then continue your enrollment
- Once your cards are registered a portion of purchases made at participating merchants will automatically be donated to PWCF

2) Shop at the eScrip online mall

Once you set up your eScrip account you can shop lots of merchants including amazon right from your personal eScrip page or install the AutoEarn program to make sure participating online merchants are redirected to your eScrip page to ensure a portion of your purchase is donated to PWCF.

Alternatively you can shop through this link: <https://secure.escrip.com/jsp/group/onlinemall/groupmallredir.jsp?gid=500042750>

3) Participate in eScrip Dining by Rewards Network

Once you enroll in the eScrip program and register your cards, a portion of purchases made at participating restaurants will be automatically donated to PWCF

Note: Safeway/Vons limit their contributions to K-12 schools therefore PWCF is not eligible to receive donations for purchases made at their stores; however purchases at all other participating merchants are eligible.

BOARD CORNER

Summary of Teleconference on July 15, 2014

Submitted by Tom McRae

Your PWCF Board met via telephone conference on Tuesday, July 15th. The meeting was attended by Board members **Whitney Bras, Julie Casey, June-Anne Gold, M.D., Diane Kavrell, Jacki Lindstrom, Tom McRae, Nisha Mehta, Kimberlee Morgan**, as well as Executive Director **Lisa Graziano** and Family Support Coordinator **Katherine Crawford**.

The Board has been using a “consent agenda” – a set of reports that get distributed and reviewed prior to the actual meeting – so that we more effectively use our meeting time. I’ll hit the high points of those reports as well as the Board’s discussion items.

People

- **Katherine Crawford**, PWCF’s Family Support Coordinator, is moving to Wyoming! The Board acknowledged and thanked Katherine for her fantastic work. Although Katherine will be stepping down from her current position, the plan is she will still help out with graphic design work as well as this newsletter. Good luck Katherine. You will be missed
- PWCF is close to finalizing a contract with **Jill Nowack**, a registered dietician, to provide PWCF families and professionals with diet and nutrition support. Ms. Nowack comes highly recommended by Board member **Daniela Rubin, Ph.D.**
- **Lisa Graziano** has started interviewing candidates for the Family Support Coordinator position as well as a new Office Manager position approved at the last Board meeting.

Member Give Back Program

The Board narrowed in on an appropriate Give Back item for our membership, something that both says ‘thank you for your support’ and is useful to our members. The plan is to deliver this secret something to you by year’s end.

2014 Grants

The PWCF Board budgets monies towards grants each year for clinics, vocational and residential training, and other organizations working to support people facing the challenges of PWS. Each Board meeting we discuss new and existing grant requests. Here’s how things stand for 2014:

- Clinics: \$12,000 budgeted. Approved \$8,651 for the San Diego PWS Clinic.
- Vocational and Residential Training: \$2,000 budgeted. Other: \$5,000 budgeted. Approved \$5,000 grant to Prader-Willi Syndrome Association (USA) (<http://www.pwsausa.org/>).

PWCF Assets Moving to UBS

The PWCF team of **Julie Casey, Lisa Graziano, Diane Kavrell, and Renee Tarica** had phone meetings with representatives of two investment firms, United Bank of Switzerland (UBS) and City National, as potential alternatives to our current firm, Morgan Stanley Smith Barney. The team’s recommendation was that PWCF should move its funds to UBS. A motion was made and approved to move our investments from Morgan Stanley Smith Barney to UBS. A second motion was made and approved to maintain an overall moderate position with respect to PWCF’s investment strategy.

Upcoming Fund Raising Events

- **Ragnar Race for PWS, Trail Vail Lake (October 10-11, 2014)**
Kim Morgan reported that 5 of the 8 slots needed for the Ragnar Race have been confirmed. Contact Kim via the PWCF Office (310-372-5053) if you are interested in running in this unique and fun race. For general info about the race see: <http://www.ragnartrail.com/locations/vail-lake-ca/course>.
- **2015 LA Big 5k and ASICS LA Marathon (March 14-15th)**
Kim Morgan reported that PWCF has been approved as an Official Charity for the 2015 LA Big 5k and ASICS LA Marathon. After reviewing how things went in 2014, the Board agreed to purchase the minimum requirements for the Marathon and 5K slots, and to not purchase slots for the charity relay as they were hard to fill in 2014. More slots can be purchased as needed. The Board also discussed the entry fees, fundraising goals and reimbursement requirements and voted to maintain the same levels as the 2014 Marathon:

Accomplishments

There is not enough room in this article to itemize every accomplishment that is in the various reports. Here are some highlights where PWCF is making a difference:

- **Lisa Graziano** provided a behavioral training session with **Susan Clark, M.D.** (who provided medical overview) for Regional Center of Orange County staff.
- **Lisa Graziano** provided a behavioral training session for families and professionals at the RCOG.
- **Katherine Crawford** provided an overview of PWCF and PWS to Regional Center of Orange County staff. Combined with the staff presentations, well over 100 people were educated about PWS.

The 2014 PWS Camp Session was held from June 19 – June 24. Fifty-eight campers attended. **Lisa Graziano, Linda Ryan**, and

continued on page 17

PWCF WELCOMES NEW CONSULTANTS TO OUR SUPPORT TEAM

Continuing PWCF's Mission to Provide Support and Advocacy

Jill Nowak-Przygodzki, R.D., CDE *Nutritional Consultant*



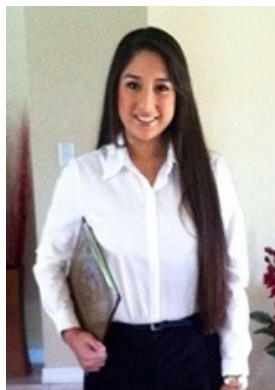
Jill Nowak-Przygodzki is a registered dietician who has been working with patients at Children's Hospital Orange County since 2004. She is a member of the Department of Endocrinology and Diabetes multidisciplinary team and provides nutrition education to patients including meal planning, weight management and behavior modification for variety of disease states 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 much-needed nutritional consultation guidance and services to families.

Now PWCF is fortunate to have Jill on our team to provide nutritional consultation services to benefit families and the professionals who serve them.

Welcome aboard, Jill!

Cynthia Martinez *Family Support Consultant*



Cynthia Martinez is currently in training to become PWCF's new Family Support Consultant. Cynthia will support families within the home setting, providing them with targeted education and information.

Cynthia graduated from California State University in 2013 with a Bachelor of Arts degree in Psychology and a minor in Child Development and Family Studies.

She is currently attaining her Master of Science degree from Mount Saint Mary's College in Counseling Psychology, Marriage and Family Therapy. She has worked with children with and without disabilities, as well as parents, in a variety of contexts and settings.

Says Cynthia, "Working for PWCF has great significance for me because of my brother's PWS diagnosis. It is through my 21 years of personal experience living with PWS that I will bring empathy and excitement to help other families with individuals who have PWS. I am enthusiastic to help families with any difficulties they may encounter and hope to make a positive impact in the lives of every person impacted by PWS. I am very much looking forward to my work with PWCF." We look forward to working with you, Cynthia!

After two years of dedicated service, we bid farewell to our Family Support Coordinator, Katherine Crawford, who moved with her husband to Wyoming in July. Since 2012 Katherine has provided education, advocacy services, and support to families and professionals. Although she will no longer work in the office, Katherine plans to continue to support PWCF's families utilizing her talents in publications and graphic design, and other projects to the extent possible across the miles. California's loss is Wyoming's gain.

Board Corner, continued from page 16

Katherine Crawford flew up a day early to provide training to all of the 40+ camp staff. Katherine and Lisa remained at camp throughout the duration to serve as behavioral consultants.

- **Katherine Crawford** and **Lisa Graziano** provided (separately) 4 PWS training sessions / school consultations / IEP trainings either in-person or via Skype.
- **Lisa Graziano** and **Katherine Crawford** provided residential training to a crisis support home that is now serving a child with PWS. Katherine provided a follow-up training to this home.

Closing

In order for us to make our vision -- "A Full Life Without Limits" -- a reality, we need your continued support! If you are interested in serving as a Board or committee member please let the office know. See <http://www.pwcf.org/home/contact-us/> on how to contact us or just send an email to info@pwcf.org.

If you shop via Amazon, an easy way to help PWCF that costs you nothing is to shop using the "Amazon Smile" program. Check it out at: <http://smile.amazon.com/ch/95-3480752>

WE GET MAIL

Dear PWCF: I so appreciated your newsletter and the personal story [Lisa Graziano] shared about your birthday experience... Your heart is in the same place as mine. I have established a special needs trust but I have never written a letter of intent. I want you to know that you have challenged me to try to take more concrete steps towards a written plan. Would love to know more about letters of intent but not even sure where to start. I was so blessed by your transparency and realness. I will read that to my husband this evening. It will be a good conversation starter. I won't have a martini in hand, but a margarita might help. *Cherie Sakschewski*



Dear PWCF: Janalee [Heinemann of PWSA (USA)] sent me a copy of your article on theft... It's a great article and very simple to follow. This kind of thing draws huge attention from our international group of parents. *Kind regards, Linda Thornton, Communications Coordinator, International PWS Organisation www.ipwso.org*

Dear PWCF: [You] helped us many times when [our daughter's] preschool didn't understand how to approach her PWS issues like her tantrums and food control. We are so thankful for PWCF for helping us through the daily parenting battles. *Sincerely, Rhonda and Andy Faust*

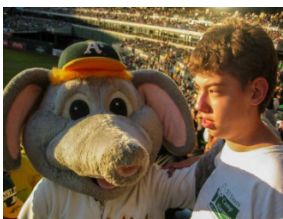
Dear PWCF: We can't thank you enough for coming to STEP [supported living services agency] and sharing yourself and PWCF with us! Looking forward to a future of collaboration to better serve folks with PWS. *Take care, Lynn Vaughan, Director of Medical Services*

Dear PWCF: When I wrote my \$30 check (in honor of Samantha Morgan) I didn't know it was the Foundation's 35th year of service, so I'm enclosing this \$5 so to make it \$35 with my previous donation! *Margaret Peacock*

FAMILY FUN & AWARENESS EVENTS THROUGHOUT CALIFORNIA



Families enjoyed a Family Fun Day at the Angels baseball game on July 26!



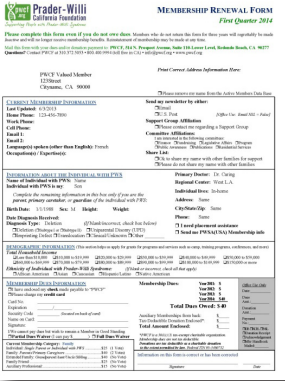
The Oakland A's Stomper visited families at PWCF's Family Fun Day event on August 24!



Volunteers raised public awareness of PWS at the Levitt Pavilion Children's Concert Series events in July and August!

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.



If you haven't yet returned your Membership Renewal Form this year, another form is on its way to your mailbox.

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 Extended Family Members

- Carina Chaij
- Pat Grey
- Ashley Hurdle
- Betty McBroom
- Mark Savit
- Linda Smith
- Celeste & Tom Von Der Ahe

Renewed Family Friend Members

- Jeremy Friend, M.D.
- Janet & Joel Goldberg
- Ronnie Raffaniello

Renewed Professional Members

- Stephanie Abrams, M.D., MS
- Lynne Bird, M.D., Rady Children's Hospital San Diego
- Suzanne Cassidy, M.D.
- Susan Clark, M.D., Children's Hospital Orange County
- Ida Dacus, South Central L.A. Regional Center
- Tony Kueter, People's Care Inc.
- Debbie Lange, PWSA of Georgia
- Luz Rasco, Talia Vi Homes
- Daniela Rubin, Ph.D., CSU Fullerton

Renewed Auxiliary Members

- Jeremy Friend, M.D.
- Linda Smith

New Family Members

- Lori & Chris Avery
- Sharon Chen & Russell Baker
- Kelly Garner & Brian Dula
- Jennifer & James Meade
- Alexis & Kurtis Wagoner

New Extended Family Members

- Nancy Harris

New Professional Members

- Stephanie Abrams, M.D., M.S.
- Mario Alvarez, United in the West

New Auxiliary Members

- Trey Wilmer, Special Education Teacher, Tesoro High School

VOLUNTEERS are *Priceless*

PWCF thanks **Jenny Wolkenstorfer** and **Dominic Ginyard** and his sons **Spencer** and **Tyler** for helping PWCF President **Julie Casey** at the PWS Information Booth at the Levitt Pavilion on August 20.

PWCF thanks **Michael Moore** for helping to coordinate the PWS Family Day at the Oakland A's event held on August 24.

PWCF thanks **Paula Watney** for representing PWCF at the Department of Developmental Services Workgroups meetings in Fresno on August 27 and August 28; and **Diane Kavrell** for representing PWCF at the meetings held in Sacramento on September 10 and 11.

Prader-Willi California Foundation is grateful to each of our donors for helping us provide quality supports and services to individuals with Prader-Willi syndrome and their families. **Thank you!**

We work hard to recognize all donors who wish to be recognized. If you don't see your name listed, please accept our sincere apologies and allow us the opportunity to include your name in the next issue by contacting us at 310.372.5053 or info@pwcf.org

DONATIONS

July - September 2014

Shining Star Donations

Canopus (\$500 - \$999)

Suzanne Privette in honor of Samantha Morgan
(monthly donation)

General Donations

Anonymous Donors via Kroger
Julie Arvan in honor of Olivia Wagner
Jennifer Cantrell via Thirty-One Gifts Fundraiser
Julie & Dan Casey
Suzanne Cassidy, M.D.
Jan Conroy & Gayle Dax-Conroy
Jennifer Decicco of New York Life
via Benevity Community Impact Fund
DirecTV via Benevity Community Impact Fund
Beverly Ginyard in honor of Spencer Ginyard
Pat Grey
Janice & Neil Hubberth
Ashley Hurdle
Lucy Jao & Bie Chuan Ong
Mary & Alan Kisaka
Susan LaChance via the Massachusetts Credit Union
League, Inc. in honor of Oliver Young
Stefanie Louie in honor of Lucas William Widdifield
Angela & Robert Lucero
William Luevano in honor of Victor Ramos
Alberto Martinez
Patti & Tom McRae (monthly donation)
Anna Montoya via Community Health Charities of the West
Fran Nicholson
Jessica & Chris Patay
Ivette & Luis Ramos in honor of Victor Ramos
Katherine Randall in memory of Keith Johnson
Jenna Reitz
Suzanne Reitz
Wendy Reyes
Mark Savit

General Donations, continued

Janice & John Shimmin
Silicon Valley Community Foundation
Matthew Taylor
Nick Watney

Donations to Support PWS Camp

Suzanne Privette in honor of Samantha Morgan (monthly donation)

Donations in Honor of Samantha Morgan at the Request of Ita & Nick Moran in Celebration of their 60th Wedding Anniversary

Margaret Peacock

Donations to Support the Walking for PWS Events

Don McRae in honor of Duncan McRae
Jamee & Arthur Price in honor of Trevor Ryan
Bonnie & Danny Resendes in honor of Emma Fluhr-Resendes

GRANTS RECEIVED

PWCF expresses its gratitude to **Esther Ray** and **Adobe Foundation** for awarding a grant to PWCF so that we may purchase much-needed computer equipment. Special thanks to **Tom McRae** for requesting the grant for PWCF.

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)