# 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 2012
Volume 23, Number 2

## In this issue:

WALKING for Prader-Willi Syndrome

*See our photos on page 16*

## PWCF Members Help Take PWS to the White House!

One of PWCF's objectives is to promote and raise community awareness of Prader-Willi syndrome. Toward this goal PWCF proudly supported the Foundation for Prader-Willi Research (FPWR) in their pursuit to win First Lady Michelle Obama's *Let's Move!* Communities on the Move Video Challenge which featured a terrific video [www.fpwr.org/vote] . After weeks of a very tough online voting competition against hundreds of other charities, FPWR's video eventually captured the most votes! Two PWS representatives will attend the Let's Move! related event in Washington, DC and have the opportunity to present the video at the event as well as have the video featured on the Let's Move! website.

Because we worked together, we created a major opportunity for national awareness of Prader-Willi syndrome. To all of you who participated and supported the effort, PWCF thanks you!

*Editors Note: Although we are confident that FPWR has been successful in this endeavor, the official announcement has not been made at the time of this publication.*

## Save the Dates

| | |
|---|---|
| August 5 | PWCF PWS Behavior Training Series Part I, Redondo Beach |
| September 1 | PWCF PWS Behavior Training Series Part II, Redondo Beach |
| October 6 | PWCF PWS Behavior Training Series Part III, Redondo Beach |
| October 17-20 | PWSA (USA) 2nd International Conference on Hyperphagia, Baton Rouge, LA |
| November 3 | PWCF General Education Meeting, San Jose Hilton Hotel |
| November 10 | FPWR Research Conference, Philadelphia Marriott, West |

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**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 | Wendy Young | 415-380-0721 | wmydmy@gmail.com |
| Sacramento | Diane Kavrell | 530-753-5928 | brandon.kavrell@cexp.com |

### *Central California*

| | | |
|---|---|---|
| Debbie Martinez (Teens & Adults with PWS) | 559-227-0294 | martinezds@gmail.com |
| Paula Watney (Teens & Adults with PWS) | 559-299-8171 | mikewat1@sbcglobal.net |
| Jennifer Rinkenberger (Infants & Children with PWS) | 559-930-7834 | jenrink@mac.com |

### *Southern California*

| | | | |
|---|---|---|---|
| Los Angeles County | Lisa Graziano | 310-372-5053 | tlcgraz@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/ Riverside County | 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*. 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

# *PWCF Hires Family Support Coordinator*

The Prader-Willi California Foundation is proud to announce that we have hired a Family Support Coordinator to help meet the multifaceted and growing needs of our families and professionals.

We welcome **Katherine Girdaukas** in her new role as PWCF's Family Support Coordinator. Katherine brings to the Foundation a great deal of personal experience with Prader-Willi syndrome. Her younger brother Michael has PWS. Says Katherine, "Michael was diagnosed with PWS in infancy. His first words were in American Sign Language (ASL) because he had a hard time getting the muscle control necessary for speech. Both of us learned simple ASL words like "shoes" and "socks", "please" and "thank you" before Michael went through speech therapy. We were best friends throughout childhood; we made forts in the forest, made up stories about fantastic kingdoms, and taught each other patience in the way that siblings do."

Katherine grew up in Wisconsin where she received her Bachelor of Arts degree from the University of Wisconsin, Madison, and studied abroad for a year at the Université de Provence, Aix-en-Provence in France. Katherine started her career in Respite Care as a provider for United Cerebral Palsy where she helped create and implement behavioral plans for clients. She has provided training to other Respite Care Providers in Wisconsin, attended IEP meetings to help brainstorm solutions to challenging behaviors, and has attended numerous PWS-related conferences and trainings around the U.S. Katherine served as a non-voting member of the PWSA of Wisconsin. She has toured the Prader-Willi Homes of Oconomowoc and can share with families and professionals her firsthand experience to those with questions about those facilities.

When she moved to California, Katherine researched PWCF from our website and contacted the executive director in hopes to connect with the PWS support community. This was just two days prior to Southern California's *Walking for Prader-Willi Syndrome* event. With very little advance notice, Katherine attended the *Walk*, stayed the entire day, and met with many Board members and staff. She scheduled an interview with the Director and was hired shortly thereafter. In just a few short weeks Katherine has already demonstrated extraordinary initiative, resourcefulness, follow-through, technical expertise, and professionalism.

Generally speaking, Katherine will uphold the Prader-Willi California Foundation's mission to improve the quality of life of persons with Prader-Willi syndrome by helping families obtain the supports and services they need. More specifically, her responsibilities as PWCF's Family Support Coordinator will include:

- ◊ Organize and facilitate Support Group meetings in the Los Angeles and/or Orange County areas. Assist with the organization of Support Group meetings for other counties throughout the state
- ◊ Provide information and support to families on the telephone, in writing, and in person. Perform necessary administrative duties such as database entry and dues billing
- ◊ Help families identify medical and therapeutic professionals to treat their child
- ◊ Provide advocacy assistance to help families receive the services they need for their child and for their family via letter writing, phone calls, in person meetings as necessary
- ◊ Provide Prader-Willi syndrome in-service trainings to schools and Regional Center personnel
- ◊ Write informational-type articles on a quarterly basis for the newsletter
- ◊ Assist with all educational seminars and public awareness events
- ◊ Provide assistance and support as needed

Says Katherine, "I am delighted to have the chance to serve families and individuals with Prader-Willi syndrome since their experiences correspond so closely with my own experiences in life."

We are equally delighted (if not more so!) to have you with us as well, Katherine!

## Gadget Tip

**Prader-Willi Syndrome Jeopardy**
http://jeopardylabs.com/play/prader-willi-syndrome

This online game was found and shared by Michelle Donaldson and is all about Prader-Willi syndrome. Play as a family for fun, or introduce the syndrome to others in a playful way. Whether you go for “Characteristics for $500” or “Early Signs for $100” you’ll learn even more about the syndrome while having fun!

## Nintendo Issues Warning

Nintendo issued a warning for parents regarding their popular new 3DS. The company wants parents of children 6 years old and younger to know that using the three dimensional (3D) function of their game may be harmful to their child’s visual development.

"For children under the age of six, looking at 3D images for a long time could possibly have a negative impact on the growth of their eyes," Nintendo says on the website. It also warned that users should take breaks every 30 minutes when playing games in 3D and stop playing immediately if they feel ill.

While the American Optometric Association issued a statement saying studies need to be done to see what the impact of prolonged 3D viewing is on visual development, there is a tremendous amount of media regarding the warning.

It is important for parents to understand that vision develops and changes as their child grows. Too much close up work and not enough outdoor sports and activities can hamper visual development. When children play video games, they can spend too much time indoors and don’t develop the necessary visual skills that are required for reading and learning.

## Food Tip

*This Food Tip is shared by Julie Casey of Burbank*

I just discovered a low calorie bread option: Foldit Artisan Flatbreads by Flatout. I bought the Multi-Grain with Flax breads which have 90 calories, 15 carbs, 7 grams of fiber (so net carbs only 8!) and 7 grams of protein. Great for sandwiches, grilled cheese, pizza, etc.

The company’s website is www.flatoutbread.com and they have some other healthy choices too, including a couple of Flatout Kidz products which are smaller in size. Looks like their products (maybe not all varieties) are sold in most major stores (Von’s, Ralph’s, Target, Wal-Mart, etc.)

# *Executive Director's Column*

Lisa Graziano, M.A.

The other night I experienced a gut-wrenching 'Is *this* what my son feels?' moment.

While visiting at the home of a girlfriend, I accidently knocked over my glass of red wine onto her bright yellow tablecloth. With horror I watched helpless as the tablecloth soaked up the staining liquid. And I felt horrible. Really horrible. My friend was extraordinarily gracious, but the damage was done. As I lay in bed that night, the thought, 'What is wrong with me?' bubbled up, and I felt flawed and ashamed.

In that instant, my body stiffened and my breathing stopped as it occurred to me that this may be what my son experiences when he accidently knocks something over, or bumps into something or someone, or trips and falls, or drops and breaks something. Does *he* think, "What is wrong with me?" Does *he* feel flawed and ashamed?

My heart ached for my boy as I imagined him feeling each of his 'What's wrong with me?' moments.

Of course intellectually I know that accidents just happen. But in the quiet of the night at the end of the day, what I thought and what I felt wreaked havoc with my sense of self. And all I could do was imagine and viscerally *feel* how badly my son's sense of self is dented when his body responds in ways other than what he intended. I thought about the times I admonished him with a "Dude, you've got to be more careful" and felt even more sad as I'm fairly certain he didn't mean to be not careful or plan on falling or dropping whatever he was holding.

We can take our child to therapeutic professionals to improve muscle tone, speech articulation, or eyesight. But when it comes to helping our child develop a healthy self-esteem, there's not a lot of guidance available. And without a doubt, how our loved one with PWS thinks and feels about him or herself has a whole lot to do with how they behave.

The next morning I shared with my son my story about spilling my glass of wine and thinking, 'What's wrong with me?' I asked him if he's ever thought there's something wrong with him too. He looked at me, eyes wide, like I had just looked into his soul. Ever so slowly he raised his head higher to meet my eyes and shook his head in the affirmative. "Yes, yes I have thought that," he said with an intense, purposeful inflection. And I knew he's thought that a lot.

We talked for a while and commiserated with each other about how bad it feels to think something is wrong with us. I learned a lot from him that morning. I became far more aware that he has deeper and more complex thoughts and feelings because he rarely shares them. I shared with him my belief that there really *isn't* anything wrong with *either* of us, that it just feels that way sometimes when something happens that we didn't intend to have happen, like when accidents happen.

At thirteen years of age, Cameron knows he has Prader-Willi syndrome and that his syndrome causes him to have weaker muscles, poorer coordination, and some other characteristics that set him a bit apart from his peers in other ways as well. Knowing this does help him put some things into perspective for himself and has helped him forgive himself for some of his mishaps. But it appears that hearing someone else, someone he trusts, share that they have felt *exactly* as he has felt, and thought some of the *exact* same thoughts he has thought helped him at an even deeper level. During our conversation, I believe – I *hope* – he experienced himself as being just more a bit more like everybody else, regardless of the fact he has PWS.

The month of May commemorated national Prader-Willi Syndrome Awareness Month. How appropriate that my wine spilling incident occurred in May as it certainly did reawaken my awareness that every human being, PWS or no, has self-esteem needs that need tending. As human beings we *all* need to feel competent at something. We *all* need to feel valued and respected. It is only from genuine accomplishment and achievement of our goals that we gain self-respect and develop a healthy sense of self. It may be more challenging, then, for some of our kids and adults with PWS to develop good self-esteem if they don't experience *genuine* accomplishment or if they experience themselves as having something 'wrong' with them. Our goal and challenge as parents and care providers is to help our loved one set lofty yet reachable-with-hard-work goals, to give them the support they need to accomplish those goals, and to help them recognize and value within themselves their personal achievement, all the while being on the lookout for any 'What's wrong with me?' moment so that we may address it.

As you'll read in this edition, there are so many exciting things happening for Prader-Willi syndrome: educational trainings and conferences, new research, and of course wonderful awareness-raising events to honor persons with PWS. The benefit to those who take advantage of any of these opportunities cannot be overvalued. I firmly believe the more you connect with others in the PWS community, the better will be the quality of life of your loved one with PWS and your family.

On a personal note, and on behalf of my entire family, I wish to take this space to express my sincere appreciation to each of you who expressed your condolences for the recent and sudden death of my husband's father. Your expressions of care and concern are so very much appreciated.

## SUBJECTS NEEDED FOR NEW RESEARCH STUDIES

### New Clue for Understanding the Hunger of Prader-Willi Syndrome: Research Volunteers are Needed for Further Studies

In the July 2010 issue of *The Journal of Clinical Endocrinology & Metabolism*, Dr. Joan C. Han, a pediatric endocrinologist at the National Institutes of Health (NIH), and her colleagues reported the results of a small pilot study of 13 patients with PWS. They observed that patients with PWS appear to have lower blood concentrations of brain-derived neurotrophic factor (BDNF). BDNF is a protein that is believed to play an important role in controlling appetite and may provide some answers to understanding the insatiable hunger of PWS and other conditions associated with hyperphagia. Dr. Han and her colleagues recently received a grant from the PWSA (USA) to conduct further studies on BDNF, and they are seeking patients with PWS (ages 0-18 years old) for this research. Participation involves providing medical information and a blood sample. For more information, please contact Dr. Han at (301) 435-7820 or hanjo@mail.nih.gov.

## CHLA Research Study

### Can the medication, Exenatide, help patients with Prader-Willi syndrome lose weight?

Prader-Willi syndrome is one of the most common genetic causes of obesity and it is characterized by increased appetite, increased food consumption as well as destructive behaviors such as food seeking and food hoarding. Obesity can lead to major medical problems such as sleep apnea, poor cardiac function, diabetes and atherosclerosis.

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. We are starting a study to see the effects of exenatide on obesity factors in overweight patients with Prader-Willi syndrome between the ages of 13-20 over a 6 month period.

The study will involve five visits to Children's Hospital of Los Angeles (CHLA). There will be an initial screening visit which involves blood tests and if the patient qualifies, four more visits will be scheduled at CHLA. All visits will include physical exams, blood draws, as well as an appetite questionnaire. In addition, two of the visits will include a mixed meal tolerance test (MMTT) and a DEXA scan. The MMTT involves placing an IV and series of four blood tests over 2 hours. The DEXA scan is an x-ray that will measure body fat.

The study is being conducted by Dr. Debra Jeandron and Dr. Parisa Salehi from the CHLA Endocrinology department. The following describes the requirements of the study. If you are interested, please contact us to discuss the study further.

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 or past history of pancreas of kidney illness or problems
- Must NOT have another diagnoses which may affect taking the medication or its results

Study Location: Children's Hospital Los Angeles, 4650 Sunset Blvd., Los Angeles, CA 90027

Payment: $50 will be provided at each visit as compensation for your participation

Contact: Parisa Salehi, M.D., Office: (323) 361-8816 Email: psalehi@chla.usc.edu

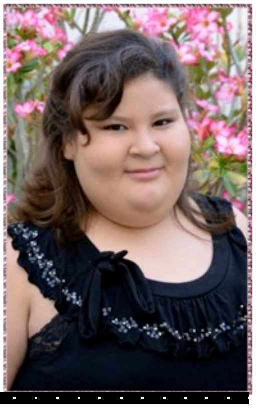
CHOC Children's

## Children's Hospital Orange County Hosts Prader-Willi Family Day

PWCF proudly supports a PWS Clinic at the Children's Hospital Orange County. A PWS Family Day was held in April thanks to the efforts of PWS Clinic Social Worker **Bobbie McGann, LCSW** and PWS Clinic Director **Susan Clark, M.D.,** with support from **Pfizer Endocrine** Care and representative **Kathleen O'Connell**.

PWCF's Executive Director **Lisa Graziano, M.A.** presented the *Principles of Food Security* as conceptualized by PWS specialists **Janice Forster, M.D.** and **Linda Gourash, M.D.** Crafts, activities and even snacks were provided to the kids while their parents attended the workshop. CHOC's PWS Family Day provides a wonderful opportunity for families to learn a bit more about management strategies as well as connect and network with each other.

## High School Beauty Queen



**Laura Sanchez Ozawa** is in the running to be crowned the Queen of her school. This is the first time the school has had a girl with special needs run for Queen.

Reports proud mom, **Ana Ozawa**, “Laura is very excited and motivated. She has already lost ten pounds this past almost two months (she is using a supplement that I bought at GNC called Oxyelite Pro). This is very good because I had never been able to make her lose weight, this is the first time.

“And we are ready to attend PWCF’s PWS Camp this summer! Thanks, PWCF, for all that you do.” We wish you all the best, Laura, although to us you’re *already* a Queen. See you at Camp!

[Editor’s Note: Ana reports that Laura was indeed elected Queen! Congratulations, Laura!]

## When She Sleeps......

by Melissa Castillo, Mommy to 7 year old Kayla Hall

Sometimes our mornings go too fast and our hurry for bed comes too soon. I'm a single parent, and sometimes my child’s bad days seem too frequent. Then I get that one great day when everything went perfectly for her, where she didn't make us late for work or school, when she managed her frustration well in front of her classmates, when she was able to stop what she was doing and make it to the bathroom on time, when I didn’t have to work so hard to convince her to make the right decision that I told her I was leaving “up to her.” I get that one great day, the day she smiles so much, when her laugh makes me so happy that all the bad days seem to no longer matter for just a little while.

This child I alone have raised is my world, my heart, my life. I couldn't think of my life without her in it. I look at her and think, “What a blessing I’ve been given.” When she’s with me I know she’s safe from becoming too angry. She goes to school every day, and I know that managing the day-to-day is a lot for her; how I wish I could be there to guide her throughout her day. When she sleeps I hear her breathe lying next to me and I see how at peace she is.

This is me taking a long-awaited exhale that I so needed, now that she's sleeping.

## IEP or IPP Meeting Suggestions

Want to create a scenario for a *disastrous* IEP or IPP meeting with your child or adult with PWS? Here’s how: Be open and honest about their negative behaviors in front of everyone at the meeting.

So I implore you, “Don’t do it! It’s a bad idea!” Like most people, kids and adults with PWS generally do not react well to negative comments about them, and hearing negative or less than positive descriptions of their behavior will often trigger a negative behavior. Meetings are much more productive with clients who are present at the IEP or IPP when positive behavior is reinforced.

You can have it written into the IEP/IPP directives that any discussion of sensitive topics such as behavior, money, health, conservatorship, etc. is done in a private meeting without the client with PWS present.

Obviously, strategizing sessions are needed. Just make sure to do these without the client present.

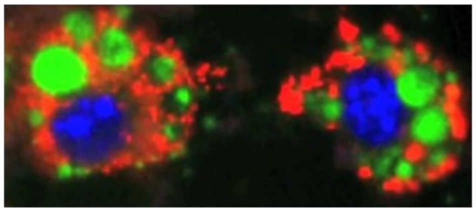
## Regional Center Case Manager Visits

Did you know that your child or adult’s Regional Center case manager is supposed to visit the group home that your child or adult with PWS lives in? Your Regional Center case manager is required to visit the group home a minimum of three times each year.

If your child or adult is living in your home, the case manager is required to visit once a year.

Title 17 of the California Code of Regulations [ http://www.oal.ca.gov/CCR.htm ] covers more of the requirements for the Department of Developmental Services. Start with Section 50201 and you will discover many more topics on client rights and residential facility care services.

*Each of the above articles was submitted by PWCF Board member Paula Watney*



## Teaching Fat Cells to Burn Calories: New Target Against Obesity Involves Brown Fat

*While the following article is not specific to PWS research, all research brings us one step closer to understanding PWS's hyperphagia symptom and one step closer to successful treatments.*

*ScienceDaily (Mar. 7, 2012)* In the war against obesity, one's own fat cells may seem an unlikely ally, but new research from the University of California, San Francisco (UCSF) suggests ordinary fat cells can be reengineered to burn calories.

While investigating how a common drug given to people with diabetes works in mice, a UCSF team discovered that a protein called PRDM16, found in both men and mice, can throw a switch on fat cells, converting them from ordinary calorie-storing white fat cells into calorie-burning brown fat cells.

This discovery makes PRDM16 a possible target for future obesity drugs. Compounds that promote the action of this protein may help people burn calories faster. Though they would have to prove safe and effective in the clinic, such compounds would represent a completely different approach to weight loss. Existing diet drugs aim to restrict the intake of calories -- by blocking the absorption of fat in the gut, for instance, or by decreasing appetite.

"If you think about the energy balance, the other way to tackle obesity is through energy expenditure," said Shingo Kajimura, PhD, who led the research in the UCSF Diabetes Center and the Department of Cell & Tissue Biology in the UCSF School of Dentistry. The work is published in the journal *Cell Metabolism*.

**Where Brown Fat Comes From**

Scientists believe that brown fat originally evolved in early mammals as a defense against the cold. It helps them maintain their body temperature and thrive in the face of challenging environmental extremes. Not all animals share this ability.

Many animals, like lizards, are "cold blooded" or exothermic. They maintain their body temperature through completely external means, sunbathing at certain times of the day and huddling in warm, protective places at night. This naturally limits their range and explains why lizards, so abundant in tropical climates, are far rarer in cold climates.

"Warm-blooded" mammals, on the other hand, are endothermic. They produce heat internally by a variety of means: shivering, sweating and regulating the size of their blood vessels. Brown fat also contributes by burning fatty acids, which heats the blood coursing nearby, and in turn warms the body.

Though scientists once thought new brown fat was only made in babies, we now know that the human body is capable of creating new brown fat cells throughout life. And in recent years, doctors also have discovered the amount of brown fat in the body is inversely proportional to the likelihood of obesity -- the more brown fat people have, the less chance they are obese.

The possibility of exploiting brown fat for weight loss became tantalizing after clinical evidence showed that certain drugs could alter the amount of brown fat a person has. In particular, a common class of drugs given to people with diabetes called PPAR-gamma ligands has been shown to increase brown fat. But scientists never understood why.

Now Kajimura and his UCSF colleagues have demonstrated how it works. In their research, they showed that PPAR-gamma interacts with the protein PRDM16, making it more stable and leading to its accumulation inside cells. This essentially throws a genetic switch and converts the white fat cells to brown -- at least in mice.

The question remains whether it is possible to do this in people as well, and if so, how. While new drugs that target this protein may be years away, knowing the target may speed their development, Kajimura said.

The question is no longer how do we make brown fat, he added. Instead it now becomes a more specific question: "Can we simply

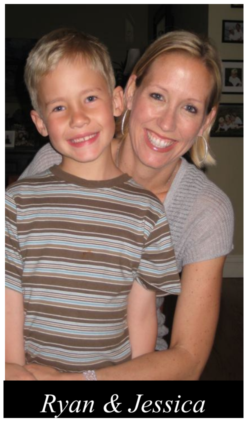
### Kids Say the Funniest Things…

*Our 13 year old son ran a mile in P.E. today. Making his way upstairs at the end of his strenuous day, he grumbled, "Geeze, my leg muscle is having an orgasm!" His dad replied very calmly, "That's 'spasm', son. The word is 'spasm'."*

## In the Trenches

### Vol. 8

*by Jessica Patay*



*Ryan & Jessica*

**I love summertime and I also truly struggle with summertime.**

I love BBQ's, festive parties, July 4thfireworks, and eating outdoors.

I love that there's no homework for my 3 kids (and me!).

I love the sunshine and warmth of Southern California.

I love seeing my kids swim and splash and play as if there were no better activity in life ever.

**But I really struggle with the kids being out of school, home more, sometimes fighting more.** And Ryan is definitely more anxious with the change in routine, and the decrease in day-filled structure. The E-L-E-V-E-N weeks of summer is daunting, let's just be real here, for us special needs parents. If we are lucky to get four weeks of **free** half-day summer school, it certainly takes the edge off. I do remember when it used to be 6 weeks. Ahhh…the good old days.

Filling up Ryan's summer is expensive, whether I hire sitters, therapists, or send him to camps. Not to mention, I have two other kids. UGH! So at the same time I am counting down the days till break, I'm also wincing a bit inside. And so is my wallet.

However, an "AHA moment" came to me just this May morning. To shift away from my fear or dread. I got a surge of hope and energy and intention. Ironically or not, it came after a silent moment of prayer and meditation. *I am going to create a bucket list for my summer, for OUR summer: a list of things to do as a family that we will joyfully check off together.* And it does not have to be expensive or extravagant or glamorous either, darnit, to count!

**Here are some ideas:**

- Visit 5 new places—which do not require plane rides or long road trips.
- Give my kids disposable cameras for the summer and make an album of their shots.
- Sleep in tents in the backyard. (And of course, bring the aero-bed out for Chris and me.)
- Get a fire-pit—find a deal, or beg, borrow or steal. *Ok, not that last one.*
- Have movie nights with friends in our garage/playroom. Invite different families each time.
- Taste something new or try some new healthy recipes that the kids will absolutely love (at least I hope).

I encourage you to do the same. Make it fun. Reconnect with friends and families. Set some easy goals. Have an adventure.

Be the nice, calm referee when your kids have had too much sibling togetherness, and figure out how to give THEM A BREAK from each other. Let your kids get dirty and sandy. I should do this as well. Often.

And if any of the above still sounds daunting or too much work or effort, call another mom/parent, and go for it together. Make your bucket lists together. *I'm much more brave* to get out of my comfort zone (even a trip to the beach), if I have another mom with me. There is power and empowerment in parental numbers. Go and **LOVE** your summer of 2012!

*Enjoy more thoughts on Jessica's blog: "She Runs a Good Race~Mothering is a Marathon."*
*http://jessicapatay.wordpress.com/*

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## Loma Linda University Medical Students Treated to PWS Awareness and Education Session

Thirteen year old **Cameron Graziano** wowed 200+ genetics students assembled at a gigantic classroom at Loma Linda University Medical Center on April 18.

PWCF Board Member and PWS researcher **June-Anne Gold, M.D.** , who teaches the class, invited Cameron to present about what it's like to have Prader-Willi syndrome. The goal of the class session is to make Prader-Willi syndrome "real" to her students and ignite their interest in PWS. Cameron presented a PowerPoint he created and deftly fielded the students' questions.

The venture is a real win-win for everyone: Dr. Gold can feel gratified that she has brought PWS "to life" for her students; her students will no doubt ace the part of their exams that address Prader-Willi syndrome; and a thirteen year old boy's confidence and self-worth soared as he experienced himself teaching over two hundred grownups-almost doctors!

## Wedding Planning and PWS

by Katherine Girdaukas

The reflections of the evening lights of Chicago skyscrapers glittered across the surface of the river as Jackson and I looked down from above. He turned to me, took my hands in his as he went down on one knee, and proposed. I said "yes".

Preparing for our wedding has been a thrilling experience. We set our date a year and a few months in advance and immediately started planning everything we could. Our wedding planning experience is fairly similar to most others, with one interesting twist: my brother has PWS, and I want him to be involved and have a wonderful and low-stress time through the whole day.

I'm the older sibling, and grew up dreading weddings for the same reason as I dreaded holidays: unrestricted food. Michael has had his share of problems at weddings, so I called him up to find out what his worst wedding experience was so I could learn from those mistakes.

I was not actually at the "problem wedding" that my family speaks of with hushed tones and the shudder of unpleasant recollection, so I can only describe it as my brother told it to me. First, the wedding was out of state, which meant hours of driving (including a car breakdown) for my family and my brother. After an otherwise lovely ceremony, the guests went to the reception hall to wait for the bridal party to arrive before dinner.

And wait.

And wait.

In the meantime this reception did have hors d'oeuvres, but of an unusual kind: they had a buffet of candy. Bowls filled with skittles, regular M&Ms, peanut M&Ms, rope candy, gummy worms, gum drops, and more filled this Candy Bar. My brother struggled as he watched young children go through the Candy Bar with an exuberant lack of restraint. Soon after came the inevitable sugar rushes and tummy aches, as well as headaches for all the adults trying to rein in their children.

At long last, the bride and groom arrived. The guests lined up for the buffet, which was, as my brother described it, *miles* of buffet. Three choices of meat and option upon option of side dishes, each of which Michael wanted to try. He filled his plate high and deep with each dish. Though my family did their best to help him make good decisions, he was already at his wit's end with the stress of trying to make good food choices amidst a room of food temptations. In the end, the stress was unbearable and he had to leave early. The entire event exhausted him, my parents, and my extended family, and he wanted me to stress in this column just how avoidable that stress could have been with a few changes at the wedding planning stage.

When I got engaged, I made a pact with myself to plan a wedding that my *whole* family could enjoy. My brother and I got together and brainstormed ways to set up an ideal wedding for a person with PWS to attend. The first, and simplest thing in terms of prevention, was to take a look at how food would be served.

We immediately nixed the idea of a buffet line at our reception. Instead, we will be serving individual plates: a choice of a beef dish, a chicken dish, or an eggplant dish. There are no surprises for anyone; the dishes are ordered well in advance when we receive all the RSVP's. Likewise, we've ordered only one flavor of cake, which will be served to guests rather than have everyone select their own slices. I will talk to the servers to make sure they only serve one slice per person. We are also avoiding ambient food items that would trigger foraging behavior: no candy favors, no help-yourself pre-dinner foods.

For the wedding itself, we made sure to choose a wedding location free of ambient food: a botanical garden. Not only is it free of food, it also happens to be the location where my fiancé and I had our first date so it is deeply meaningful for us. Luckily even our indoor inclement weather alternative is food-free. This is not a given: so many indoor locations have unexpected food, from places of worship to hotels. It's possible that such locations might be willing to accommodate a specific food request, but it would have to be looked into well in advance.

Since so many of my fiancé's family are coming from several states away, my parents wanted to host a small lake luncheon cruise as a "thank you" for coming all this way for the wedding. This is the only place where a buffet of any sort takes place, but unfortunately that was the only food option they gave. Luckily, we picked a buffet option with minimal choices and plenty of fresh fruit and vegetables, with a chocolate-dipped strawberry dessert and toast that is served once everyone is sitting down. We've been working with Michael closely trying to make sure that this part will go smoothly, and he more than anyone wants to keep this part as low-stress as he can.

After having looked into ways we could tailor our food choices to foster a healthy, happy wedding day, we moved on to looking at other ways to ensure the day is calm for Michael and my family. We have a clear schedule for the day which we will be carefully following. My family is very fortunate, because we have a very good In House Service Specialist and he is coming to the wedding to work with Michael and provide additional support. This means that Michael will be "free" of my parents, so to speak: he doesn't have to stay next to them, and if he wants to go dance he can do that without either of my parents having to stop their conversations and go with him. This is no surprise for Michael either, since he's actively been helping plan a smooth wedding. He wants a low-stress and happy time, and he has good intuition about his own needs when we talk together, brother-and-sister.

And, since I wanted my brother involved in more than just planning, I gave him an important role on the special day. I am honored to have him as my usher, and he will sit with me and my bridesmaids at the head table at the reception.

*In my next update, I will write about how the wedding went under my new last name: Crawford!*

## Social Responsiveness and Competence in Prader-Willi Syndrome: Direct Comparison to Autism Spectrum Disorder

Journal of Autism and Developmental Disorders, 2012 May 11.

Dimitropoulos A, Ho A, Feldman B., Department of Psychological Sciences, Case Western Reserve University, 11220 Bellflower Road, MTHM 109, Cleveland, OH, 44106-7123, USA, axd116@case.edu.

**Abstract**

Prader-Willi syndrome (PWS), a neurodevelopmental disorder primarily characterized by hyperphagia and food preoccupations, is caused by the absence of expression of the paternally active genes in the proximal arm of chromosome 15. Although maladaptive behavior and the cognitive profile in PWS have been well characterized, social functioning has only more recently been systematically examined. Findings to date indicate the social impairment exhibited may reflect specific difficulty interpreting and using social information effectively. In addition, evidence suggests that there is an increased risk of social deficits in people with the maternally-derived uniparental disomy (mUPD) subtype of PWS in comparison to those with 15q11-13 paternal deletion (DEL). Using the Social Responsiveness Scale (SRS) and the Social Competence Inventory, our goal was to compare social functioning in PWS to individuals with autism spectrum disorder (ASD). Participants with mUPD scored similarly to the ASD group across most SRS domains. All groups had difficulty with social competence, although the DEL group scored highest on prosocial behavior. Findings suggest further characterization of social behavior in PWS is necessary to aid in advancing the understanding of the contributions of genes in the 15q11-13 critical region to ASD susceptibility, particularly with respect to the overexpression of maternally expressed genes in this region, as well as aiding in awareness and development/implementation of interventions. PMID: 22576167 [PubMed - as supplied by publisher]

## PWSA (USA) 2nd International Conference on Hyperphagia

Pennington Biomedical Research Center
Louisiana State University - Baton Rouge, LA
October 17 - 20, 2012

Join the top international scientists in the fields of appetite control and obesity for an opportunity to hear the latest in research and strategy. Parents are encouraged to attend and learn more about this vital aspect of PWS and expand their knowledge for more effective advocacy.

From genetics to neurology to hormones to addiction to drug studies, all the key avenues for insight will be explored. Twenty-three top international scientists will present their ideas. Twenty of those scientists are "PWS conference rookies" and have never presented at a PWSA (USA) scientific conference. The new ideas will be flowing freely, so don't miss out on this unique opportunity!

Top Ten Reasons to Attend the 2nd International Conference on Hyperphagia

- Learn the latest progress in the fight to solve the mystery of hyperphagia from twenty-five world-renowned scientists.
- Tour the largest most sophisticated facility in the world dedicated to appetite, nutrition and obesity research and meet their world-renowned collection of scientists, the Pennington Biomedical Research Center.
- Add to your understanding of the new role stem cell research will play in developing treatments for different aspects of human disease, including the neurology of appetite control.
- Understand the real meaning of hyperphagia and its implications in the public health menace of obesity.
- Observe a debate about the Pros and Cons of bariatric surgery, behavioral therapy and pharmacotherapy in treating hyperphagia, particularly in Prader-Willi syndrome.
- Hear about the connection between the hypothalamus, the brain stem and the various neurological signaling chemicals.
- Answer the question is ‘Prader-Willi syndrome really the "Window of Opportunity" to help solve the hyperphagia and obesity problems?’
- Build your understanding of the many ways genetics, including epigenetics, the SIM1 gene and gene sequencing are at the forefront of medical research especially appetite control and obesity.
- Enhance your understanding of addiction as a possible central force in runaway appetite.
- Hear about the 2009 Best Idea Grants and meet the grantees and their progress.

For registration details see www.hyperphagia.org

## What *Are* Carbohydrates, Anyway?

Explanation excerpted from LiveStrong.com by PWSA (USA) Member Anne Taylor
http://www.livestrong.com/article/27398-list-complex-carbohydrates-foods/

Carbohydrates are a macronutrient that your body needs in high doses on a daily basis for proper functioning. When you eat carbohydrates, they get converted to glycogen and either used immediately for energy, providing a steady dose of blood sugar, or they are stored in the muscles and liver for energy at a later time. Simple carbs, by contrast, cause a spike in blood sugar that quickly dissipates. For sustained energy, eat foods rich in complex carbs.

### Whole Grains

Whole grains are high in fiber, have moderate protein levels, are low in fat and are also a good source of complex carbs. Specific examples include millet, oats, wheat germ, barley, wild rice, brown rice, buckwheat, oat bran, cornmeal and amaranth. Any product that is made from these grains is also complex as well. Whole grain bread, bagels, buns and rolls are examples of these. Also pasta, macaroni and breakfast cereals that are made from whole grains are complex carbohydrates.

### Fruits

Fruits are high in water content, fiber, vitamins and they have virtually no fat at all. Fruits packed with complex carbohydrates include apricots, oranges, plums, pears, grapefruits and prunes.

### Vegetables

Vegetables are high in water, low in fat, have multiple vitamins and minerals, and most varieties are complex carbs. Broccoli, cauliflower, spinach, turnip greens, eggplant, potatoes, yams, corn, carrots, onions, all types of lettuce, celery, cucumbers, cabbage, artichokes and asparagus are all examples of these.

### Legumes

Legumes are oftentimes called pulses. These are characterized by seeds that have an exterior pod surrounding them. Beans are a type of legume that is a complex carbohydrate. Specific examples include lentils, kidney beans, black beans, peas, garbanzo beans, soy beans and pinto beans.

### Miscellaneous

Dill pickles are made from cucumbers and they are complex carbs. Soy milk made from soy beans is a complex carb and dairy products like low-fat yogurt and skim milk are also complex carbs.

## Parent to Parent

*Our son is 3 years old and we'd like to get him a pet. What experiences and ideas can other parents share about how this has worked out for you? Which pet do you think is best for a child with PWS?*

GiGi (12) and her sisters Maya (10) and Carly (7) all wanted a dog. GiGi had been asking the longest. Busy schedules, virtually no yard…we had all the reasons for NOT getting a dog despite our love of dogs too. It wasn't until one day that GiGi was sobbing about how much she wanted a dog that I broke down. "OK! I promise we will get a dog before you get to 5th grade!" (the next school year). So, it was almost a year and a half ago that we adopted Dutch, our German Shepherd rescue. He was supposed to be about 2 years old but we swear he keeps getting bigger and bigger. Yes, he is a lot of work but it is a labor of love. He has a wonderful disposition and the entire family adores him as he does us. (Why a German Shepherd you may wonder? Both my husband and I had them growing up and loved their loyalty and intelligence. However, one should know that they do take a commitment to training and they are protective.)

GiGi does not interact with him the way I'd hoped. She doesn't fuss over him a lot but she loves him in her own way. When she has had a bad day or something goes wrong, she will say, "But I am still happy because I am so lucky to have Dutch!" *Submitted by Elizabeth Greskovics, mother of GiGi, age 12*

Getting our little Daisy was the best thing we could have done for our son. Before Cameron was even born we had a wonderful 100 pound Golden Retriever dog. As loveable and gentle as Max was, he was still a giant of a dog and even the swish of his tail would knock Cameron over, so Cameron never felt all that close to the dog. A few years after Max died we brought home Daisy, a 12 pound Maltese and Shih Tzu mix. From the moment we took her home, Cameron and Daisy have been the best of friends. Having Daisy has helped us teach Cameron empathy, "How do you think Daisy might feel if we leave her at home alone too long?" and taking the other's perspective, "Why do you think Daisy tore up that shoe while we were away?" Beginning at age 11, Cameron's job has been to make sure that Daisy always has food and clean water, to get up from whatever he's doing to let her outside when she scratches at the door to go outside, and to keep the lawn cleaned up. Best thing we ever did was to get Cameron a small dog to love and be loved by. *Submitted by Lisa Graziano, mother of Cameron, age 13*

Next issue's Parent to Parent question is *"What incentives do you give to your child or adult child to encourage them to exercise?"*

# Board Corner

PWCF Board of Directors TeleMeeting, March 27, 2012
by Paula Watney

Board Members Present: Julie Casey, Kim Morgan, Renee Tarica, June-Anne Gold M.D., Whitney Bras, Roger Goatcher, Julie Tauscher, Tom McRae, and Paula Watney.
Staff Present: Lisa Graziano, Executive Director
Board Members Absent: Chris Patay, Don Carlson

I. Executive Committee Report – For tax purposes, Lisa Graziano was reclassified as an "employee" not a "consultant." The Board will look for someone to take on payroll tasks and quarterly filing reports.

II. Public Awareness Report – Julie Casey is continuing to post information and articles about Prader-Willi syndrome on PWCF's Facebook page. She also keeps members updated on *Walk* dates, support group meetings, the golf tournament and other PWCF-sponsored events. Julie has our Twitter account up and running. The *Putt for Prader-Willi* golf event, co-ordinated by Sam and Kristin Cropper, will be held on June 22 at the Windsor Golf Club located in Windsor, CA (Sonoma County). Registration starts at 11:00 am, followed by lunch at 12:00 p.m., the Shotgun start at 1:00 pm, and dinner at 6:00 pm. Golfers and non golfers are welcome. Donations to support the event which will benefit PWCF are most welcome and can be made on the Registration Page at http://golfdigestplanner.com/20310-PuttforPraderWilli or call the PWCF office make your donation by credit card or check.

Julie Casey will represent PWCF at a booth at the Levitt Pavilion in Pasadena for their Free Summer Concert Series on June 27. We are hoping to sponsor some PWS Family Day events with the Galaxy (L.A. soccer), Warriors (Oakland basketball), and Oakland A's (baseball).

III. Program Committee Report – PWCF's PWS Camp at Easter Seals Camp Harmon has 40 campers registered to date. The dates for camp are June 21-26, 2012. Cost to PWCF members $500.00 (PWCF will pay the additional $226 registration fee to Easter Seals). There is still room for more campers.

The 2012 General Education Meeting will be held on November 3 at the San Jose Hilton Hotel.

Tom McRae is working on improving our website and is looking for help editing and writing content.

IV. Residential Services Committee – Our new residential staff training DVD will be provided gratis to all group homes and supported living agencies that provide services to persons with PWS. Roger Goatcher created a Note Taking Guide and Home Study Exam to accompany the DVD as training tools. Austin deLone, President of the Richard deLone Special Housing Project, donated $500 to PWCF to help cover the costs of postage and mailing.

V. Long Term Strategic Planning – HOPE – The Board addressed our long term goal to improve residential life and day programs for persons with PWS. We would like to create a series of workshops with directors of day programs to be able to share information about what strategies work for them. Julie Tauscher of PRIDE Industries has agreed to lead this task. We are also working to identify potential crisis centers to serve the PWS population in California.

VI. Treasure's Report – The draft operating budget shows that PWCF needs $30,000 to balance the operating budget. PWCF operates on a $220,000 budget that covers the cost of our educational conferences, awareness programs, educational programs, training programs, PWS Camp, the purchase of educational and awareness materials, newsletter production, and much more. Lisa Graziano and PWCF's grant writer Maureen Spindt are working on grant proposals but we need donations to continue the very important work that benefits our PWS population and their special caretakers.

VII. Membership Report – Lisa reported that there are nine new pending members processed since January's Board meeting. She also reported that her son, Cameron Graziano, will present on a teenager's perspective having PWS to June-Anne Gold's M.D. genetics students at Loma Linda University Medical Center.

The next meeting of the Board of Directors will be held on June 9.

*Journey.*

*The bend in the road is not the end of the road,*
*unless you refuse to take the turn.*

# Neuropsych Testing and Mental Retardation

by Lisa Peters, Massachusetts

Last week, I traveled to Children's Hospital alone.

The results of Nicholas's Neuropsych testing were complete. Dr. Boyer requested to speak with me alone so she could review her findings with me in private.

I head off to the hospital, minus my faithful companion, Nicholas. The car ride is unusually quiet. There is no singing coming from the backseat as I fight my way through Boston traffic. I take a deep breath and remind myself that the results of this testing are not important, but still I am anxious.

I park in the hospital garage. The silence now is almost deafening as I miss Nicholas's laughter when he sees the coveted garage. There is no little voice to announce, "Mummy, we made it! We're in the garage!"

I walk alone through the hospital until finally I reach Dr Boyer's office.

As I check in at the front desk, I am confused. Do I give the attendant my name or Nicholas's? I decide to give her both. The young woman smiles, but I am still anxious and wonder, inappropriately of course, if she knows something that I do not. I am dreading this meeting.

I sit in the waiting room and see the tiny, "Dora the Explorer" table and chair set where Nicholas loves to play. I feel alone and vulnerable. I miss Nicholas's calm, happy spirit, his loving and healing energy. I miss his angelic face. I hold back my tears.

"Mrs. Peters?" I hear, as Dr Boyer approaches me to shake my hand.

*This is it*. I think to myself and take a deep breath.......*it doesn't matter, it doesn't matter*....I repeat inside my head trying to gather my strength to face the awful words I know I am going to hear.

Dr Boyer seems nervous. On her face, her most professional demeanor and suddenly I realize that she too is struggling to find her inner strength.

She sits at her desk and places Nick's file in front of her. She follows her professional script and begins our meeting by describing Nicholas's strengths. But my thoughts are distracted, I hear only single words, "***Pleasant***...talk, talk, talk.....***loving***.......talk, talk, talk......***hard working*****....."** I am struggling to be patient, waiting to hear what I came 30 miles to acknowledge.

And then finally it comes....

"We performed many verbal and abstract tests and they display results that are similar to your parental questionnaire responses."

In other words, she knows that I already know what she is going to say. "Your son is significantly delayed. I am diagnosing him with mental retardation."

Mental retardation.

It is a terrible word.

Immediately, disturbing images flood my mind, thoughts of straight jackets, barred windows and dark institutions. Inside my mind, I hear the screams of deranged individuals sentenced to a life of imprisonment. A not so distant reality for many diagnosed with this condition.

It is as if a demon has suddenly materialized inside my brain. He is laughing and sneering. He is running through the halls of my mind, smashing the happy pictures that hang there. And on the floor of my brain, he stomps on the shards of glass and shattered photos of Nicholas smiling and singing. He laughs as he creates a hellish bonfire burning the tiny torn pieces of my dreams for my son. He extinguishes the last fragile shreds of my hope.

Mental retardation.

It is a word no parent is ever ready to hear.

Parents of children with special needs are prohibited from living in denial.

Any positive outlook you may possess for your child's bright future, is quickly tempered by stark intellectual reality. You are surrounded by professionals who remind you often of your child's handicaps, his issues, his disability. Teachers, therapists, physicians, and psychologists are strategically placed throughout your life to remind you that your child has been diagnosed with a mental illness. They are armed with test results and progress reports. They are persistent and eager to share their unwelcome findings with you. You may disagree with their methods or test results, but it is irrelevant, all that matters is that you listen to their emotionless results.

Continued on page 18 ...

# We Get Mail

Dear PWCF: I am the mother of an 18 year old young man with PWS. Now that I am in regular contact with your association, I have asked myself why it took me so long to come to you for aide and support. The conclusion I came to was this: All my energy throughout my son's life has gone for his care. I did not have the extra energy to even make an extra call to talk about him. I realize now that I was in the role of a Hero and very often felt isolated and alone in my struggles in caring and management of him. I now realize that your association is helping me carry my load and making it lighter. I have sincere gratitude for all you have done for me and just listening to me in my pain. I wish I had availed myself to you earlier. I am thrilled to have you now and look forward to lifelong communication and support. *Sincerely, Petra Martinez-Ali, mother of Aiden, age 18 years*

Dear PWCF: I talked to you a few years ago when my son was born with PWS. I have been a member to keep up with your organization and love what you guys do. I am wanting to organize a Walk in my town and love your mailings. Is there any way I could get the brochure or anything for that fact that could help us organize one. I have never done one so have no clue where to start. We also will be ordering some of your items as I love them. Any help you could offer would be great. Thanks so much for all you do!!! *Crystal Redner, mother of Trevin, age 4, and 4th Grade Teacher at La Junta Intermediate School in Colorado*

Dear PWCF: Thank you so much for attending our Information Fair & Festival last Sunday! We could not have done it without your support! Thank you for making our Fair successful! We welcome and value your comments/suggestions so we can make our Fair better for the next year. Thank you for your time and help! Have a wonderful day! *Cindy Cheng, M. A., Family Support Specialist, Parents' Place Family Resource Center*

Dear PWCF: We were so happy to attend this year's Prader Willi *Walk*. Melanie Zepeda is our goddaughter and we were so happy to support her, her parents, and the organization. We can't wait to do it again next year. *Diana Brown*

Dear PWCF: On behalf of the Arc of San Diego's Community Living Services Department, please accept our appreciation for your generous grant of $1,500 to purchase exercise equipment and gardening tools to benefit our residents at Corte Maria group home. Your contribution will help us to ensure that quality services and support are provided to our residents with Prader-Wili Syndrome… Once again, thank you for your contribution and supporting The Arc of San Diego's mission to support and empower persons with disabilities to achieve their life goals. *Our sincerest thanks, Joseph Tontodonato, Director of Community Living Services; Kristine Marvel, Residential Services Program Manager; Marilou Malvar, Residential Services Nurse Administrator*

Dear PWCF: What a great job you and your staff have done, again and again....! Thank you for all your hard work and dedication to PWS. I will mail in my membership fees and donation for the *Walk*. *Sincerely, Helen Lim, mother of Amie, age 26 years*

Dear PWCF: My name is Laren and my son Ahlyjah is 4yrs. He was born with PWS and CF. We went to the PWS *Walk* in San Francisco. It was our first time. We had a great time!!! We had to leave a little early [because] our younger son wasn't feeling well. Can't wait for the next one!!! *Laren Latu, mother of Ahlyjah, age 4 years*

**In response to our question, "*What do you think of the new format of the* PWCF News*?*:**

Love the new look of the newsletter and the logo and appreciate all of the hard work that went into making it possible! *Linda M. Ryan, Family Member*

I love the digital format - looks great. When we get the new and improved [web]site [up and running], it will be great to create some hyperlinks for more info to drive some traffic there. Good job. *Cheers, Drew Marich, Family Member*

The "spiffy new look" is great! *Mary Williams, Extended Family Member*

Nice! *Warm regards, Janalee Heinemann, MSW, Director of Research & Medical Affairs, PWSA (USA), Vice President, IPWSO*

## Volunteer Corner

PWCF extends our sincere appreciation to:

**Ivette Ramos** for distributing PWS glow in the dark wristbands and PWS brochures at her garage sale in March!

**Jessica Acosta** for "womaning" the PWS Booth at the San Gabriel–Pomona Parents' Place Information Fair on April 29.

**Angela Lucero** and her ADP work colleagues **Maria Cabassa-Gonzalez**, **Debra Fernandez-Chavez**, and **Marci White** who helped prepare the arts and crafts boxes and raffle prizes for the Southern California *Walking for Prader-Willi Syndrome* awareness event.

**Angela Lucero** also helped secure $90 for PWCF through her company's Book Fair.


EGISTRATION
WALKING
r Prader-Willi Syndrome
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TEAM RJ

**PWCF thanks the following persons and organizations who worked so hard to produce these amazing statewide events:**

**Central California**
Paula Watney – Event organizer
Debbie & David Martinez – Volunteers
Roxanna Hein – Volunteer
Jamie Damm, Pfizer Endocrine Care

**Northern California**
Mike Moore – Event organizer
Patti & Tom McRae – Event organizers
Maddy Fluhr & Eddie Resendes – Event organizers
Austin DeLone & The PWS Noisemakers Band – Event organizers
Mary & Paul Hill – Event organizers
Sara Formslag – Event organizer
Renee Tarica – Event organizer
Julia & Jeremy Rutledge – Event organizers
Diana Vega – Volunteer
Roger Goatcher – Volunteer
Julie Tauscher – Volunteer
Charlotte Young – Volunteer
Fran Moss – Volunteer
Todd Landwehr, Pfizer Endocrine Care

**Southern California**
Julie Casey – Event organizer
Renee Tarica – Event organizer
Fran Moss – Volunteer
Henry Tarica – Volunteer
Carolyn Meyer – Volunteer
Jeanine & Mark Milner – Volunteers
Liane & David Noddle – Volunteers
TJ & Cameron Graziano – Volunteers
Renee Compere – Volunteer
Joe Raleigh – Impromptu Volunteer!
Jessica & Christopher Patay – Volunteer
Kimberlee Morgan – Volunteer
Paula Watney – Volunteer
Kimberly Storr – Volunteer
Linda Ryan – Volunteer
Hilda Hernandez – Volunteer
Regina Livingston – Volunteer
Susan Hedstrom – Volunteer
Shandra Beer – Volunteer
Whitney Bras – Volunteer
Mercedes Rivera – Volunteer
Susan & Russell Quan & Umina Produce
Melanie Cross, RN, PHN, MSN, Mt. St. Mary's College Director of Nursing & her magnificent crew of nursing students
Ronnie Salem and her extraordinary crew
Tarix Printing
Balloon Factory
Tarzana Subway
Susan Russell Quan & Umina Produce
Jimmy Rudon – DJ Extraordinaire
Kathleen O'Connell, Pfizer Endocrine Care

# *12th Annual Walking for Prader-Willi Syndrome* Events Commemorate PWS Awareness Month

May is an exciting month. Each year all over the country, individuals and organizations celebrate National Prader-Willi Syndrome Awareness Month. Prader-Willi California Foundation hosted our 12th annual statewide walkathons to raise the public's awareness of the syndrome and raise funds to support the Foundation's programs and services.

This year the Southern California *Walk* was held in Griffith Park, Los Angeles (thank you, **Julie Casey**, for securing this site!); Central Californians walked in Fresno's Woodley Park (thank you, **Paula Watney**, for security this site); and Northerners walked at Crissy Field under San Francisco's Golden Gate Bridge (thank you, **Mike Moore**, for securing this site). Over 500 Californians attended a *Walk* event this year!

PWCF's *Walks* offer families the opportunity to have fun and play together in a family-oriented setting. Each *Walk* offers arts and crafts activities, games, music, and exercise-oriented relay games for the kids. Southern Californians get an extra special treat with a catered Subway lunch, complete with a delicious side of fruit donated by Umina Produce thanks to **Susan and Russell Quan**. Northerners have a very special live band, **The PWS Noisemakers**, led by PWCF member **Austin De Lone** (musician extraordinaire), with **Steve Grogan** (guitar), **Buffalo Bill Barlow** (bass), **Dick McDonough** (drums), and **Lisa Kindred** (vocals). **Duane Shewega and Delene Waltrip**, good friends of **Tom and Pattie McRae,** posted a fantastic video of Northern California's event. Check it out on YouTube at http://www.youtube.com/watch?v=DY-rTO49O1Y&feature=youtube Thank you, Duane and Delene!

New *Walk* sites offered new challenges (particularly directional signs and parking!) which our Planning Committees will address next year. If you attended a *Walk* event and haven't yet provided your review or suggestions for improvement for future *Walks*, please help us by completing a brief online survey at:

Southern California https://www.surveymonkey.com/s/SoCAWalk2012

Central California https://www.surveymonkey.com/s/CentralCAWalk2012

Northern California https://www.surveymonkey.com/s/NoCAWalk2012

So far we've raised a little over $46,000 but because donations in honor or in memory of your loved one, family friend, or patient to support *Walking for Prader-Willi Syndrome* made can be made all year long, we hope to reach our goal of $50,000. If you haven't already, please make your tax-deductible donation by sending your check to PWCF, make your donation on line at www.PWCF.org/WalkingForPWS.htm or call us with your credit card information.

Be a part of the next generation of events by contacting PWCF to get involved!

## ***The Southern California Walk From My Eyes,*** by Katherine Girdaukas

The first thing I saw was the balloon archway: cheerful green and white balloons that marked my way as I drove through Griffith Park to get to my very first *Walking for Prader-Willi Syndrome* event. When I pulled up to park, a full fifteen foot tall balloon arch welcomed the *Walk* participants. There were activities set up for all ages, from a giant inflatable castle jumper to a fun raffle. PWCF's executive director Lisa Graziano took the microphone, welcomed everyone to the event, and signaled the *Walk* to begin.

Family after family strode beneath the balloon arch, following a path flanked by signs that list various facts about the syndrome to educate not only our families but the general public about the Prader-Willi syndrome, and Footprint signs that honor someone with PWS. Kids walked alongside their parents and caregivers with a sense of purpose and drive. The *Walk* participants made their way around the course and finished back at the arch with smiles on their faces. It was incredible seeing everyone walking together and working together, raising funds to support such an important cause.

*Continued on page 18…..*

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As a parent of a child with special needs you cannot run and hide, you cannot bury your head in the sand, you must listen patiently as yet another professional tries to pigeon hole your child. You must face the cold reality of your child's diagnosis....again and again and again.

These professionals will remind you that academics is no longer the focus of learning for your child. They tell you life skills training is the only hope your child has for a happy future. Any chance of intellectual greatness is gone. Recognition or acclaim in society is only a passing shadow, a parent's delusional dream. Your child is somehow less. He is less smart, less able......less of a human being.

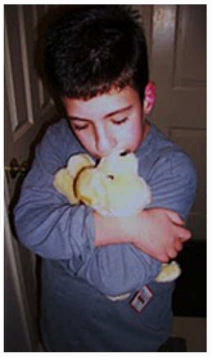
Dr Boyer is speaking, but I do not hear her. Instead, I am distracted by a new vision in my brain, a vision of Nicholas. In my mind's eye he is holding his teddy bear tight to his chest. He is swaying back and forth, comforted by the love he feels for his beloved toy. This vision of Nicholas renews my lost courage and hope. I am awakened. I can finally hear Dr Boyer.

I thank her for her time. I tell her that I am not in denial and understand what steps I must take to ensure my son has a viable future. I tell her that despite this testing, I will insist that we continue to teach my son all that he can learn and that this diagnosis does not give us a license to become complacent about our approach. I tell her that I understand my need to know who will care for my son when I am gone. It is a silent fear that haunts me every day.

I tell her that I appreciate her report but believe it is important to remember that I have hope for my son and his happy future. That to me, intelligence has never guaranteed happiness. Instead it is a loving heart that brings contentment. It is the ability to think about and truly love others that fulfills a person's soul and makes the world a better place for everyone. Perhaps in time we will find a test to measure *this* important quality for.... "to love" is truly "to live".

I left Dr Boyer's office feeling somewhat numb and although I felt sad, something kept me calm, something stopped me from crying.

It was time to pick up Nicholas from school. I drove to his school and waited in my usual spot on the benches inside. A few minutes later, Nicholas came around the hallway corner, as he saw me he ran into my arms.



"Mummy," he says, "I had a great day!"

I hug him tight, thankful that I am once again in his calming presence. "Are you proud of me?" he asks.

I hold him tighter. "Yes, Nicholas, Mummy will always be proud of you."

And finally, in my son's loving presence, I can no longer hold back my tears.

*To read more about our family experiences, please come visit us at:* www.onalifelessperfect.blogspot.com

*Walk continued from page 17...*

The funds being raised through the *Walk* events have a big impact. I've gotten to see first-hand how this fundraiser helps families and adults with the syndrome. Each dollar helps bring PWS-specific training into your child's school and into group homes, helps fund the production and distribution of informational materials for families and doctors, and helps us get critical clinical consulting to doctors at no cost to the families.

**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
Malea & Rich Bonk
Tracy & Roger Goatcher
Mary & Paul Hill
Michelle & Kevin Donaldson
Cassie & Michael Arellano
Patti & Tom McRae
Maddy Fluhr & Eddie Resendes
Delene Waltrip & Duane Shewaga
Francis & Dave Sim
Diana Vega
Tonya & John Wilson

**Southern California**
Angela & Robert Lucero
Shandra & Larry Beer
Whitney Bras
Renee & Henry Tarica
Maria & Ken Knox
Lisa & TJ Graziano
Julie & Dan Casey
Kimberlee Morgan
Linda & Mark Ryan
Julie & Deron Van Boxtel
Michelle Christian
Mary Culver & Rob Fuller
Fran Moss
Allison Mahan
Mercedes Rivera
Carmen & Juan Zepeda

Back at the main site, a variety of booths were home to information, face painting, arts & crafts, and other games. The information booth hosted books, brochures, DVDs, and handouts for parents, schools, and residential settings. I talked for a long time with Paula Watney who was manning that booth with a number of other volunteers. She passed along useful advice and handouts to any and all who stopped by. Meanwhile, kids enjoyed a relay race and a game with the DJ where everyone danced until the DJ paused the music, when they'd have to freeze. By the end of the song, everyone was grinning.

The day finished up with a big raffle that was enjoyed by kids of all ages. The whole event was like the best kind of family reunion because we're all in this together, in one big supportive PWCF family. Just as our tag line reads, together, we *will* make miracles for our children.

See you at the next *Walk*!

## Especially Generous Donations Received to Support *Walking for Prader-Willi Syndrome*

Verica Balarin
Jean Bender
Barry Vitro Blair
Mary, Holger & Kean Bracht
Samuel Breneiser
Marc Brown
Julie & Dan Casey
Richard & Pat Casey
Emma Cordova
RDAD Enterprises
Car West Auto Body
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David Fields
Nancy & Steve Fox
Libby & Rob Fuller
Dolores Horn & Mel Goldberg
The Gonzales Family
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Michele & Edward McDonald
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Patti & Tom McRae
Nisha & Minesh Mehta
Allison & Byron Moldo
Judy & Bill Morgan & the Morgan Family
Pat Noland
Pfizer Endocrine Care and Representatives
Jamie Damm, Todd Landwehr, and Kathleen O'Connell
Terri Grass & Robert Priest
Ivette & Luis Ramos
Suzanne & Mark Reitz
Claudia Rosenthal
Daniela Rubin PhD, CSUF
Jimmy Rudon
Julia & Jeremy Rutledge
Beverly Schwartz
Jacqueline Smalley
Susan Tashima
Hannah, Lauren, & Brad of the Umansky Family Trust
Ginna Vega
Billy Vitro
Paula & Mike Watney
Sharon & Richard Willis

## *MEMBERSHIP ACTIVITY*

### April-Jume 2012

*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**
Laura & Michael Tomelloso

**New Family Friend Members**
Yisan Tai

**New Auxiliary Members**
Jeremy Frend, M.D.
Erika Manriquez
Sharon & Richard Willis

**Renewed Extended Family Members**
Terri Canales
Carina Chaij
Sally & Chet Collom
Mary Culver
Wendy & Bob Graziano
Barbara & Stan Haberman
Tod Holdorf & Cassie Wilcox
Carolyn & Gordon Jones
Betty McBroome
Linda McGee
Carolyn Meyer
Kathleen Minor
Tracy Patay
Judy Schlafer
Frances & Dave Sim
Joyce & Norman Smith
Linda Smith
Peggy Jean Smith
Margaret & Bill Spinelli
Mary & Pat Williams

**Renewed Family Friend Members**
Andrew Cantos
Irene & Kyle Kaiser
Nancy & Jim Kaiser
Patrick Maxon
Ronnie Raffaniello
Tyna & Ray Triggs

**Renewed Auxiliary Members**
Kathy Lewis

**Renewed Professional Members**
Sarah Bishop, North Bay Regional Center
Gayle Anne Cronic of Puckett Residential Services
Rawate's Home

**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**

**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 2012

### *SHINING STAR DONATIONS*

**Alpha Centauri ($250 - $499)**
Mr. & Mrs. Bob Morgan in honor of Samantha Morgan

**Arcturus ($100 - $249)**
Karen & Russell Benedikt in honor of Barbara Olson
Rita & Jim Koerber via Chevron Humankind Matching Gift Program

**Vega ($1 - $99)**
Arstein-Kerslake Family

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**Magnanimous General Donations**
Anonymous donation in honor of Nolan Bonk
Susan & Mark Lewis
Nisha & Minesh Mehta in honor of Siena Mehta
Storr Family Foundation
Monique and Peter Thorrington in honor of the Patay Family

**Donations In Honor of Samantha Morgan**
Suzanne Privette

**Donations in Memory of William Graziano**
Patricia Arnett
Mirjana "Micky" Files
Dana & Stephen Gray
Nancy & Mitch Mohr
David Soloway in honor of Robert Graziano
Mieke Sorrentino
Kathleen & Chester Sprinkles
Renee & Henry Tarica

**Donations in Memory of Christine Applegate & in Honor of Nolan Bonk**
Diana Merlo
Friends from CalSAE in honor of Christine Applegate
Barbara Reid

**Donations Received to Support the *Putt for PW Charity Golf Tournament***
Diane Bourassa
Samuel Cropper
TJ & Lisa Graziano
Dorothy Kime

**General Donations**
Shandra & Larry Beer
Mary & Holger Bracht
Judy, Bill & Jason Castle in memory of Adelaide Castle
Randeep Binning
Catherine Capper
Carina Chaij
John Cheng & Liang Yu Tai
Angela & Wing & Sim Cheung
Mary Culver
Richard de Lone Special Housing Project to support the distribution of PWCF's new *PWS Residential Staff Training* DVD to group home and supported living providers throughout California
Michelle & Kevin Donaldson
Foothill Civitan Club in celebration of Tony & Sylvia Pusateri's 50th wedding anniversary, who are grandparents to a child with PWS
Keith E. Fromelt via Johnson & Johnson Campaign
Sally & Mark George
Barbara & David Gow
Elias G. Deeb via United Way of Rhode Island
Susan & Gary Grace
Barbara & Larry Gunter
Lisa & T.J. Graziano
Jean & Lowell Hobrock
Tod Holdorf & Cassie Wilcox
Lucy Jao & Bie Chuan Ong
Rosanna & Mark Jimenez
Karen & Timothy Jobe
Irene & Kyle Kaiser in honor of Cameron Graziano
Margot & Gerry Lawrence
Julia Lindstrom in honor of Great Uncle Frank Lindstrom
Gitta Meyer-Green in honor of Cameron Graziano
Mary & Paul Hill
Nathan Miller
Kathleen Minor
Fran Moss
Muriel & John Parrish in memory of Susan Parrish
Rawates Inc. Group Home
Rich Rust & Mary Jane Morris
Masani & Hanif Nassor-Covington
Linda & Mark Ryan
Patricia Salwak in honor of Jamilet Knox
Kevin Scott
Janice & John Shimmin
Joyce & Norman Smith
Tyna & Ray Triggs
United Way California Capital Region
Paula & Mike Watney
Gretchen White
Amy & Paul Wissmann
Jay Woodruff of Books Are Fun in honor of RJ Lucero

**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).
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