PWCF NEWS

pwcf.org
Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

The Newsletter of Prader-Willi California Foundation
AN AFFILIATE OF PWSA (USA)

April ~ June 2013
Volume 24, Number 2

In this issue:

13th Annual Walking for Prader-Willi Syndrome

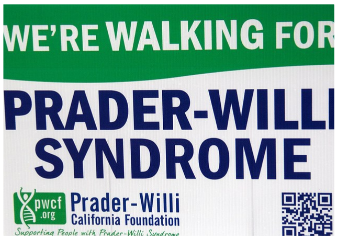
PWCF held our statewide Walks in April and May to celebrate Prader-Willi Syndrome Awareness Month. We raised public awareness of PWS in Los Angeles at Griffith Park on April 7; in Woodward Park in Fresno on April 27; and under the Golden Gate Bridge in San Francisco on May 4. This year's Walks were lovingly dedicated in memory of Yvette Tarica, daughter of Renee and Henry Tarica, co-organizers of the very first walkathon and long-time supporters of the event and PWCF from its inception.

This year, even if unable to travel to a site, families could participate in a Walk by posting a Virtual Walk sign in their yard. PWCF's Family Support Coordinator, Katherine Crawford, designed the Virtual Walk signs with a QR code that links directly to our website. It was fun to receive the first donation from someone who let us know they'd seen our Virtual Walk sign in their neighbor's yard and wished to make a donation "to support our worthy cause." Katherine also created cool green flags to represent each of our Virtual Walkers which were excitedly carried along the Walk paths by volunteers.

The Walks are awesome opportunities for families to enjoy being together. There's a special feeling of "oneness" at the Walks that families don't experience during many other times of the year. Statewide almost 600 people gathered at a Walk site and enjoyed the good company of other family members. Each site featured picnicking, fun and games for the kids, raffles, face painting, and great music! See our photos on pages fourteen - fifteen.

So far the Walks have raised $48,000 to fund the programs and services provided by the Prader-Willi California Foundation. Every donation helps support our PWS Clinics, our PWS Camp, family education services, professional education services, school trainings, residential staff trainings, advocacy services, and so much more. But our funding needs are far greater than our income, so if you've not yet made a donation to support a Walk, we encourage you to give what you can at www.PWCF.org It's *never* too late to make a tax-deductible donation!

PWCF extends our grateful appreciation on page nine to some exceptional people for their contributions toward making this year's Walks a great success. If you'd like to get involved in planning next year's events, please let us know!



PRADER-WILLI CALIFORNIA FOUNDATION

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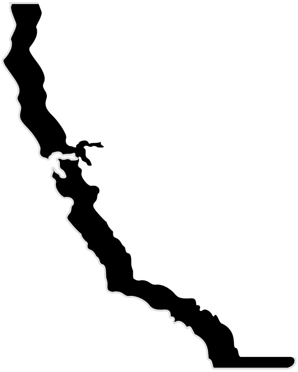


"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families."

PWS Support Contacts And Groups

Northern California

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

Central California

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

Southern California

Los Angeles County	Lisa Graziano	310-372-5053	pwcf1@aol.com
	Julie Casey	818-843-7321	julie.casey@att.net
Orange County - Contact	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 Rivera (Adults with PWS)	619-822-5742	mercedes_rivera2002@yahoo.com
Maria Knox (Adolescents with PWS)	909-421-9821	teachknox@aol.com
Kilma Carillo (Infants and Children with PWS)	760-427-1100	kilmab@excite.com
Veronica Baez (Infants and Children with PWS)	760-357-8189	vbaez92@yahoo.com

On-Line Support

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

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

Awareness

Hasmukh Amarasekera (center)

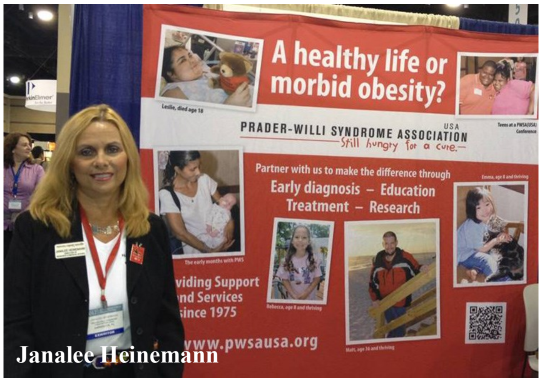
PWS at Cancer Walk

PWCF member **Hasmukh Amerasekera** raised awareness of Prader-Willi syndrome at the Pediatric Cancer Research Fund's walk in Irvine. Thank you, Hasmukh!

Be the change you want to see in the world
~Mahatma Gandhi

PWS at Endocrine Conference in San Francisco

The Endocrine Society, dedicated to hormone research and the clinical practice of endocrinology, held its 95th Annual Meeting & Expo in San Francisco from June 15-18. Representing the PWS Booth were our very own Professional Member **Suzanne Cassidy, M.D**. (who also serves as Board President of the International Prader-Willi Syndrome Organisation)**, Janalee Heinemann, MS.,** PWSA (USA)'s Director of Research and Medical Affairs, and PWCF Family Members **Mary and Paul Hill.**



Janalee Heinemann

This conference provided a unique opportunity for endocrine clinicians to learn about the latest research in fields as diverse as obesity, endocrine disruptors, diabetes, growth hormones, sex steroids, thyroid cancer, and much more. With over 9300 attendees from around the world it was the largest, most dynamic meeting in ENDO history!

PWS at Levitt Pavilion

Summer Concert Series

Prader-Willi California Foundation's mission is to improve the lives of those living with PWS. We believe that increasing public awareness is paramount to this mission. As such, PWCF was proud to be a community partner with Levitt Pavilion Pasadena and host a PWS Information Booth at concerts in June.

Levitt Pavilion is a non-profit agency with a strong commitment to contribute to the well-being of families through the arts in an outdoors learning and entertainment environment. Thanks to PWCF President, **Julie Casey** and PWCF member **Mercedes Gutierrez** for hosting our booth and distributing PWS brochures and our cool PWCF glow-in-the-dark wristbands.

Food Tip

This food tip is submitted by Matthew McKinley of Santa Clarita

Mathew and others with Prader-Willi syndrome often have a hard time digesting cow's milk.

Mathew suggests some alternatives: Lactaid is real fat free milk with all the protein, vitamins and calcium of regular fat free milk but with no lactose.

Silk makes delicious soy and almond milk.

Mathew writes, "Please help people with PWS drink these options and not the cow's milk."

Gadget Tip

"The Shower Manager"

Does your loved one with PWS lose track of time in the shower? Quite a few people with the syndrome struggle with time perception and pacing. Add a shower into the mix and you get even more problems. One family solved this problem by purchasing special shower heads for their showers. The shower heads screw in place between your normal shower head and the shower pipe, as shown in the picture to the left. You set the amount of time you want to allow for the shower at 5, 8, or 11 minutes.

The device beeps when there is one minute left so you have time to wash away any soap or shampoo. Then at your pre-set time, the device slows the water flow down to a gentle trickle, as seen in the picture to the right. It is enough water to wash any soap that might be left over, but not enough to encourage you to linger in the shower. There is also a reset delay so that you can't just turn the shower off and turn it back on again to get shower extensions. The result? No more battles of will about shower times, no more cold showers for the rest of the family when the hot water runs out, and a lower water bill.

You can find out more information and order it online at www.showermanager.com

Free Admission to Parks and Recreation Sites
The National Parks and Federal Recreational Lands Pass

http://store.usgs.gov/pass/index.html

The National Parks and Federal Recreational Lands Pass or ***Interagency Pass Program*** is a suite of annual and lifetime passes that provides U.S. citizens and visitors an affordable and convenient way to access more than 2,000 Federal recreation sites. A free, lifetime pass is available to U.S. citizens or permanent residents of the United States that have been medically determined to have a permanent disability**.** At many sites the Access Pass provides the pass owner a discount on "Expanded Amenity Fees" such as camping, swimming, boat launching, and guided tours. Learn more about the requirements and how to get your pass at http://store.usgs.gov/pass/access_pass_application.pdf . You can also download a PDF file that lists federal recreation sites around the country where you can get a pass at http://store.usgs.gov/pass/PassIssuanceList.pdf Visit Recreation.gov http://www.recreation.gov/unifSearch.do for more information about parks, forests, campgrounds and other recreational areas near you. Have a great summer!

Executive Director's Column

Lisa Graziano, M.A.

Seems like just as I learn about one important area and feel fairly comfortable traversing within it, it's time to move on to the next completely unknown, anxiety-raising area and start all over again.

Just like many of you, shortly after my son was born I was introduced to the Regional Center's Early Intervention system of care. I learned about the various therapies that are available to babies with low muscle tone who are deemed "at risk." I learned how to request a new service and how to request a different therapist. I learned how to request an Informal Meeting, how to file an appeal, and how to represent my son in a Formal Hearing. I learned how to connect with our state's PWCF and our national PWSA (USA) and learn from other families who would teach me even more of what I needed to know. The learning curve was steep but after three years I was finally beginning to feel like I could do this.

And then we entered the world of Special Education.

Once again I knew absolutely nothing about this foreign, parallel universe within the world of education. I had no idea what any of the alphabet soup acronyms meant while everyone around me seemed to take it for granted that *everyone* knew what these letters stood for. I knew my then-Kindergartner needed it but I didn't know how to get physical therapy services from the school district. In the second grade I knew he needed *something* to improve his reading comprehension, but I didn't know what and I didn't know how to find out "what." So, as I'd been learning to do, I asked a lot of questions, listened to the good advice of parents and professionals I trusted, and reached out to PWSA (USA) and PWCF families who taught me more of what I needed to know about the unique educational needs of children with PWS. By the time fifth grade rolled around, I felt pretty confident that I understood the ins and outs of elementary school.

And then it was time to move on to Middle School.

Once again the ground beneath my feet turned to mush and I felt the familiar crush of anxiety as I prepared not only my son but myself for another transition. How would we help him navigate a larger campus and make it on time to classes where students transfer from classroom to classroom every hour? How would we educate not one but now *seven* teachers plus all ancillary staff about PWS? Would he be able to manage the hall and gym lockers that would require he remember two different lock combinations *and* have nimble and strong fingers? How on earth would we help the school secure the now extensive food sources that seemingly beckoned from every nook and cranny of the school campus? In the beginning the anxiety was unbearable – *my* anxiety, that is! And once again I reached out to people I trusted and learned from other PWCF and PWSA (USA) families about how they managed some of these challenges. My son did well and once again by the end of Middle School I felt knowledgeable and very prepared… for Middle School.

But now we are looking square into the red-devil eyes of the special needs curse they call High School and I am absolutely petrified about this transition.

I try to reassure myself that I felt exceedingly anxious when he started Pre-School and he did just fine. And I was incredibly worried when he started Elementary School and he did beautifully. And I was truly terrified when he started Middle School and he did, quite frankly, absolutely great. So, I tell myself, we will once again reach out to our PWCF and PWSA supports and we will figure out what we need to do so that he will not only do well in High School but also enjoy it.

Transitions are a lot like death and taxes… they are an inevitable part of life. At every life stage there is change and transition. Transitions can be really, really scary because they are so unknown. If I *knew* he'd enjoy high school then I wouldn't feel anxious about the transition. Transitions can also be scary because we believe we already *know* that something not-so-good will happen because it happened the last time. But really, we can't *know* because life is quite simply unpredictable.

Most kids and adults with PWS are acutely aware of how unpredictable life can be. Most feel nervous about transitioning to something else or something new either because they either don't know what to expect or because they fear what they expect. Most rely upon us, their parent or care provider, to paint the picture of what things will look like and assure them that they will be just fine. They need this constant and unwavering support.

This is particularly hard to do when we're staring down the face of our own anxiety about an upcoming transition. But this is our challenge – to do our own homework and learn as much as possible about a given situation, to connect with and learn from others who have traveled the same or similar path before us, and to always strive to appear calm and confident on the outside to reduce the ubiquitous anxiety felt by our loved one with PWS.

One constant and unwavering support to which I can point during the past 14 years of navigating this still new world of PWS is my connection with PWCF and PWSA (USA). Over the years, the stories of families I have read about or had the privilege to personally meet through these organizations have taught me how to think, how to question, how to problem-solve, and how to manage the inevitable anxiety I will feel as my son and our family transition to the next life cycle experience.

As you read this quarter's edition of *PWCF News* I hope you too will enjoy the stories and insights that are shared by families and professionals. I hope too that, like me, you already do or will come to experience your membership in PWCF and PWSA (USA) as a source of constant and unwavering support.

For right now, though, I sincerely hope you enjoy your transition into summer!

In the Trenches

Vol. 11

By Jessica Patay

Just as laughter can be rich-belly-laughter, so can tears come in a way that you know they are from deep within one's soul.

Kate had those kind of tears a few mornings ago. And I had to pull the minivan off the road just to hug her and hold her.

We were on our way to drop Luke off at middle school, which is always a feat to get the three of them out the door *that early*.

Not more than a minute in, Ryan started to annoy Kate. (But of course, what else are car rides with kids for?) And she told him to stop. He liked the rise he was getting out of her, especially as her pitch rose and her passion ensued. He was smiling (I could feel it) and relishing in his pestering of her.

And then she broke. She started crying and yelling at him to stop. And it was primal and guttural.

Not the whiny-crying.
Not the manipulating-crying.
Not the baby-in-the-family-type-of-crying.
It was grief.
It was hurt.
It was disappointment.
It was anger.
It was sadness.

It came from a deep place, and she could no longer squash it and just be the sweet, motherly sister who cares dearly and is so uber protective of her older-and-younger-brother, Ryan. All about Ryan, and having "special needs" that she wished he didn't have. And wished nobody knew about.

I pulled over to the side of Grayslake Road. I did not care one bit if we were running late. Kate needed me. She NEEDED a hug. She needed everything to just stop, for one bless-ed moment, so she could be comforted. By me.

I slid open the van door and just swooped around her little body. I held her tight. And I held in MY TEARS so tightly.

She then whispered as our heads were so close to each other, "I love you, Mom, I love you." As if to say, "thank you for validating my tears, and EVERY SINGLE THING I am feeling right now."

It was a morning that started out like every rushed, hectic before-school chaotic morning. Unremarkable. The usual.

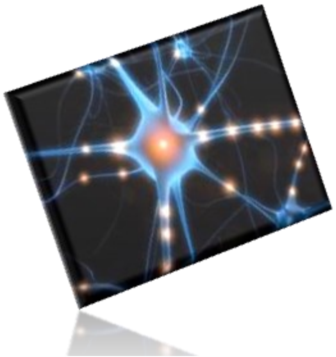
But that moment with Kate, I will never forget.

For more of Jessica's thoughts on Mom-Life visit http://jessicapatay.wordpress.com/

Save These Dates!

Visit www.PWCF.org or Call 310-372-5053 for More Information,
to Register or Purchase Tickets

August 24	PWS Behavior Training Session, Redondo Beach 1:00-5:00 pm
Sept 20-21	Ragnar Race, Napa Valley
October 6	IEP Training Session, Redondo Beach 1:00-5:00 pm
October 12	PWS Behavior Training, Redondo Beach 1:00-5:00 pm
November 2	Annual PWCF Conference, Crown Plaza Los Angeles Airport
November 7-9	PWSA (USA) National Conference, Orlando, FL



Coenzyme Q10 (CoQ10) & Prader-Willi Syndrome

PWSA (USA) Clinical Advisory Board
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Coenzyme Q10 (or CoQ10) is a naturally occurring vitamin-like substance in the body. CoQ10 is essential in energy production in all living cells, especially in the muscle. If deficient in CoQ10, an individual may feel less energetic, have reduced muscle function and have a decreased metabolic rate. CoQ10 also acts as an antioxidant in the blood and all cell membranes.

Individuals with PWS may have decreased levels of CoQ10. A blood test can determine if an individual's CoQ10 level in the blood is lower than normal. A muscle biopsy would be the best way to determine cellular CoQ10 level, but at this point we do not feel muscle biopsies are warranted.

When CoQ10 levels are low, supplementing with CoQ10 may help increase energy level, muscle function and metabolism. Some parents also see an increase in activity and attentiveness after supplementing the child with PWS with CoQ10. However, while some parents feel that their child demonstrates improvements with CoQ10, others feel that it has no effect. Also, parents should be clear that CoQ10 supplementation is not a substitute for growth hormone treatment which has clearly been shown to have multiple benefits for individuals with PWS.

The information we have on the effectiveness of CoQ10 is all “anecdotal” data (i.e., from parents commenting on their personal experiences with their child). There have not been any controlled scientific research studies about the effects of CoQ10 in individuals with PWS. At this time, there are no KNOWN adverse side effects of taking CoQ10 if taken in an appropriate dose.

The recommended starting supplemental dose of CoQ10 varies according to different groups. It is anywhere from 1-30 mg. per kg per day for infants, and no more than 180-200 mg per day for older children. We have typically found that 60-100 mg per day in the older children and adults is sufficient to raise the blood level to the normal range in those individuals who were initially found to have low levels. If families are contemplating supplementation with CoQ10, we would recommend testing a blood level before and after starting CoQ10. Dissolved CoQ10 in softgel capsules (which contain vitamin E and other lipids to help the body absorb the CoQ10) are better absorbed than dry powder CoQ10 tablets or capsules.

The CoQ10 softgels typically come in 60- or 100-mg doses. Therefore, older children and adults will need to take 1 -3 capsules per day.

CoQ10 can be purchased over-the-counter at most pharmacies OR can be purchased directly through various medical suppliers. There is also a liquid preparation available for children who cannot swallow pills.

Some families use Coenzyme Q-10 Gel Capsules produced by Jarrow Brand Formulas found at Whole Foods stores. CoQ10 gel caps may also be purchased online from NOW Foods www.NowFoods.com. Liquid CoQo10 may be purchased from International Nutrition, makers of LiQ-10 syrup at 800-899-3413. For other suggestions as to where to purchase this supplement, connect with families via the PWCFmembers Yahoo Group (http://health.groups.yahoo.com/group/PWCFmembers/) or PWSA’s online sharing groups (http://www.pwsausa.org/egroups/index.htm)

> *Failure is scarier than regret.*
>
> *~ Unknown author*

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.

Nominate yourself or someone you believe has the skill set that will benefit PWCF. Contact Kim Morgan, Chair, Nominating Committee via email PWCF1@aol.com or write to PWCF, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277. **The deadline to submit nominations for the 2013-2015 Board of Directors is August 5, 2013.**

Regional Center Purchase of Service Expenditure Data Now Available Online

The Lanterman Act was recently changed to require Regional Centers to post detailed information on their websites showing exactly how they spend their Purchase of Service (POS) funds. The new rules require the Regional Centers to post data with respect to consumer age, race or ethnicity, language, and disability. Click on the name or enter the web address below to read the POS data. If you don't see your Regional Center listed, contact your case coordinator to request the data.

Eastern Los Angeles Regional Center
http://www.simplesend.com/simple/uploadedimages/000525/2013-06_POSData.pdf

Harbor Regional Center
http://www.simplesend.com/simple/uploadedimages/000525/2013-06_ExpenditureReport.pdf

Frank D. Lanterman Regional Center
http://www.simplesend.com/simple/uploadedimages/000525/2013-06_Disparity2.pdf

North Los Angeles County Regional Center
http://www.nlacrc.org/index.aspx?page=34&recordid=171&return

San Gabriel/Pomona Regional Center
http://www.simplesend.com/simple/uploadedimages/000525/2013-06_Disparity.pdf

South-Central Los Angeles Regional Center
http://www.sclarc.org/transparency-portal.php (*Scroll to the bottom of the page to find the POS data*)

Westside Regional Center
http://westsiderc.org/sp/sp_pos.htm

PWCF Thanks Each and Everyone One of This Year's WALK Volunteers. Without their help we couldn't have the fun at the Walks that we have!

Southern CA Walk - April 7

TJ Graziano
Cameron Graziano
Naomi Storr
Kimberly Storr
Carolyn Meyer
Kevin Amarasekera
Renee Tarica
Henry Tarica
Lianne Noddle
Jeanine Milner
Fran Moss

Jessica Patay
Jocelyn Navarro
Boy Scouts of Troop 50
  Ryan Zahrae
  Andrew Frastaci
  Brian Frastaci
  A.J. Toth
  Jimmy Elliot
  Oliver McLeod
  Alex Leraci
  Rick Elliot (Adult Leader)
  Mark Seip (Scoutmaster)

Balloon Factory for donating the balloons for the archway

Melanie Cross, RN, PhN, MSN of West Coast University and Mount Saint Mary's College Department of Nursing for bringing her enthusiastic nursing students

Ida Dacus of South Central L.A. Regional Center for recruiting Ms. Sonia Barksdale who recruited her wonderful Pathfinders volunteers!

Honda Corporation for sending their Helpful Honda Dealers who really were very helpful!

Rob Meier of Pfizer Endocrine Care for providing education support

Kathleen O'Connell and Pfizer Endocrine Care for donating the waters

Kit Treharne of Albertsons for donating all of the fruit and more water

Jimmy Rudon, DJ Extraordinaire

Pam, owner of Tarzana Subway (5579 Reseda Blvd, Tarzana, CA 91356) for providing our delicious sandwiches

Thank You
Redondo Van & Storage and
Greg Halvorsen, President
for donating boxes!
www.redondovanandstorage.com

Central CA Walk - April 27

Paula Watney who single-handedly organized the entire event!
Debbie Martinez
Monte McAbee of Pfizer Endocrine Care

Northern CA Walk - May 4

Patti & Tom McRae
Austin de Lone and the AWESOME PWS Noisemakers band members Steve Grogan (guitar), Eric McCann (bass), Dick McDonough (drums), and Lisa Kindred (vocals)
Maddy Fluhr
Sara and Kelsey Formslag
Diane and Brandon Kavrell and the entire Kavrell clan!
Michael Moore who secured the park
Julie Tauscher and her helpful kids
Mayuri & Venkat Paruchuru
Julia Rutledge
Diana Vega
Felix Kirchner
Michelle Donaldson
Monte McAbee of Pfizer Endocrine Care

Northern California's Walk under the Golden Gate Bridge as sketched by Katherine Crawford

From Crisis to Opportunity
Navigating Major Life Transitions with PWS
By Katherine Crawford

For the past few weeks, I've been talking to my brother over the phone daily. We used to talk once a week, but things have changed. But no one ever said change was easy, and that maxim goes double for people like my brother with Prader-Willi syndrome.

The whole challenge started once I moved out to California with my husband, the biggest family change we'd had since I left for a year abroad in college. Michael was finished with High School, but without a job. As a result, he was living back at home, with staff that came in to take care of him during the day while my parents were out at work. Even if everything went perfectly during the day, my parents were still on-call the entire night after having worked a full exhausting day. And things rarely went perfectly during the day.

It had gotten to the point where Michael's staff were not allowed (for risk-related reasons) to take Michael outside, period. He had a reputation for being a "runner", taking off for the local library to steal food from their food-pantry donation collection barrel on the slightest whim. And since they weren't allowed to take him outside, the only time he got exercise was when he walked off to food-seek. His weight and health suffered. That was when my mom contacted The Children's Institute of Pittsburgh.

The Children's Institute, or TCI, has a PWS-specific behavior management and weight loss clinic for families in crisis. Borderline diabetic and only getting worse, my mom realized that the crisis was *now.* Michael's doctors agreed and they told him, "You'll be a new man" once he got back down in weight and started exercising again at TCI. By that point, even Michael was fed up with being cooped up at the house with nothing but TV time, computer time, and couch time. Michael agreed to go to The Children's Institute.

It took my family two days on the road to get from southern Wisconsin to Pittsburgh. At long last, Michael arrived at TCI. Several states away, I was holding my breath. Change is hard, and that goes double for my brother. And it turns out that, though he was prepared for the *idea* of TCI, the reality was a bit different than his expectations.

TCI, like many hospitals, has locking doors by default. It's for everyone's safety. As soon as Michael saw that the doors were locked, he decided that he was not going to TCI. His immediate (and inaccurate) assumption was that the residents were never allowed outside, which would mean up to three months being stuck indoors. I note that he came to his conclusion before even going on the tour where he would have seen the outdoor playground and gardens. But once he had made up his mind, he felt he didn't need to see anything other than the exit.

As someone with a loved one with PWS, you may know what it feels like getting "the call". As soon as I saw TCI's number flash across the screen of my phone, my heart started to race. I had been on my drive home from work, so I pulled over immediately and picked up the phone. It was a staff member at TCI, saying that my brother wanted to speak with me.

At that moment, he had barricaded himself in an elevator at TCI. He was sitting on the floor to make it harder for them to move him. As soon as he could get the staff to move their foot away from the elevator door, he would be down the elevator, to the lobby, and out the door. So here I was, on the phone, trying to calm him back down and talk about all the reasons he had wanted to go to TCI in the first place. But you all know how well logic works when someone is not in a logical state of mind. From Michael's perspective, it was simple: nothing was good, everything was bad, and he wanted *out*.

I talked with him for over an hour by the side of the road. But even fifteen minutes in, I could tell that there was no logic or reasoning, no idle pleasant distraction, no words said or unsaid that could shake him from his current fixation. TCI could have had been a theme park with waterslides and roller coasters and it would not have changed his mind. But that's the heartbreak of PWS somtimes, isn't it? Logic does not always enter into the decision-making process.

Eventually he did get his way, just not how he expected. He did get to leave TCI, but he hopped right out of the frying pan into the fire. The police picked him up, and he was sent to a nearby hospital's psychiatric ward.

I had that gut-wrenching feeling in my stomach. He had just gone from a place with an outdoor playground, a swimming pool, video games, fun therapies, and a healthy diet to a place where there was absolutely no outdoor time under any circumstances, and any tantrum or aggressive behavior would be swiftly met with medical sedation.

That's when I started calling him every day. The ward was a wake-up call for Michael, and it made TCI look peachy keen by comparison. Only now, Michael had to *earn* the privilege to go to TCI, not to mention regain the trust of the entire staff he tried to intimidate. Plus, he had learned that all of his bluster didn't work with the staff; it backfired. For the first time, he had gotten himself into trouble that only he (and his good behavior) could get himself out of.

Michael had to *want* to change.

Continued on page 13 ...

Research

Stanford
University

Individuals with Prader-Willi Syndrome Who Engage in Skin Picking Age 6-25 Years Needed for Stanford University Research Study Does your child with Prader-Willi syndrome engage in skin picking? We are conducting a study to evaluate how environmental and/or neural factors influence the display of skin picking commonly exhibited by individuals with PWS. Our hope is that the results of this study will lead to an increased understanding of why skin picking occurs in PWS and thus inform more successful treatment approaches in the future. We are looking for individuals with PWS who engage in skin picking on a daily to hourly basis, producing tissue damage on a regular basis (e.g., sores, open wounds). Because the study involves an MRI scan of the brain, individuals who engage in skin picking on their head will not be able to be included.

Participation involves: Travel to Stanford University (San Francisco Bay Area) for 3 days; behavioral assessment; cognitive testing; MRI scan. Benefits of participating: Potential improved understanding of the variables that influence your child's display of skin picking; honorarium of up to $50 for participation. There will be no travel or lodging costs to families for participation. For more information or to enroll contact: Kristin Hustyi, M.A., BCBA khustyi@stanford.edu (650) 724-7395.

SAINT LOUIS UNIVERSITY
Higher purpose. Greater good.

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

PWS and Early-Onset Morbid Obesity Natural History Study – All Persons with PWS
Conducted by Virginia Kimonis, M.D., Chief, Division of Genetics and Metabolism, UCI Med Ctr. The purpose of this study is to collect natural history information on PWS and early onset morbid (severe) obesity.
WHO: Persons with a confirmed diagnosis of Prader-Willi syndrome ages birth-60 years, receiving and not receiving growth hormone.
WHERE: UCI Medical Center and General Research Centers at UCI 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 Marie Wencel, research coordinator at 949-824-0521 or email at mwencel@uci.edu.

CHLA Research Study: Can Exenatide help patients with Prader-Willi Syndrome lose weight?
Exenatide (Byetta; Amylin Pharmaceuticals, San Diego, CA) is a subcutaneous injection given twice a day which has been shown to lead to weight loss in adults. The study looks at the effects of exenatide on obesity factors in overweight patients with PWS the ages of 13-20 over a 6 month period. The study involves 5 visits to Children's Hospital of Los Angeles (CHLA) located at 4650 Sunset Blvd., Los Angeles 90027. The initial screening visit involves blood tests; if the patient qualifies there will be 4 more visits. All visits include physical exams, blood draws, and an appetite questionnaire. Two of these visits will include a mixed meal tolerance test (MMTT) and a DEXA scan. The MMTT involves placing an IV and series of 4 blood tests over 2 hours. The DEXA scan is an x-ray that measures body fat. $50 will be provided at each visit as compensation for your participation. The study is conducted by Drs. Debra Jeandron andParisa Salehi from the CHLA Endocrinology department. To participate in this study you:

- Must have Prader-Willi Syndrome; must be 13-20 years old; must have a body mass index >85th percentile; must NOT be using or have used exenatide or related medication; must NOT have a current of past history of pancreas of kidney illness or problems; must NOT have another diagnoses which may affect taking the medication of its results.

For more information contact Dr. Debra Jeandron (323) 361-8816 djeandron@chla.usc.edu .

Worst End of School Year Mom Ever

by Jen Hatmaker

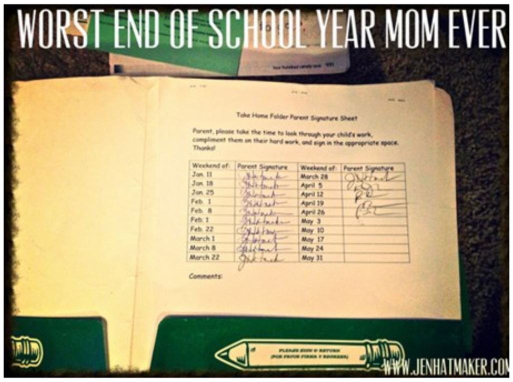
You know the Beginning of School Enthusiasm? When the pencils are fresh and the notebooks are new and the kids' backpacks don't look like they lined the den of a pack of filthy hyenas? Moms, remember how you packed innovative and nutritional lunches and laid clothes out the night before and labeled shelves for each child's work and school correspondence and completed homework in a timely manner?

I am exactly still like that at the end of school, except the opposite. We are limping, *limping* across the finish line, folks. I tapped out somewhere in April and at this point, it is a miracle my kids are still even going to school. I haven't checked homework folders in three weeks, because, well, I just can't. Cannot. *Can. Not.* I can't look at the homework in the folder. Is there homework in the folder? I don't even know. Are other moms still looking in the homework folder? I don't even care.

I feel like any sort of school energy required at this point is pure oppression, like the universe is trying to destroy me. I'm so tiiiiiiiiired and I have five kids and that is just too many to educate well. I can only handle around two, so I'm going with Sydney and Caleb because they both like to read and the other three are just going to have to enroll in Life Skills Class one day and develop a trade.

Yesterday Remy brought her books to me at bedtime – an hour notable for its propensity to incite rage and trauma – and chirped, "We need to read for 20 minutes!" and a little part of my soul died.

"No, we don't have to read tonight."
"YES WE DO!!! MRS. BURKE SAID!!! WE HAAAAVE TO!!!"
"We already read."
"NO WE DIDN'T!!! YOU ARE FAKING ME, MOM?"
"When I talk to you during the day, that's like reading. You have to listen to the words I am saying and then make sense of them. It's really hard work for you. It's called *auditory reading*. We've been practicing all day. I'll write the minutes down in your log."



Take Home Folder Parent Signature Sheet

Parent, please take the time to look through your child's work, compliment them on their hard work, and sign in the appropriate space. Thanks!

Weekend of:	Parent Signature	Weekend of:	Parent Signature
Jan. 11		March 28	
Jan. 18		April 5	
Jan. 25		April 12	
Feb. 1		April 19	
Feb. 8		April 26	
Feb. 1		May 3	
Feb. 22		May 10	
March 1		May 17	
March 8		May 24	
March 22		May 31	

Comments:

My friend Glennon over at Momastery described nighttime reading like this: *"The little one wants to 'help read' her book. So, let's see. It takes her about six minutes to sound out each word, and so if the book is one hundred words, well, I don't specialize in math but I am telling you that I am stuck in that room FOREVER. It feels like I will be reading that book with Amma until* ***I die****."*

UNTIL WE DIE. Children should not be allowed to learn to read until they are already good at it. And why do we have to do this at bedtime when I'm one click away from becoming that scary under-the-bed-mother in "Mama" (**GO TO BED OR I AM ACTUALLY GOING TO DIE AND THEN HAUNT YOU FOR THE REST OF YOUR LIFE AS A TERRIFYING CLOWN**). I know having an emerging reader is exciting. Because of the reading! And the literacy! But at the end of the school year, when I've logged approximately 688 million hours with such gripping plots like *The mother and the brother went to the store*, which takes 12 minutes to decode, then I have to look at the ceiling and sing hymns in my brain to get through it.

Then Ben tells me Tuesday that he needs a Ben Franklin costume for the Living History Museum **today**, and I'm like *what fresh hell is this??* I have no idea how I missed the correspondence on this (because I'm not checking backpacks is just a theory), but Brandon is the Costume and Project Parent and I am the Daily Grinder, which is a division of labor we agreed on to ensure our kids actually graduate one day and move out, but he is out of town on a mancation, so this is on me. **I cannot even handle signing a folder in late May; a colonial costume is cause for full, unrestrained despair.**

So Ben went to school [in a costume I threw together] and there is no way this will ever not be a part of his childhood. [My] scarf hangs out the bottom of his vest, [with] soccer socks stretched over his Adidas pants. Just whatever, man.

My shame was somewhat mitigated when I saw a kid wearing a random t-shirt and jeans with a pair of swim goggles around his neck (Michael Phelps) and another girl with a piece of paper taped to her shirt with her character's name written in marker. I caught the eyes of their moms and was all *solidarity, you guys.*

Teachers, we need to make a deal that after April testing, we don't have to do anything else. You don't. I don't. I don't care if you watch movies in class five days a week and take four recesses a day. I mean, Caleb had to bring an About Me poster with *five school days left in the year*. In September, this might have produced something noteworthy, with pictures perhaps, even some thoughtful components to describe his winning qualities, but as we've used up all our bandwidth, *we yanked trash out of our actual trash can*, glued it to a poster, and called it a day. I am not exaggerating when I tell you this is the very most we can do on May 29th.

The emails coming in for All Of The Things – class gift, end of year letters, luncheon signup, party supplies, awards ceremonies, pictures for the slide shows, final projects – are like a tsunami of doom. They are endless. I mean, they will never ever end. **There is no end of it.** I will never finish and turn it all in and get it to the (correct) Room Mom and get it all emailed and I am pretty sure the final week of school will never be over and this is the end for me.

Continued on page 13...

Support PWCF Without Spending Any Extra Money!

Register your Ralph's Reward Card online in the Community Contribution Program and PWCF receives a donation every time you shop!
Go to www.ralphs.com

1. In the Search box enter Click "Community Contributions"
2. In the middle of the page, under "Participant" click on "enroll"
3. Follow the directions to establish your online account or sign-in to your existing account
4. Designate Prader-Willi California Foundation – Organization #93694. Now, whenever you use your Rewards Card, a portion of your purchases will be donated to PWCF!

Sign up for eScrip to Support PWCF 3 ways!

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

- 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

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 and that a portion of your purchase is donated to PWCF
- Or shop through this link: https://secure.escrip.com/jsp/group/onlinemall/groupmallredir.jsp?gid=500042750

Participate in the eScrip Dining by Rewards Network

- Once you enroll in the eScrip program and register your cards, a portion of purchases made at participating restart aunts will automatically be 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.

School Year Mom continued from page 12 ...

Brandon: "You don't have to do all that, you know. Just blow it off.

Me, staring blankly: "Well, what a lovely thought you're having there in your brain. How nice for you to be thinking that thought. I want to live in your imaginary world where my failure to do the School Stuff doesn't mean our kid is the only one not wearing a purple shirt or didn't have his pictures in the slideshow or didn't bring in a handmade card for his teacher like every other student. I'll just 'blow it off' and our kids can work it out with their therapists later."

"Touchy."

"You don't even know about all this, man."

So, Mom out there sending Lunchables with your kid, making her wear shoes with holes because *we're.almost.there*, practicing "auditory reading" with your 1st grader, I got your back, sister. **We were awesome back in October; don't you forget that. We used to care, and that counts for something.** Next year's teachers will get a fresher version of us in August, and they won't even know the levels of suckage we will succumb to by May. Hang in there, Mama. Just a few more days until summer, when approximately 19 minutes into our glorious respite from homework, liberated from the crush of it all, ready to party like it's 1999, our precious children, having whooped and celebrated and "graduated" and squealed all the way home will announce: **"I'm bored."**

Transitions continued from page 10 …

Over the phone, I could hear his daily struggle. The ward was incredibly hard on Michael and the location didn't make it easy for him to keep a cool head. I asked him how he was going to keep calm and qualify for release to TCI, and his reply was to just "stay in his room". My parents could only see him twice a day, during visiting hours. But in spite of that, Michael started to open up to the doctor from TCI during his visits and ultimately represented himself in front of the judge to be allowed to be released back to TCI.

After over a week of managing his own behavior better in order to qualify for re-admission, he got a second chance. With a few modifications - including the development of a fancy new low-cal ranch dressing, on Michael's request - things went much more smoothly. He started earning special store-money with good behavior and attending his therapies on time. His first purchase was for colored pencils to illustrate scenes and characters from a story we're creating together. He started playing games with the other residents at TCI, and is slowly starting to come out of his shell and meet new people. He had one more behavioral wrinkle where he tried to get outside without permission (once again met by being sent back for a few days to the psychiatric ward), but *this* time he didn't use intimidation. This may seem small, but it isn't. *Michael is learning.*

Michael is still in his program at TCI, losing weight and participating in activities. I still call him every day. No one ever said change was easy, but sometimes change is necessary.

And you know what? In spite of all the change, he's the happiest I've ever heard him.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I am Just a Girl

By Lisa Peters, Massachusetts

The greatest challenge I face, as a parent of a child diagnosed with Prader Willi Syndrome, is my inability to face my fear.

I am afraid.

I am afraid that if I neglect appointments, therapies or new treatment options, my son's life will suffer.

I am afraid if I do not make a better effort to manage his anxiety and his resulting behavior, he will become a monster.

I am afraid, if I do not secure our home, he will wander the neighborhood searching for food and instead find harm and danger.

I am afraid if I am not a "good enough" parent, my son will die.

I have been running away from this fear all of his life.

It has finally caught up with me.

When my son Nicholas was first diagnosed with this monstrous syndrome, I experienced a type of shock. I buried my fear by devoting my life to a constant state of movement. I figured if I stayed busy enough, I wouldn't have time to feel anything. Nick's complex medical needs made this warped philosophy a convenient reality.

I became selfless, devoting myself completely to my weakened child. This chaotic lifestyle took me to a lonely place where few folks in my life could relate. I lost friends and family members. But still I persevered. I tried to make sense of my suffering by researching many forms of religion and spirituality. Here, I was interested to learn that most, if not all of these beliefs shared a similar philosophical promotion of selflessness and a belief in its path to peaceful living and enlightenment.

The only problem was...I didn't feel enlightened.

All I felt was tired.

After much soul searching, I have discovered that perhaps my selfless intentions are somewhat misguided.

Am I being selfless because I truly want to be selfless?

Do I enjoy it and feel energized by the experience?

Or am I staying busy just to hide my fear?

These are difficult questions but I believe the answer is....

I am afraid.

I am afraid if I allow myself to feel this fear, it will consume me.

So, I don a new persona. I compare myself to the likes of superheroes and soldiers and in the process I begin to lose myself. I bury my hopes, my dreams, and my health, so that I can better care for my son.

I have become a cartoon caricature and not a human being.

Last week, I got my wake-up call.

A visit to my primary physician indicated that I may be headed down the dreadful path of self destruction.

My blood pressure has begun to increase. I have always had low blood pressure. This shocking news made me think of my father who passed away suddenly from a stroke shortly after my first son was born. Realizing there was a good chance that I could face a

Continued on page 17 ...

Mothers

By Felix Kirchner

Mothers give love to us little ones, protect us when we're scared.
Mothers give birth to ev'ryone, and make us clothes to wear.
Mothers make us feel special in oh-so many ways;
When we love our mothers, Jesus smiles upon our days.

Mothers here, mothers there, make our world alive.
Mothers love us dearly, and help us when we strive.
Because we love our mothers, we want them to be safe.
Without mothers there'd be no life on earth… Luckily, there's FAITH!

Angels fly over mothers as they protect their little ones.
Jesus shines the light of day… and warms us in the sun.
Mothers' job is caring for us – helping us to grow.
Jesus, mother and angels – the story's still being told!

Mothers are beautiful, this is their special day.
We bring love, smiles, flowers and hugs along the way.
Since this is Mother's Day we have one more thing to do:
Gather up our mothers and say, "I love you!"

Felix Kirchner is 22 year old young man with PWS who lives in Gilroy with his family. This song was written for Mother's Day by Felix in collaboration with his friend-musician/songwriter, Allen Douglas. Felix sang it for his mother – and all of the mothers in attendance – at their family's church.

I'm Just a Girl continued from page 16 ...

similar fate, I did some soulful reflecting and found that my previous motto of "to do" needs to be replaced with a healthier "to be" philosophy. If I do not find a more relaxed mindset, and do not take better care of myself, who will care for my children? This is, of course, my biggest fear.

I I need to find my peace.

I realize however, that this will take some time.

I am considering things like exercise, meditation, and creating new hobbies. I am also visiting with a mental health professional who is well versed in the stresses associated with raising children with special needs.am learning that...

Before I can give selflessly to another, I must first be fearless in my understanding of myself.

I must realize that I am not a superhero or soldier, I am just a girl.

I am a girl with a very big responsibility.

I am responsible for the quality of life of a medically fragile child.

This responsibility often makes me tired and scared.

It is very OK to feel this way.

My son Nicholas has endured many medical, physical and emotional difficulties and yet he faces each one of these challenges with a sense of calm acceptance and fearless resilience.

It is this spirit that I need to embrace.

Ironically, it is my son who makes me want to become a better human being.

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Lisa Peters writes about family life at www.onalifelessperfect.blogspot.com.

Parent to Parent

My child is in the 4th grade and still cannot read well at all. Is this very common? For those of you with children who have very poor reading skills, how did or do you help them?

When our children were small we would take index cards and tape them on everything! Door, wall, sofa, etc. Even guests in our house got an index card taped to them - friend, aunt, uncle! Silly, but it helped with sight words and spelling.

I attended a funeral yesterday and the grown son of the deceased told us that his dad would have them earn toys and games they wanted by saying "read this book (or chapter) first." I really love that idea and wish I had used it.

Lastly, share books and reading time together. Play Hangman, point out and read road signs as you drive, find books on topics they love. Praise them for trying! Make reading fun! *Linda Ryan, mother of Trevor, age 23*

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Be sure to have the child checked for dyslexia. That is the number one reason children do not learn to read. *Marilyn Bintz*

Next issue's Parent to Parent question is ***"My adult with PWS lives in a group home and has begun to smoke cigarettes because the other residents in the home also smoke. I'm concerned about the health risks but don't really know how to approach the issue with the home's House Manager. Anyone have any suggestions?"***

Increased Tummy Time

May Help Reduce Risk for Plagiocephaly

This article is excerpted from UCLA Health's Vital Signs, Summer 2013, Volume 59, page 3

"Newborns spend most of their time sleeping during the first few months of life as they grow, learn and gain the strength necessary to practice important motor skills. Placing babies on their backs during sleep reduces their risk for sudden infant death syndrome (SIDS) but may cause an unintended side effect – plagiocephaly, a disorder in which the back of or side of an infant's head becomes flattened.

"Misshapen heads are not uncommon in newborns," says Yoshio Setoguchi, M.D., former pediatric coordinator of the UCLA Craniofacial Clinic. Tight or shortened neck muscles that prevent an infant from moving his or her neck around (torticollis) has also been traditionally associated with plagiocephaly.

"More recently, the number of infants who develop plagiocephaly has increased fivefold, according to some estimates. "We've seen many more cases of positional plagiocephaly since we began recommending that parents place infants on their backs during sleep, which is important to prevent accidental suffocation," Dr. Setochi says.
"All babies are at risk for positional plagiocephaly if they repeatedly spend time on their backs or side with their heads resting against a flat surface, such as a crib, swing, or car seat. This occurs because infants' heads are soft to allow for brain growth during their first year.

"Babies with developmental delays are at highest risk for positional plagiocephaly because they begin to roll or sit up late and, as a result, will be on their backs longer," says Marinda Tu, M.D., a pediatrician in the UCLA Craniofacial Clinic. The condition is most often diagnosed when parents become concerned about a flat spot on their child's head or during well-child examinations at two or four months. The condition will often resolve itself without treatment or with conservative therapists that involve repositioning babies when asleep and stimulating developmental activities, Dr. Tu says.

"We encourage beginning 'tummy time' early, which will help the child begin to roll over, crawl and sit up without support," Dr. Tu says. "The idea is to get the baby off his or her back so that their head shape can round out over time." [Families should work with their baby's Occupational or Physical Therapist to gradually increase tummy time.] "Dr. Tu cautions that young babies should never be left unattended while on their stomachs."

"For some babies with positional plagiocephaly, therapy using a corrective helmet, or cranial orthosis, may be required to redirect the growth of the skull. Surgery is rarely required.

"Few people have perfectly round heads," Dr. Tu says. "Treating plagiocephaly is purely cosmetic and not related to brain development. It's really more about what we can do to make the condition less obvious."
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We Get Mail

Dear PWCF: Canyon Verde was honored to receive such lovely press in your impressive PWCF News! Your observations and comments about Canyon Verde were right on target and I appreciate your support. I am enjoying reading the rest of the "News" and found the articles and resources to be interesting and helpful. Thank again for your visit and kind support! Happy Summer, *Nancy Langdon, Executive Director, Canyon Verde*

Dear PWCF: Thank you for all of the extra help you have given Tim and me recently… all time on phone calls, FAX's and Emails to doctors' offices, and follow-ups to make sure my wonderful son gets to camp despite his mom and her funky, uncooperative computer! We are so appreciative of your help and your creative problem solving skills. Thank you, thank you! See you in Boulder Creek! *Love from the Dignan's, Kathie & Tim*

Dear PWCF: First, I want to thank you profusely for sending us Mary and Paul Hill. They were great help with our PWS booth at the Endocrine Society meeting. There were about 9,000 attendees, mostly endocrinologists and endocrine researchers. We handed out 200 full packets of information and a bunch of smaller educational items. It was cool to have a booth representing state, country and world at the same time!... *Suzanne Cassidy, M.D.*

MEMBERSHIP ACTIVITY

April-June 2013

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

New Individual Members
Natalie Milana

New Family Members
Danielle & Keith Adamson
Andrea Barraza
Kristine Eddy
Kunie & Ray Ford
Heather & Dominice McInnes
Elena & Darrell Mulligan
Jenny & Jay Wolkensdorfer

New Extended Family Members
Jo & Floyd Hatcher

Renewed Family Friend Members
Samuel Breneiser
Audrey Dunn
Jan Nakagawa & Steve Grogan
Nancy & John Jenkins
Irene & Kyle Kaiser
Nancy & Jim Kaiser
Michele Maher
Suzanne & Mark Reitz
Tyna & Ray Triggs

Renewed Extended Family Members
Karen & Russell Benedikt
Lisa Ann Bonk
Mary Culver
Sally & Chet Collom
Laura & Ray Esau
Wendy & Bob Graziano
Pat Grey
Linda & Stephen Hedstrom
Kelly Jaeger
Carolyn & Gordon Jones
Linda McGee
Carolyn Meyer
Kathleen Minor
Kathy & Ralph Paige
Stephen Patay
Mark Savit
Judy Schlafer
Margaret & Bill Spinelli
Mary & Pat Williams

Renewed Professional Members
June-Anne Gold, M.D.
Rawate Inc.
Rick Swartwout, Pfizer Endocrine Care

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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 PWCF1@aol.com

DONATIONS ~ April—June, 2013

SHINING STAR DONATIONS

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Vega ($1 - $99)
Carolyn Meyer in honor of Cameron Graziano

Magnanimous General Donations
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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).