

PWCF News

The Newsletter of Prader-Willi California Foundation

An Affiliate of

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USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

The Missing 15 and the RACE for PWS

The RACE for PWS went better than even **Jessica Patay** envisioned or expected.

Nine months ago when Jessica hatched what she calls the crazy idea to enter into the grueling 200+ mile Ragnar Relay Race, she wondered if she could find twelve people to take on such a wild challenge. It certainly would have been easier (in some ways...) to just all train for a marathon, show up, run a few hours (or four or five), and then have a little party at the end of the day. Taking on the Ragnar Relay was a logistical feat. It was a huge time commitment for each of the participants to train and to actually participate. Jessica knows her Team made sacrifices. She knows each participant's family made sacrifices. Team members shamelessly asked for favors and funds and donations, and gave up sleep and comfort, and agreed to be in a van with some strangers for 30 hours. Who were these amazing participants? **Jessica Patay (Team Captain), Chris Patay (Team Captain), Kim Morgan, Chris Onufrak, Drew Marich, Mercedes Gutierrez, Jamie McLaughlin, Brad Patay, Chris Brown, Christian Rollino, Andrew Purdy, Paul Hill, Daniela Rubin, PhD, Linda Ryan, Mark Ryan, Jimmi Ng, Jason Ng, Jeremy Tan, and James Tufano.** "Pacers" Jimmi, Jason, Jeremy and James are students of PWS researcher Dr. Rubin who gave up their time and sleep and didn't even get a medal at the end. They deserved one.



And those vans! Two way cool and amazing vans transported the next-in-line runners to each destination, thanks to **Chris Brown** who designed each van pro bono and whose employer donated them. Did the vans help raise awareness of Prader-Willi syndrome? You bet they did! As did the name of the Team, The Missing 15, referring to the missing genes on Chromosome 15 that cause the symptoms of Prader-Willi syndrome. Everyone who asked – and a lot of people asked – about the meaning of The Missing 15 was treated to a brief synopsis of PWS.

Drew Marich worked to get the Clif Bar company to donate boxes of Clif Bar products to keep the team nourished. Van drivers **Brad Patay, Linda Ryan, and Mark Ryan** were a huge blessing for the runners who, because of them, did not have to drive *and* navigate the whole time.



Jessica & Chris Patay

Jessica is proud of her husband, **Chris Patay**, who, she writes “was an amazing team captain and master of logistics and details who kept everyone on track so that from start to finish, everything went smoothly and successfully.” Jessica adds, “I truly enjoyed this experience and would do it again! Ok, maybe I *really* did not like running in the heat of Corona, but I will just train better next time.”

The RACE for PWS raised not only awareness of PWS but \$25,000 for PWCF to spend on the programs we provide to support individual with PWS and their families. PWCF is so very grateful to each and every one of these amazing people!

In This Issue:

Growing Older with PWS.....	6	Walk Photos	14
Oakland A's Family Day Baseball Game.....	7	In The Trenches Vol 5.....	15
Snorkeling with Oscar.....	8	Save the Date.....	17
Medical Alert.....	11	London Marathon	19

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CALIFORNIA FOUNDATION**

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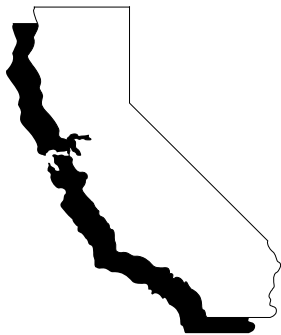
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"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families."

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Wendy Young	415-380-0721	wmydmy@gmail.com
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Inland Region Area

San Bernardino/ Riverside County	Maria & Ken Knox	909-421-9821	teachknox@aol.com
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Spanish Speaking

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On-Line Support

PWCF Online Information Sharing Group for Members. This online information sharing group is for PWCF members. To join the group, go to www.yahogroups.com. In the search box under the heading "Join a Group" enter *PWCFmembers*. When the *PWCFmembers* group name appears, click and follow instructions to join.

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

PWSA Online eSupport Groups.

www.pwsausa.org Click Enter. Click Support.

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

for Spanish-Speaking Families
for Military Families
for PWS + Autistic Symptoms
for Persons with PWS
for Grandparents

International PWS Organisation

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

Parent to Parent

Sandy O'Connor asks, "I am thinking of trying hypnotherapy sessions for my 42-year son with PWS, Tom, to see if it might be helpful with the eating problem. I'm sure it must have been tried but I've never heard for sure. I would appreciate any feedback you might give me, successful or unsuccessful. Wouldn't it be wonderful if hypnosis could relieve some of the stress our kids have about food."

Our experience with hypnosis was for picking when our son was 10 or 12, and I took him to a few sessions with the Psychologist. The doctor's opinion was that he didn't have the capability to understand the process to make it work. We also tried acupuncture for the picking and after several sessions we stopped because the effort to get him to the appointment became way too stressful for him and me! Our son is now 41 and he can control the picking in inappropriate settings but it will always be part of his idiosyncrasy. However, everyone is different, and we feel that it's worth trying anything and everything to find what works!
Judy Castle, mother of Jason, age 41

Next issue's Parent to Parent question is, "What supplements do you find most helpful and how do you determine the correct dosage?"



A Parent Asks and PWS Expert Phillip Lee, M.D. Answers: Why do people with PWS tend to bruise more easily?

Actually, we don't really know (epidemiologically) that bruising is more prevalent in persons with PWS. There is always the possibility of observational bias where individuals with a certain condition (e.g., PWS) or treatment (e.g. PWS-GH) are observed more frequently and intensively on a daily basis, and positive findings are more likely to cause an alert than if the same findings are observed in other individuals. For PWS, this type of observational bias accounted for the recent scares regarding GH-deaths, congenital hypothyroidism and adrenal insufficiency.

On the other hand, there is no doubt that bruises are often noted in certain individuals with PWS. Contributory factors probably include decreased peripheral pain sensation (leading to a relative lack of avoidance of potentially traumatic events), a certain degree of clumsiness and motor discoordination that may be related to hypotonia, and behavior patterns (e.g. physical outbursts).

I'm not aware of any evidence for an increased association of bleeding or clotting disorders (e.g. von Willebrands, etc.) with PWS. I have wondered whether skin strength/thickness and skin capillary integrity might be decreased in some patients with PWS -- perhaps related to lack of underlying muscle, lack of sun exposure, etc. (the things that make skin stronger) -- but I am not aware of any reliable data relating to skin histology in PWS. However, based on experience, individuals with PWS do not appear to be more prone to bruising from injections, such as GH injections or surgical bleeding.

Collecting scientific data on the prevalence and causes of bruises in individuals with PWS could be difficult. There would be questions about the control group selection, methods of observation and selection bias. In my experience, bruises are often observed in children (with or without PWS) without recollection of the contributory event.

Of course, most bruises are benign and self-limiting. The usual PWS recommendations for preventive care apply, as frequently stated for avoiding and detecting bone fractures. In individual cases, the main issues would be whether a current bruise could be part of a more significant associated injury (e.g., fracture) and whether recurrent bruising could be indicative of a risk for potentially significant injury and/or coincidental occurrence of a bleeding/clotting disorder such as von Willebrands, which is not uncommon in the general population. Medications may also be contributory in some cases (aspirin, NSAIDs, steroids) and in severe recurrent cases, physical abuse or purposeful self-injury may need to be considered.

Dr. Phillip Lee is Professor in the Department of Pediatrics and Director, Division of Endocrinology at the University of Texas Medical Branch where he provides support to the PWS Clinic. Dr. Lee's research and clinical interests include growth factors, biomarker assay development, disorders of growth and development, obesity, diabetes, and Prader-Willi syndrome. He is a former member of PWSA(USA)'s Scientific Advisory Board, Clinical Advisory Board, and co-editor of the Management of Prader-Willi Syndrome Third Edition.

Gadget Tip

The Snack Time Survival Kit
by Beanstalk Express

\$49.95 <http://www.child-nutrition.us/snack.html>



How it works:

1. Each morning, Mom or Dad selects snack cards that are available that day
2. From these cards, kids can choose their snacks for that day.
3. Parents set the control clocks to the desired snack times and hang the snack cards on the corresponding hooks.
4. The clock can now be used as a visual cue as to when it's SNACK TIME!
5. Mom takes the snack card off the hook and serves up the snack.

Features one working clock, 3 control clocks with moveable arms, 3 corresponding hooks to hold snack cards in place, and 33 Snack Cards. Of course not every snack featured on a card will be appropriate for someone with PWS, but parents can make your own healthy snack cards.

Food Tip

This food tip was submitted by Reiko Nakamura of Garden Grove

My daughter, Aska, has been taking flax oil since she was three months old. At that time, my mom began searching for a substitute for fish oil because it can be difficult for small kids to take. During a visit with a friend of ours who lives in Japan whose daughter also has PWS, we learned about flax oil and my mom ordered some for my daughter. When Aska was younger, she took the flax oil with her formula. Now at almost 2 years old, she is eating it with her yogurt. My mom also likes the oil and uses it as dressing for salads. Flax oil is weak to heat, so we cannot use while cooking with heat, but it'll be OK to put in hot soup and hot meal. I purchase our organic flax oil at Whole Foods.

WebMD.com explains that "Although flaxseed contains all sorts of healthy components, it owes its healthy reputation primarily to three ingredients:

Omega-3 essential fatty acids, "good" fats that have been shown to have heart-healthy effects. Each tablespoon of ground flaxseed contains about 1.8 grams of plant omega-3s.

Lignans, which have both plant estrogen and antioxidant qualities. Flaxseed contains 75- 800 times more lignans than other plant foods

Fiber. Flaxseed contains both the soluble and insoluble types.

The following amounts of flax oil per day are suggested from a Japanese company's site:

Approximately 6 months	1/4 tsp
6 - 12 months old	1/2 tsp
1 - 2 years old	1 - 2 tsp
Over 2 years old	2 tsp
Adults	1 - 2 Tbs

Do you have a Food Tip you'd like to share? Send, fax or email it to PWCF!

Executive Director's Column

Lisa Graziano, M.A.

I don't watch too much television, or at least not as much as I'd *like* to. If I could, I'd watch TV all day: while lying in bed, jammies on, no one needing me for anything, free entirely of the pull to return a call, reply to an email, change the laundry, find something for someone. But my TV viewing time is limited to the evening and my choice of good shows is also fairly limited given our 9:30 pm bedtime. I do like to end the day watching a comedy, though. It just feels good to be forced to smile, and the occasional laugh-out-loud endorphin rush feels great.



We recently got a DVR and I now record two shows daily. One is a comedy series for that just-before-bedtime viewing, and the other is my most favorite syfy-ish drama series. I watch episodes of the latter day after day after day. Fortunately, my son loves the same series and is a good sport about sharing our limited television viewing time between his after-school show and mine. But it drives my husband crazy to see us watching an episode we've already seen 17 times. I think it must be a hereditary "OCD thing" because my brother does the same thing -- watch a beloved series or show ad infinitum. I used to think it quite obsessive-compulsive of him, but now I totally get it and think it's just... something to accept.

Acceptance. It's a term I'm quite familiar with in my work as a psychotherapist. It's a term I struggle with as a parent.

Twelve-step programs teach the serenity prayer: Grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference. A parent's job is to teach our child so he or she is well prepared for their future. As our child grows, we're supposed to back off and give the burgeoning young lady or gentleman the opportunity to demonstrate that they've learned what we've tried to teach. I know there are some things that we will *never* stop providing our child because he has Prader-Willi syndrome, namely a calm, safe and secure home and food environment. But as he enters tweenhood – the years between being a little boy and a young teenager – it gets more difficult for me to know how much to push and how much to let go and just accept.

My husband and I were talking with our son the other day, asking him how he's liked his first year of middle school, what he thinks about starting 7th grade, what he likes about his life, and what in his life he would change if he could. To the latter he answered, "Mom not being so hard on me." In that moment I felt stunned to the core. But if I'm honest with myself, I shouldn't be all that surprised. Thinking back over a typical week I can hear the words as they spill out of my mouth: "Slow down, Cam. Chew your food, swallow, and *then* take another bite." "Stop biting your lip, Cam. When you feel the urge to bite, get a piece of gum." "Stop picking your nail, Cam. Remember, when you notice yourself picking, ask for a Band-Aid." "Have you already told me this story? Then think of a *different* way to tell it, or tell me something *new* about what's happening right *now*." "Eyes, Cam. Remember to *look* at the person you're speaking with." "You need to *listen*, Cam. Your friend was telling you what he thought. You weren't *listening* but were more interested in telling him *your* story. A good friend is a good *listener*." Yikes! No *wonder* the poor kid feels his mother is so hard on him. *I am!*

When he was a little boy, I had more patience. I was more inventive of strategies to persuade him to do what he needed to do. Back then I incorporated more fun into life lessons and I used a lot more positive parenting techniques compared with now. Twelve years of relentlessly working hard to teach him, lead him, persuade him, stay calm on the outside for him, think one step ahead of him, and I feel spent. Lately my storage of patience feels depleted and my mind feels void of creative ideas. My parenting repertoire has been reduced to critical observations rather than creative teaching strategies wrapped in loving language. I find myself engaging more in unnecessary power struggles where *I* want to have the last word, all the while knowing *if I say one more word it will* land us both in unwanted territory. I seem, however, utterly unable to stop myself. I then feel disappointed in my son for taking my bait, and ashamed of myself for baiting him. It seems lately I expect more from my son than I'm capable of myself. I tell myself I'd have more patience if I got a break, a reprieve from the daily grind, an extended vacation from... my life. But deep down I know that what I *really* need to do is to reassess my expectations.

Reassessment is a good thing, a necessary thing. It means taking a look at what works, what has gotten us where we are today, and what needs to be tweaked or totally changed to get us where we want to be tomorrow. It's the stuff from which progress is made.

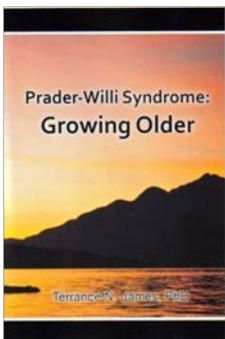
Throughout this newsletter you will read about parents, friends, and professionals who are working hard, pushing hard, constantly assessing and reassessing, reaching far beyond their comfort zone to create opportunities for their child or opportunities for others. You will read how incredible people pushed themselves farther than they believed they could go, with no guarantees about the outcome, sustained only by an inner trust that what they were doing was what they needed to do. These are the heroes who walk quietly among us. There are many more people whose stories are not shared in this newsletter; these are the heroes who walk invisibly among us.

Continued on page 19 ...

Prader-Willi Syndrome: Growing Older by Terrance James, PhD

A Review by Barb Dorn (USA)

Prader-Willi Syndrome: Growing Older by Terrance James, PhD is an enlightening book that begins to explore a topic that is becoming very pertinent - our aging population of adults with PWS. James interviewed parents, caregivers and 14 adults with PWS ages 40+ years who reside in Western Canada. He covers a variety of topics that impact these aging adults including services, genetics, health, residential supports, and employment as well as their aging parents and/or caregivers. He also focuses on quality of life issues and shares the personal views and experiences of these adults.



The first few chapters are very informative and help readers gain a historical perspective on the changes and advances in the field of developmental disabilities and Prader-Willi syndrome. “Younger” readers will learn to appreciate the advances in genetics and diagnosis of PWS. (Most adults 40+ years old did not and many do not have genetic confirmation of the diagnosis). James briefly touches upon the many areas impacted by the aging process (cognition, behavior, physical health, mental health – just to name a few). He shares research resources from all over the world that supports his findings.

James also devotes one chapter to the topic of aging parents – an emotional topic near and dear to all parents of adults with PWS. He touches on several concerns about the future including family, residential and funding concerns of government programs. Even though most references are for Canadian programs, it was interesting to learn that we share many of the same challenges and concerns.

My favorite part of the book includes the chapters that share the personal life experiences of 14 older adults. They share their accomplishments and what things have helped to improve their quality of life. It is enlightening to read about the various models of residential support these adults are utilizing. It is also great to see how many of them are taking advantage of volunteer opportunities out in their community to keep them connected to social and cognitive stimulation when employment was no longer a full time option. As the parent of a young adult with PWS, these profiles forced me to take a personal look at my son’s current life and reflect on his personal needs and dreams.

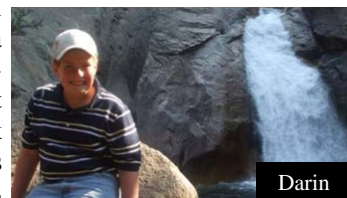
Prader-Willi Syndrome: Growing Older is a quick, enjoyable resource on a topic that needs more research, discussion and attention. Even though the book focuses on aging adults with PWS residing in Canada, the topics, issues and concerns cross national boundaries. It begins an initiative in starting to share more on this much needed topic of aging with PWS.

Poplar Publishing, ISBN 978-0-9685838-1-4. \$113 pages, Perfect bound. \$18.

To purchase book visit <http://www.prader-willi.ca/my-books/>

Our Amazing Kids with PWS

Nearly 12 years old, **Darin Murphy** takes seriously doing his part to help future physicians learn about Prader-Willi Syndrome (PWS), and what it means to live each day with this syndrome. As a person with PWS, he has shared his story with first-year medical students at the University of California, Irvine for the past three years. This year when he addressed the class, Darin talked about having low muscle tone and poor balance when he was younger, and how therapy and horseback riding have made him stronger, though he does admit he still tires easily. Darin also shared about his experiences at school (both positive and negative) and when asked, named science and history as his favorite subjects. He discussed emotional upsets – how many people don’t understand they are not intentional, and how he has learned to better see them coming so he can prevent them or work through them when they do occur. For Darin, body temperature and hydration, as well as level of fatigue, factor greatly into these incidents. Of course, Darin talked about always feeling hungry and having to watch what he eats. And he talked about giving himself growth hormone injections every night. He also shared about his favorite activities which include soccer and horseback riding, and about his plans for a career as a veterinarian. Finally, when prompted, Darin closed by offering this advice to families as they first face a diagnosis of Prader-Willi Syndrome: “Know that you may be given all these symptoms your child may have, but know it’s going to be OK. Your child is their own unique person. Believe in them and believe in their ability to excel despite these troubles.”



Cameron Graziano, age 12, presented to over 150 first-year genetics students of Loma Linda University about what it’s like to be a student with Prader-Willi syndrome. The presentation was organized by PWCF Board member **June-Anne Gold, M.D.**, and was orchestrated by Dr. Gold’s students Richard, Jules and Marcus. Seated at the head table in the front of a very large lecture hall, Cameron looked not the least bit nervous. He was cool, calm, self-confident, and quite poised as he spoke, and did a wonderful job making PWS “real” and memorable for these students, our future physicians and researchers!

PWCF Wants to Take You Out to the Ball Game!

Oakland Athletics vs. Texas Rangers

Saturday, August 13 at the Oakland Coliseum

12:30 p.m. Pre-Game Gathering / 1:10 p.m. Game

It's time for the first annual Prader-Willi California Foundation Family Day out at the Oakland Coliseum, to watch the Oakland A's take on their Division rivals, the Texas Rangers! Field level tickets are only \$26 per ticket, with \$13 from every ticket sold benefiting PWCF!

PWCF attendees will sit together in Field Section 127, with a Pre-Game visit from the A's Mascot, Stomper at 12:30pm, and a PWCF Jumbotron welcome during the game!

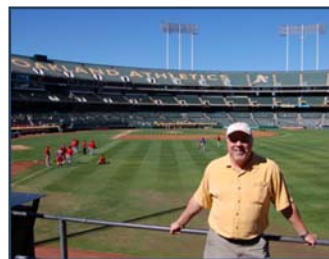
Out of town? Why not stay at a nearby hotel such as one of these:

Hilton Oakland Airport (510-635-5000 // www.oaklandairport.hilton.com)

Holiday Inn Hotel Suites Oakland Int'l Airport (510-569-4400 // www.oaklandhiexpress.com)

Courtyard by Marriott Oakland Airport (510-568-7600 // www.marriottoaklandairport.com);

Don't miss the fun!



PWS Family Day with the Oakland A's Ticket Order Form

Please send me _____ Oakland A's Tickets Name: _____

Shipping Address: _____ Telephone: _____

City, State, Zip: _____

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

Name as it appears on card _____

Credit Card No. _____ Email: _____

Expiration _____ Security Code (on back of card) _____

Billing Address _____
(if different from shipping address above)

Signature _____

Office Use Only

Date Rcvd: _____

Check #: _____

Date Sent: _____

**Mail this form to Prader-Willi California Foundation
514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277
Tickets will be mailed as soon as payment has been processed**

Snorkeling with Oscar

By Mary Hill



Just this morning, though it seems days ago now, we tread carefully down the steep grassy bank below our condo and then inched our way across the slippery old volcanic rock toward the snorkeling bay. It's 8:30 am and our flight leaves Hawaii in just a few hours, but Oscar declared last night that he wanted to swim with the giant green Honu turtles one last time and we are trying to make it happen.

As we approach the snorkel spot Oscar sees the waves crashing against the black pitted rock, white spray bursting high off the water, and he starts to panic. "I don't want to. Uh-uh. I changed my mind." His voice is still calm but his resolve is clear.

Paul and I communicate over his head with eyebrows and shoulder shrugs. I'm on the fence – the surf is much rougher than it was yesterday when Paul and I snuck away for a half hour in the bay. I've been here many times before during high surf and have been slammed against the rocks when an especially big wave rolls in. Paul thinks we can still do it. He slings Oscar up on his back and carries him across the slickest parts over to the edge where I am already sitting with my flippers and mask on. Oscar's protests increase and soon he is screaming. "I won't do it. You can't make me. STOP!!!"

I pull Oscar's right flipper on up over his stubborn low-toned foot while Paul talks to Oscar about his mask. The mask is all-wrong – it's squeezing Oscar's lip. It's hurting his hair. The snorkel will let water in. Oscar yells reason after reason why it won't work today, even though it worked just fine yesterday. He pulls the right flipper off but I wrangle it back on and somehow the left one too. "NO NO NO. STOP!"

The flippers are off again. Oscar is still screaming and I am definitely not looking up at the grassy banks filled with snorkelers and onlookers. A woman calls to me from the water and I just know she's saying I'm a horrible mother to be putting my son through this. I ignore her and the words I think I am hearing.

Paul says jump, and I do, into the cool jostling water and try to find my balance on the rocks beneath me before another wave crashes in. He picks Oscar up, still screaming and hands him down to me.

We've compromised – no flippers, no mask, just goggles and a boogie board. I help Oscar adjust the goggles. Now in the water he calms down and we set out to find the enormous turtles whose scaly heads we see popping up for air from our balcony. Large greenish brown shells float along the surface of the bay at all times of day here, but especially in the morning, and up until five minutes ago Oscar was clamoring to go.

We spot our first turtle quickly, thankfully. The turtle's flippers pull gracefully through the water. He points his head down and slowly glides to the bottom of the bay where he nestles under a rock. I lead Oscar over and show him where to look. He does, and after watching for a half minute, he comes up for air giggling hysterically. Oscar immediately wants to search for more turtles and we find them easily. The smallest, a youngster, is still much larger than Oscar himself and I think our whole family together would still take up less space than the largest. We swim across the bay spotting them at the surface, resting under rocks and just swimming along peacefully. After half an hour, and seven Honu turtle sightings, I finally convince Oscar to head to shore where Paul is waiting to pull him out.

Usually Oscar forgives his grudges quickly, especially when the experience is worth it, like today. But as I lift him out of the surging waves and safely into Paul's arms he yells, "That was wrong! Don't force me like that again!"

Back in the condo, as I hurriedly cram the last stray items into our bulging duffle bags, I reflect on how difficult it is to know just how much to push Oscar. We face this dilemma constantly with everything from simply trying a new book to far more challenging tasks like snorkeling. Today was definitely borderline but Paul and I were in agreement -- we knew that he would love swimming with the turtles and we also know that each time we push him an inch (or a foot) beyond his comfort zone, we are creating memories for Oscar that he will draw upon for courage and confidence in the next difficult situation.

I don't regret our decision today, though maybe I should. I do regret that in order to help Oscar overcome his rigidity and his fears that sometimes we have to step outside the boundaries of what I consider to be our parenting style and literally force him. I think we're doing the right thing, and Oscar's recent willingness to try some new activities (without being coerced) seems to indicate we are on the right path, but still I am just not sure.

Mary blogs about life with Oscar (who has Prader-Willi syndrome) and the rest of her family at Finding Joy in Simple Things.

Call for Research Subjects

Study of Behavior in Prader-Willi Syndrome:

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

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

Parental Coping Strategies Qualitative

Research Study: University of Phoenix education doctoral student Carol McLurkin is conducting a study entitled, *How Parents Cope with Raising Children with Developmental Disorders: A Case Study*. The purpose of the study is to explore parental coping strategies. Ms. McLurkin is interested in conducting face-to-face interviews with seven parents of a school-age child (age 5-21) with PWS who live driving distance to the Antelope Valley.

For more information, contact Ms. McLurkin at (661) 264-8948 or carol@mclurkin.com.

PWS and Early-onset Morbid Obesity Natural History Study – All Persons with PWS:

Conducted by Virginia Kimonis, M.D., Chief, Division of Genetics and Metabolism, UCI Med Ctr. The purpose of this study is to collect natural history information on PWS and early onset morbid (severe) obesity.

WHO: Persons with a confirmed diagnosis of Prader-Willi syndrome ages birth-60 years, receiving and not receiving growth hormone.

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

CONTACT: Virginia Kimonis, M.D. at (714) 456-5791 or email at vkimonis@uci.edu or Sandra Donkervoort, MS, CGC research coordinator at 949-824-0521 or email at sdonkerv@uci.edu.

ACTIVE PLAY AT HOME STUDY

RECRUITING PARTICIPANTS

Interested in having your family be more physically active?

The Kinesiology and Health Science Departments at California State University Fullerton (CSUF) are evaluating a home-based physical activity program (Active Play at Home) for children and adolescents.

Children ages 8-11 years who are overweight and one parent or guardian are invited to participate. Families will participate in a 24-week home-based program using interactive console and playground games provided to them at no cost. Participation also requires four to five visits (3.5 hours long) to the CSUF campus. During the visits, the child will complete a health assessment, a very easy and accurate body fat measurement, and movement-related assessments. Children and parents will also complete questionnaires.

Incentives include: 1) \$30 gift cards for visits, 2) keeping the provided sports and media equipment, 3) \$60 gift cards during the program.

Parents/guardians will be reimbursed for mileage for the visits to CSUF.

For more information or to participate in this study, please contact the research office at:

657-278-8737

pwstudy@fullerton.edu

Or Contact Dr. Daniela Rubin at
657-278-4704
drubin@fullerton.edu

Hablamos español.



California State University, Fullerton

Board Corner

PWCF Board of Directors Meeting April 2, 2011

By Julie Casey

The Board of Directors met in Redondo Beach for the regularly scheduled Board meeting. After the initial business of approving the agenda and prior minutes, Julie Casey reported on actions taken by the Executive Committee since the last meeting. The only item was that Pfizer had brought to PWCF's attention pending legislation (AB 310) that would cap co-pays/co-insurance on specialty medications such as injectables like growth hormone therefore it was determined that this is legislation that PWCF would want to encourage members to support if and when there is a call to action.



A significant portion of the meeting was spent on **Strategic Planning** - reviewing progress and status on the 2011 goals:

1. Create PWCF DVD – The objective of this goal is to create a marketing DVD that could be used to solicit donations and grants. Lisa has talked with Albert of Albert Salzar, Jr. Productions about this project and he is enthusiastic to take it on. They talked about getting footage of the *Walks* this year to be used in the DVD.
2. Hire a Grant Writer – The contract with the Grant Writer has been signed so they can start working on our behalf. Executive Director Lisa Graziano noted that she had a positive meeting with them wherein she outlined our grant objectives.
3. Progress on long-term project – Julie Casey noted that the online survey has been largely completed; just a few final changes need to be made before it will be ready to be distributed. There was a discussion about the best way to distribute the survey. Online is the best way, however some people, particularly group home residents, won't have internet access. It was noted that although online is the preferred way to deliver the survey, print copies will also need to be available. The discussion raised a few more changes that need to be made to the survey.

The Board also discussed the name for the project. Several names were proposed and then the group narrowed it down to the top 4 choices to be included in a final poll to all Board Members so that those not present would also have input.

4. Outreach to Spanish-speaking population – The main progress this year for this goal will revolve around the GEM by having the brochures in Spanish and translation at GEM (advertised on GEM brochure). Other ideas discussed for the future include: Spanish section on website, and translating the newsletter (or at least parts).
5. GEM – As always, one of the annual goals is to hold a great General Education Meeting. The Program Committee has already begun discussing speakers and topics. A hotel in Southern California will be secured for this year's November 5th date.
6. Finish Residential Staff DVD - The DVD is in the editing process. Fran will be meeting with Michelle Freier this week to help critique the draft in order to make recommended changes.
7. Website Redesign – Tom McRae provided an update on the website re-design informing the Board that working with Ryan of WSmad is going well. Ryan has emphasized how lucky we are to have a four letter website (pwcf.org) and that we should capitalize on that when designing a logo. Tom showed the Board several logo designs that Ryan had prepared. The Board discussed them and also discussed getting some additional design ideas. Julie C. mentioned she has a friend who is graphic designer and she will talk to him about possibility putting some ideas together. Also, Mike mentioned he could have his friend put together some ideas. The Board agreed to pursue other design possibilities before finalizing a logo.
8. Fundraising – In addition to PWCF annual *Walk* Events, the Board wants to actively pursue corporate grants and, as already noted, a contract with a professional Grant Writer has been signed. Additionally, two new fundraisers are coming up: The Race for PWS, a team relay race across California led by Chris and Jessica Patay, and John Gold (husband of Board member June-Anne Gold, M.D.) will be running in the London Marathon.
9. Improve Public Awareness – Mike Moore proposed a combination awareness event and family day at an Oakland A's game. The Board voted to go forward with this event. Mike will finalize the arrangements. The Board also discussed a similar event for Southern California with the Galaxy however additional information is needed before approving this event.
10. Create PWS Camp – This will be the first year with Easter Seals' Camp Harmon and the Board hopes it will be a long-term relationship, therefore an annual goal to offer a PWS specific camp each summer has been established. Lisa reported that 35 people have signed up for camp already. Lisa also reported that the Camp Committee had to make the difficult decision not to allow smokers due to the logistics being impractical to ensure the health and safety of all of the participants.

11. Generate interest in research – Although PWCF is a support organization and not in the business of conducting research, the Board values research and feels it is important to encourage researchers to study PWS as well as help researchers by advertising for research subjects. Dr. June-Anne Gold has a special interest in this goal and proposed that PWCF offer a grant to

Continued on page 11 ...

a junior doctor to attend PWSA's scientific day at future conferences. The Board agreed that is something that should be pursued. Also, Dr. Gold had seen a news article on Sensa Powder that one sprays on food to supposedly reduce appetite and she wants to further explore if this is a viable area for PWS research. Dr. Gold also indicated that she is still interested in doing a study on Coenzyme Q-10 and that Loma Linda University may be willing to help with this study. June-Anne suggested that we may want to poll the PWCF members as to where they would like to see research directed.

The remainder of the meeting discussed the following topics:

Residential Services Liaison Committee Report: In addition to the update on the DVD project reported above, consultant Fran Moss presented a written report of her contact with the group homes noting that weight gain during home visits remains a big problem. The Board discussed the need to retain additional residential training consultants as this service is so valuable to the PWCF membership. Fran also reported that she met some people from TERInc.org (Training, Education, Recreation Institute.) and that they have a variety of programs of people with disabilities including residential facilities. Fran was excited about the possibility of getting them interested in PWS.

Treasurer's Report and Finances: Treasurer Renee Tarica distributed recent investment statements which show that the investment accounts are starting to increase and stabilize again. Executive Director Lisa Graziano submitted a 2011 draft budget for approval. The budget layout has been revised to make it easier to track line item income and expenses and also make it more consistent with what is required for tax filing. After making a few minor changes the Board voted to approve the budget.

Executive Director's Report: Lisa Graziano submitted a written report highlighting her activities and office administration since the last Board Meeting. Of note is that PWCF's lease expires the end of 2011 therefore a new lease needs to be re-negotiated; Lisa has already begun work on this. Additional highlights include that the DVD from January's mini conference *Brain & Behavior in PWS* has been completed and ready for sale; Lisa's trip to Sacramento to speak on behalf of the PWCF membership to oppose budget cuts to Regional Center and other services provided by the Department of Developmental Services, and the participation of her son Cameron (age 12) to speak about what it's like to have Prader-Willi syndrome to genetic counseling students at Loma Linda University.

As always it is my great pleasure to work with such a wonderful group of dedicated individuals who donate their time to serve on the Board to improve the lives of those with Prader-Willi Syndrome. I remind everyone to "like" PWCF on Facebook at www.facebook.com/pwcf1 and encourage you to contact the office if you are interested in serving on a committee or serving as a Board member.

Medical Alert Regarding Formula Thickening Agents

Reprinted with permission from PWSA (USA)

The Federal Drug Administration has reported 15 cases of necrotizing enterocolitis (NEC) including two deaths, involving infants who were fed "Simply Thick" for varying amounts of time. NEC is a serious and sometimes fatal condition where the tissue of the intestine is damaged. It mostly affects premature newborn infants.

Health Canada is strongly advising Canadians who are using Simply Thick or any other thickening agent to speak to their healthcare practitioner with any questions or concerns. Simply Thick is a product that can be added to liquids, such as breast milk and infant formula, to thicken them to make them easier to swallow. It is sometimes used for premature infants to help with swallowing difficulties.

Norma Terrazas, a registered dietician on PWSA (USA)'s Clinical Advisory Board advises that parents and care providers "... should contact their healthcare provider if they are on a thickening agent and their child is less than 3 months corrected gestational age.

Below are some guidelines instituted at Texas Children's Hospital. It is highly likely that every major hospital institution will have some guidelines made available to their staff.

1. External thickening agents, including Simply Thick, Thick It, and several other similar products should not be used under any circumstances for any infants under 44 week postmenstrual age * (gestational age plus chronological age). At present the cases of NEC and similar illnesses are limited to those born before 37 weeks who developed illness at under 43 weeks PMA. This puts a small boundary around it.
2. It is not recommended to use these products for any infants less than 3 months corrected age to provide a further safety margin while the investigation is underway and cases collected.
3. Alternative thickening approaches including rice cereal are not recommended as they are nutritionally inadequate, do not often work with human milk and have little if any evidence of efficacy in our patient population. However, in an individual circumstance, on a risk:benefit consideration in which no alternative was deemed available, a practitioner could use rice cereal for a formula-fed infant. We do not believe this is the correct solution however to any feeding related problem in newborns.
4. Use of specialized anti-reflux infant formulas is also not recommended for our preterm infant population, although these formulas are probably safe and can be considered in special circumstances. Again, we do not believe this is the correct solution to feeding related problems, especially in preterm infants. Any infant discharged in the last 4 weeks on any thickening agents who was born at less than 37 weeks gestation should immediately have the product stopped.

* Postmenstrual age is the time elapsed between the first day of the last menstrual period and birth (gestational age) plus the time elapsed after birth (chronological age). Postmenstrual age is usually described in number of weeks and is most frequently applied during the perinatal period beginning after the day of birth. Therefore, a preterm infant born at a gestational age of 33 weeks who is currently 10 weeks old (chronological age) would have a postmenstrual age of 43 weeks.

This information is posted on PWSA(USA)'s website at <http://www.pwsausa.org/medical/thickeningagents.htm>

Walking for Prader-Willi Syndrome!

PWCF's 11th annual *Walking for Prader-Willi Syndrome* events were held in May during National Prader-Willi Syndrome Awareness Month. PWCF's *Walks* cover the state of California, with Southern California's events organized by **Renee Tarica** and **Lisa Graziano**; Central California's events organized by **Paula Watney** and **Debbie Martinez**; and Northern California's event organized by **Patti and Tom McRae**, **Mary and Paul Hill**, **Maddy Fluhr** and **Eddie Resendes**, and **Lesley and Austin de Lone**. PWCF member **Misty Adams** even organized an impromptu *Walk* in Redding which garnered media attention from a local news station who interviewed mom and PWCF member **Star Perez**.

The purpose of the *Walks* is to raise the public's awareness about the syndrome and to raise funds to support the important programs funded by PWCF. To spice things up a bit this year, **Mary Hill**, **Renee Tarica**, and **Lisa Graziano** re-vamped the Information Signs that are posted at each *Walk* site, adding a great deal of information about the syndrome and successful management strategies so that the signs now serve to also educate families who attend the event.

PWCF's *Walks* offer various family-oriented activities. Southern and Central *Walkers* were treated to arts and crafts activities and exercise-oriented relay games for the kids. Southerners enjoyed music by our very own DJ **Jimmy Rudon**, a jumper for the kids, sandwiches provided by **Tarzana Subway**, and fruit donated by **Umina Produce**, thanks to PWCF members **Susan and Russell Quan**. Northerners were treated to our very own live band, **The PWS Noise-makers**, performed by PWCF member **Austin De Lone** (musician extraordinaire), **Eric McCann** (bass), **Dick McDonough** (drums), **Steve Grogan** (guitar), and **Lisa Kindred** (vocals). This year, Austin and Lesley de Lone's talented daughter **Caroline** added her vocals and guitar to open the *Walk* singing *The Climb*, flanked by back-up singers **Emma Resendes** and **Duncan McRae**. PWCF's *Walking for Prader-Willi Syndrome* DVD featuring Miley Cyrus' rendition of *The Climb* is posted on the PWCF website (www.PWCF.org) and on YouTube (www.youtube.com/watch?v=UMr7qGUNZul). DVDs are also available from PWCF.

And you've just got to check out this out... Long-time friend of the McRae's and long-time PWCF supporter **Duane Shewega** posted a video of the fun at the Northern California event on YouTube [www.youtube.com/watch?v=zcr5LXQkOLQ].

So far we've raised about \$40,000! But because YOU CAN ALWAYS DONATE TO SUPPORT YOUR LOVED ONE OR FAMILY FRIEND, you can still help us reach our \$50,000 goal. If you haven't already, please make your tax-deductible donation by sending your check to PWCF or use your credit card at www.PWCF.org/WalkingForPWS.htm.

PWCF's Board and *Walk* Planning Committees will soon begin planning next year's *Walk* events which will likely be placed in brand new Southern and Northern California locations. Be a part of the next generation of events by contacting PWCF to get involved!



PWCF extends our gratitude to *everyone* who collected or made a donation and helped increase awareness. We are especially indebted to these extraordinarily generous donors:

Walk Major Donors

Steven Albeda & Suzanne Fluhr
Terri Canales
Patricia Casey
Comet Electronic, Inc.
DX-CT-MRI Weekend Radiology
Joe DiFilippo
Nancy & Steven Fox
Dolores Horn & Mel Goldberg
Griffin Family Group Home
Adam Grogan & Jan Nakagawa
Peter Harmon
Sue & Hanan Haskell
Mary & Bob Hill
Patricia & Richard Hill
Kevin Hixon
IMPACT Center, LLC
Jackson Rancheria Band of Miwuk Indians
David & Tammy James
Chris Jones
Cyndie & Tony Kelly
Robert Klein
Rudy Labrado
Phillip Lee, M.D.
Marie-Claire Leon
Jason Liberman
Mirian & Elias Liberman
J.P. Lindstrom, Inc.
Jacquelynn & Jeffrey Lindstrom
Michele Maher
Ed Mann
Kirsta Martino
Dennis Martino
Douglas Martino
Patti & Tom McRae
Suzanne & Don McRae
Lindy Marich (Raffle Items)
Michele & Ed McDonald
Allison & Byron Moldo
Kim Morgan (Raffle Items)
Judith & Robert Morgan
Noddle Surety & Insurance
Pat Noland
Larry O'Rourke
Ojeda Professional Cleaning Service
Roberta Parsons
Terri & Bob Priest
Ivette Ramos
Noel and Cecilia Ramos
June Reifeiss
Steven and Lori Rutledge
Beverly Schwartz
Marisa & Daniel Shea
Judy Soden
Paul Sokolowski
Todd Van Boxtel
Edward Vitro
Michael Vitro
Ronald Vogrin
Evan Youngflesh

PWCF thanks the following persons and organizations who worked so hard:

Central California

Paula Watney – Event organizer
Debbie Martinez – Event organizer
Krista Bruen, Pfizer Endocrine Care

Northern California

Patti & Tom McRae – Event organizers
Maddy Fluhr & Eddie Resendes – Event organizers
Lesley Austin & De Lone – Event organizers
Mary & Paul Hill – Event organizers
Renee Tarica – Event organizer
Krista Bruen, Pfizer Endocrine Care
The PWS Noisemakers Band

Southern California

Renee – Event organizer
Henry Tarica
Jeanine & Mark Milner
Liane & David & Justin Noddle
Taylor Moldo
Fran Moss
TJ & Cameron Graziano
Carolyn Meyer
Susan & Russell Quan & Umina Produce
Ronnie Salem and her extraordinary crew
Kristen Foley, Pfizer Endocrine Care
Tarix Printing
Balloon Factory
Tarzana Subway

PWCF extends our most sincere appreciation to each and every one of our *amazing* Fundraisers:

Central California

Paula & Mike Watney

Northern California

Julia and Jeremy Rutledge
Lisa & Neil Vitro
Ivette & Luis Ramos
Tracy & Roger Goatcher
Kirsta & Mike Moore
Eileen & Drew Higgins
Patti & Tom McRae
Maddy Fluhr & Eddie Resendes
Mary & Paul Hill

Southern California

Angela & Robert Lucero
Renee & Henry Tarica
Ken & Maria Knox
Lisa & TJ Graziano
Lindy & Drew Marich
Marisa & Daniel Shea
Julie & Dan Casey
Julie & Deron Van Bostel
Michelle Christian
Mary Culver & Rob Fuller
Fran Moss



PWS Family Day at CHOC

The PWS Clinic at Children's Hospital Orange County hosted a Prader-Willi Family Day on May 7. PWCF's executive director **Lisa Graziano, M.A., MFT** presented on strategies to help reduce the unwanted behaviors associated with Prader-Willi syndrome. This special day was organized by **Bobbi McGann, LCSW**, who ensured that fun activities were organized for the kids while their parents attended the presentation and networking event. **Susan Clark, M.D.**, endocrinologist and the PWS Clinic's director, and **Virginia Kimonis, M.D.**, geneticist for the PWS Clinic, made sure that all families, whether or not CHOC patients, were invited to the event!

Free Download of the Disability Law Handbook

Available from the Southwest ADA Center in both English and Spanish, the Disability Law Handbook answers questions about the Americans with Disabilities Act (ADA), the ADA Amendments Act, the Rehabilitation Act, Social Security, the Air Carrier Access Act, the Individuals with Disabilities Education Act, the Civil Rights of Institutionalized Persons Act, and the Fair Housing Act Amendments. **Free copies** can be downloaded or viewed at <http://www.swdbtac.org/html/publications/dlh/index.html> for the English version, and <http://www.swdbtac.org/html/publications/Spanish/gld/index.html> for the Spanish version.



For more information or to purchase a copy, contact the ADA Center at (800) 949-4232.

Did You Know...

PWCF is underwriting a minimum of \$11,000 to send kids and adults with PWS to our brand new PWS Camp at Easter Seals' Camp Harmon from July 28 – August 2?



Volunteer Recognition Corner

PWCF is grateful to the following persons for helping to mail the *Walking for Prader-Willi Syndrome* brochures:

- **Renee Tarica**
- **Sally & Chet Collom**
- **Bill Morgan**
- **Fran Moss**
- **Dolores Horn**
- **Cameron Graziano**

Thank you to **Cameron Graziano** for helping to affix stamps to the Membership Renewal/Dues Forms.

Thank you to **Chet Collom** for creating designs for the 2011 Shining Star campaign.

Thank you **Jessica Acosta** for organizing the PWS booth at The San Gabriel/Pomona Parents' Place Family Resource & Empowerment Center's Information Fair & Festival on Info Fair on May 1



2011
Walking for Prader-Willi Syndrome

In the Trenches

Vol. 5

By Jessica Patay

When was the last time you got rope burns? As in tug-of-war from childhood days? A fellow runner, mother, and writer I admire, Kristin Armstrong, writes joyfully and profoundly about watching her kids in an old-fashioned tug-of-war game at school: "Watching them work together toward a common goal reminds me of everything that is pure and good and redemptive about humankind." She then goes on to say, "When was the last time you gave something your all? When did you pull so hard for a dream that you got red-faced and your hands hurt from your simple and adamant refusal to let go? When did your effort simultaneously exhaust and invigorate you? For what (or whom) are you willing to dig in your heels, get rope burns on your palms, and slide across the dirt on your behind?"



Ryan & Jessica

I am still floating high as I think about our Ragnar Relay Race experience. Watching our amazing team of individuals come together for the cause of raising funds for PWCF and for raising awareness of PWS was a dream come true. Really. In the summer of 2010 I was inspired by friends who had taken on a physical challenge to do good in the world. I was hooked; I had a vision. Thankfully, my husband, Chris, grabbed onto the vision with me and supported me fully.

Twelve runners, comprised of parents of children with PWS, family members and dear friends, made up "The Missing 15" to represent chromosome 15, which is affected in PWS (to put it rather simply). For all of us, it was our first relay race. A 202.2 mile course. Overnight. (That means running *through* the night.) In the daylight and darkness. In hot and cold temperatures. With little to no sleep promised. What would possess 12 runners and a support crew to do this crazy challenge? All for the love of children with PWS. We got our "rope burns" as we trained mile after mile, and shamelessly sent fund-raising emails to everyone we knew. We got "red-faced," literally, in the 85+ degree weather of Day 1 of the race. We were exhausted, punchy and smelly as we completed our final legs, but we dug in our heels. No one got sick, injured or lost, and we didn't give up.

When we crossed the finish line made up of an orange balloon arch on the beach at Coronado Island, I was so sappy-touched-in-my-heart that I could have cried. Not because I was relieved it was over. Not because I was excited about a hot shower and hotel bed awaiting me. (Okay, maybe I was looking forward to that!) Not because I was ready for a hot meal. My first thought was, "WE did it!" Our vision came to fruition. It IS possible to dream big and see it somehow magically materialize.

Before it all began, I had my doubts...many doubts. Who would run with us? Do I have the time? I'm too stressed, I'm too busy, and I'm too pulled in a million directions! Who am I? Do I really want to ask everyone for money, in this economy, and in a time when a plethora of fundraisers are going on? How will this lofty vision be executed? I can't, I can't I can't!! But I was compelled, convicted, and suddenly courageous.

I am a runner. I'm not fast or competitive, but I run. I'm not an athlete by background. Stories of my humble beginnings as a runner in my high-top 80's aerobic shoes would make you belly laugh. BUT, I always tell people/potential runners, "If I can run, anybody can run." And now, I say, "If I can dream big, you can dream big." You can pull hard for a dream. It may be your own personal hidden dream. Or a dream that benefits your child with PWS directly or benefits our PWCF community at large. I encourage you, and I implore you, get some rope burns on your precious hands.

PWCF Gets Mail...



Dear PWCF: Another great job on the newsletter! ... The columns by Mary Hill and Jessica Patay are priceless. I am in awe of these young mothers who not only are in the trenches daily but find the time to express their feelings so beautifully. I'm sure they have no idea of the far reaching impact these stories have on other families. I read them and nod my head in solidarity!

Linda Ryan

Dear PWCF: I just wanted to take this time and say thank you so much for your time in speaking to us over the phone and tak[ing] time out of your busy schedule to send us information about Prader-Willi along with the bracelets. I appreciate what you have done for us, because of you, we had enough information to present to our class and the teacher along with the class are now also more informed about what exactly is Prader-Willi, and that, there is a support system out there for people who need help... Thank you so much. You have a wonderful day. James Williams, Project for Child Development Class [Junior College]



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

- Ability to listen, analyze, think clearly and creatively, work well with people individually and in a group
- Willingness to prepare for and attend Board meetings (3 in-person, teleconferences as needed), committee meetings, and other special events.
- Ability to ask questions, take responsibility and follow through on any given assignment, contribute personal and financial resources as generously as your personal circumstances allow
- Possess honesty, sensitivity to and tolerance of different views; a friendly, responsive, and patient approach; community-building skills; personal integrity; a developed sense of values; concern for the Foundation's development; a sense of humor
- Willingness to develop certain skills if you do not already possess them, such as chairing a committee or project, the ability to read financial statements, ask for donations, recruit new Board members and other volunteers
- Willingness to commit to serve a 3-year term

If so, PWCF's Board of Directors Needs YOU!

What will you gain by participating at the Board level?

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

What will you give up by sitting on the PWCF Board?

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

To run for a vacating seat on the Board or to nominate someone else, submit in writing the name and contact information to Kim Morgan, Chair, Nominating Committee, PWCF, 514 N. Prospect Avenue., Suite 110-Lower Level, Redondo Beach, CA 90277 or via email at PWCF1@aol.com. **The deadline to submit nominations for the 2012-2014 Board of Directors is August 15, 2011.**

Save the Date!
Saturday, September 17

**Galaxy Soccer
PWS Family Day**

**Staples Center,
Los Angeles**

Galaxy v. Vancouver

**Pre-Game Picnic!
Post Game Autograph Session!**

**Reduced Price Tickets
for PWCF members
Proceeds benefit PWCF!**

We Remember

Keith Patrick Peerson
September 7, 1978 – February 14, 2011

Keith Patrick Peerson, 32, died on Monday, February 14, 2011. He was born on September 7, 1978 in Stockton and passed in his sleep at his residence in Citrus Heights, California.

Keith was diagnosed at a young age with Prader-Willi syndrome. Where some people allow their challenges to rule their life, nothing in Keith's life would point to anything but a young man living his life to his fullest. Where some people dwell on the "can't do's", Keith was someone who wanted to dwell on the "can do's and want to's."



Keith enjoyed woodworking and working with his hands. He quite often made items for family and friends. And like most young men, he was sports-minded. He was an outdoorsman who enjoyed fishing. He also enjoyed playing video games and working on the computer as so many people do. Keith worked at Pride Industries in Roseville, California.

Keith was an active member of the Prader-Willi California Foundation. He served as the president of People First – Roseville Chapter, and attended Aim Higher Day Program where he participated in art, painting, singing, plays and so much more. As a youth, Keith was active in Sequoia Heights Baptist Church youth group and volunteered his time working with the A.V. team in Manteca.

Keith is survived by his parents Clifford and Tina Peerson, as well as his sister Deanne and brother-in-law Caelen Klopson. Keith leaves behind his nephews Wade Riffle and Gavin Klopson and niece Mackenzie Klopson, all residing in Lincoln, CA. He also leaves behind his grandparents Norval and Lorraine Peerson of Holdenville, OK and many uncles, aunts, cousins and friends.

*It is difficult to say what is impossible,
for the dream of yesterday
is the hope of today
and the reality of tomorrow*

Robert W. Goddard

GRIFFIN FAMILY CARE HOME

The newly remodeled Griffin Family Care Home in Vacaville is now open and taking referrals. This home is licensed for six adults (male and female) with Prader-Willi syndrome. Residents of this home will participate in the IMPACT day program in Fairfield. Please contact Joetta Griffin for more information at 707-974-7279.



Additionally, Ed & Joetta Griffin have developed a therapeutic riding academy also in Vacaville. "Take the Reins Inc" will serve individuals with developmental disabilities. To learn more about this great opportunity, please contact Joetta at the number above.

SAVE THE DATE

Saturday, November 5, 2011

General Education Meeting

Sharing Sessions

Youth & Adult Program

Annual Membership Meeting



RACE for Prader-Willi Syndrome Donors

Philip Abraham
 Peggy Abkemeier
 James Alstrum-Acevedo
 Ariane An
 Rock Arnold
 Susan Arth
 Tania Aslanian
 Auc Pro and Troy Thoreson
 Felice Balarin
 Thomas Barden
 Charles Beeler
 Kirsten Benjamin
 Bob Bennett
 Adam Bettino
 Gregory Bettinelli
 Thomas Biery
 Greta Binkley
 Lorna Borenstein
 Mary & Holger Bracht
 Camille Bratkowski
 Alexis Brayton
 Maureen & Tristam Brown
 Linfield Brown
 Karen Buetzow
 Andi Bushell
 David Bushnell
 Cindy Byun
 James Cahan
 Jamie Calvert
 Andrew Cantos
 Jennifer Cech
 Dana Chelf
 Joel Cherry
 Edward Chin
 Robert Coneybeer
 Monica Crone
 Tim Croshaw
 Rudy DeFelice
 Malea DeNatale-Bonk
 Sherri DeRosa
 Brandon Dickerson
 Claudette Didul
 Laura Dillard
 Michelle Donaldson
 Bradford Douglas
 Rich Douros
 James Doyle
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 Maria Elliot
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Gold's London Marathon for PWS



Jon Gold is an English business consultant who is a resident of Arizona with strong links to people and businesses in California and around the world. He is a father of four and grandfather of two. He notes he "is old enough to know better," but nonetheless he recently attempted his fifth London Marathon, an event that he considers to be one of the world's greatest sporting events.

Jon was made aware of Prader-Willi syndrome and what he calls "the great work of the Prader-Willi California Foundation" through his wife, **June-Anne Gold, M.D.** who is a leading supporter of genetic research into the condition and a member of PWCF's Board of Directors. Jon has met many people with PWS and their families and observes that "Most people are not aware of Prader-Willi syndrome and the devastating affect that it [can have] on the sufferers and their families. While financial support is greatly needed to support research into curing this condition, I hope that I can also help to raise awareness of a problem that affects hundreds of children every year who deserve the chance of a normal life."

And raise awareness he did. He ran the marathon which he described as "torture" and he finished! He even saw someone running for Prader-Willi UK but couldn't get a chance to talk to her. Says Jon, "I hope that my small contribution will make some difference." Indeed it has, Jon! PWCF expresses its gratitude!

Donations in Support of Jon Gold's

London Marathon for PWS

Robin Clark
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June-Anne Gold, M.D.
Mich Golowatsch
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Martha Paaren-Fletcher
Julia Platt
Andrew Schlosser
Colin Schofield
John Shand
Jouni Vesa
Ueli Zaugg

Executive Director's Report Continued from page 5 ...

Last week I dropped off my son at school and watched him make his way up the sidewalk. Another boy was dropped off just behind us. I watched as this other boy quickened his pace and yelled, "Hey, Cam, wait up!" Side-by-side they walked, engaged in some wonderful animated conversation. This was a moment every mother of a child with Prader-Willi syndrome longs for... pushes so hard for.

I know that I am hard on my child, that I have *always* pushed him, and that more recently I have been *too* hard on him, expecting more than is probably appropriate for any 12 year old, PWS notwithstanding. While I work to speak less and soften my tone more, I try to forgive myself if only a bit because I know that my pushing (ok, nagging) is born benevolently from my hopes for his future. I'm still relatively new to PWS and have a lot to learn. I know I need to determine which of my son's behaviors I must continue to work to influence because they're still malleable, and which behaviors I simply need to accommodate to and learn to accept because they're too heavily influenced by PWS. More importantly, I need to reassess the strategies I use and hearken back to the days where every intervention was backdropped with more compassion. I think I'm coming to realize that one of the ways my son will get the better end of this disorder is first by his mother coming to a greater acceptance of it.

Whether it's as "mundane" as forcing yourself to drive your loved one with PWS to an appointment when you're feeling utterly exhausted, or more along the lines of the outlandish, say, running a Marathon or participating in a 200 mile race to raise awareness of PWS, I hope some opportunity presents itself for you to extend outside *your* comfort zone toward something *you* believe in with all your heart.

I wish you a great summer and hope you end each day having enjoyed at least one laugh-out-loud moment.

Every day we decide who we will be by the actions we take.

~ Anonymous

The *PWCF News* is the newsletter of the Prader-Willi California Foundation (PWCF) and is sent to all its members. The opinions expressed in the *PWCF News* represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the Officers and Board of Directors of the Prader-Willi California Foundation. For contributions to this newsletter, questions or comments, please write: Attention Editor, *PWCF News*, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277 – or phone – 310-372-5053 ~ 800-400-9994 (within CA), or email us at PWCF1@aol.com

PWCF is grateful to the following supporters for helping us continue to 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 do not see your name listed, please accept our sincere apologies and allow us the opportunity to include your name in the next issue by contacting us at 310.372.5053 or PWCF1@aol.com

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in memory of Peter Meyer
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#### **Donations in Memory of Joseph Thomas Scelfo**

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### **MEMBERSHIP ACTIVITY**

#### **April ~ June 2011**

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

#### **New Family Members**

Maritza & Collin Chan  
Rhonda & Andy Faust  
Linda & William Go  
Savati & Michael James  
Reiko Nakamura & Tsuyoshi Nagayama  
Cristina Puentes & Jose Vazques  
Tomoko & Matthew Wolfe

#### **New Family Friend Members**

Ariane An  
Thomas Barden  
Gregory Bettinelli  
Robert Coneybeer  
Suzanne Eisenbrand  
Dawn French  
Brenda HarrisonJean & Lowell Hobrock

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Michael McGuire  
Mitchell Milam  
Helene Toomey  
Jeanne Tumanjan  
Jonah Van Zandt  
Jeannette & Keith Wagner  
Nehemia Zucker

#### **Renewed Family Friend Members**

Peggy Abkemeier  
Charles Beeler  
Bob Bennett  
Valerie Gellner  
Mel Goldberg & Dolores Horn  
Tom Innis  
Carolyn & Gordon Jones  
Irene & Kyle Kaiser  
Nancy & Jim Kaiser  
Robert Klein  
Andrew Lieberman  
Judy & Bob Morgan  
Jeffrey P. Nedelman  
Bob Priest & Terri Grass  
Tyna & Ray Triggs

#### **New Auxiliary Members**

Lynnette Collins  
Meeha Hwang  
Shin Ja Kim

#### **Renewed Extended Family Members**

Lisa Ann Bonk  
Mary Culver  
Joseph DiFilippo

#### *Renewed Extended Family Members continued ...*

Laura & Ray Esau  
Bob Graziano  
Mary & William Graziano  
Pat Grey  
Sue & Hanan Haskell  
Mary & Bob Hill  
Patricia & Richard Hill  
Kelly Jaeger  
Sharon Marich  
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Storr Family Foundation  
Celeste & Tom Von Der Ahe

**Prader-Willi California Foundation** is a nonprofit, 501 (c) (3) corporation established in the state of California in 1979. Prader-Willi California Foundation is an affiliate of Prader-Willi Syndrome Association (USA) and shares in their quest to serve individuals and families affected by Prader-Willi syndrome. PWCF's vision is that people with Prader-Willi syndrome may pursue their individual hopes and dreams to the full extent of their talents and capabilities and that we will help them achieve their goals.