PWCF NEWS

Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

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

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Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

2015
Annual State Conference
Nov. 14, 2015

PROGRESS in MOTION

See page 11 for details!

PWCF Held 5th Annual PWS Camp

June 18-23, 2015

Campfire songs. Tie-dye. Baby piglets and goats. Sports, games, and hiking. A fairytale scavenger hunt. Daily swimming. A rockin' Luau dance. And if all *that* weren't enough, how about a giant swing that takes you 50 feet up in the air, then releases you in an exciting (and safe!) free-fall. This and more is what our fifty-nine campers experienced this year at PWCF's PWS Camp at Easter Seals Camp Harmon.

This was PWCF's fifth year of PWS Camp and boy, was it fun! Trained by PWCF's **Linda Ryan** and **Lisa Graziano**, Easter Seals' awesome Camp Counselors took great care of our campers who ranged in age from 10-55. Remaining at Camp throughout the week to provide on-site behavior consultation were Lisa and **Emily Dame**, PWCF's Education and Training Coordinator. This year, PWS Camp had extra special help from our very own **Kevin Amarasekera**, a sibling who helps with many PWCF events and was hired by Camp Harmon to work all of their camp sessions, including our PWS Camp!

What did our campers have say about Camp?

*"Enjoyed all activities, **I made friends** to keep in touch with"*
*"I was happy and **learned new things** about farm animals"*
"I liked the counselors and staff and loved the kittens"
*"**I felt good**"*
"I had fun and made new friends"
*"**I loved all the activities**. I was happy on the way there and exhausted on the way home"*
*"I made new friends. **I felt no stress about food** since it was structured for PWS"*
*"**Camp made me feel great**. I made two new friends I'm still in touch with. I liked my counselors*
"Camp is a great stress relief. I love seeing friends and making new ones"
*"**I'm glad to make friends who also have PWS**"*

And what did their families think?

"This is the only time of year we get to have time away from the kids and we enjoyed the respite"
"There have been fewer outbursts since camp and he is still talking about it"
"It's a great benefit to our family. We felt she was safe"
"We felt our child was safe. We enjoyed our only couple-time all year"
"It was nice to meet other parents. We felt he was safe and we were glad that food was managed appropriately"

PWS Camp continued on page 12

PRADER-WILLI
CALIFORNIA FOUNDATION
A Full Life Without Limits

Lisa Graziano, M.A. - Executive Director
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Our Mission:

Individuals with Prader-Willi syndrome should have the opportunity to pursue their hopes and dreams to the full extent of their talents and capabilities. The success of people with Prader-Willi syndrome depends greatly upon the knowledge and support of the community around them. The Prader-Willi California Foundation provides individuals with PWS, and their families and professionals with a state network of information, advocacy and support services.

PWS SUPPORT GROUPS AND CONTACTS

Northern California

SF Bay Area (young child)	Patti McRae	408-920-8003	pmcrae@sbcglobal.net
SF Bay Area (teen to adult)	Michelle Donaldson	707-843-4221	michelle.sf@comcast.net
Sacramento	Diane Kavrell	530-753-5928	diane.kavrell@gmail.com

Central California

(Teens & Adults with PWS)	Paula Watney	559-299-8171	paulawatney@pwcf.org

Southern California

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

Inland Region Area

San Bernardino County	Ester Del Real	909-213-5992	esterdelreal@ymail.com

Spanish Speaking

Mercedes Hernandez (Adults with PWS)	619-822-5742	mercedes.hernandez711@yahoo.com
Kilma Bournigal (Infants/Children with PWS)	760-679-2300	kilmab@hotmail.com
Veronica Garcia (Infants and Children with PWS)	760-357-8189	vbaez92@yahoo.com

Online Support

PWCF Online Information Sharing Group for Members. This online information sharing group is for PWCF members. To join the group, go to www.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 (USA) 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 Organization, **IPWSO** offers information about PWS in other languages. Go to www.ipwso.org

PWS SHARE & SUPPORT GROUPS MEETING CALENDAR 2015

Southern California

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

Sunday, October 25
Time: 2:00 p.m. - 4:30 p.m.

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

Northern California

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

September 19
Time: Check-in 10:15 a.m.
Meeting 10:30 a.m. - 1:30 p.m.

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

ASK THE EXPERTS

1: "What are your thoughts regarding persons with PWS playing video games such as Candy Crush and Soda Crush and other similar food-related games?"

2: "What are your thoughts about the use of flavored chap sticks and lip balms, such as cookie dough or other desserts? Do either of these stimulate increased anxiety in the 'typical' person with PWS?"

The correct answer to all of your questions is: *it depends on each individual and how these items are used in the person's daily living context*. Videogames are highly addictive for everyone and should be scheduled and time-limited across the day, regardless of the content. The board game Candyland has been around forever. Has this caused any problems?

Flavored chap sticks are likely to be eaten or over-used, just the way flavored waters can be intoxicating. But chewing gum also has outrageous flavors and can be used in a very therapeutic way for sensory stimulation, provided the amount is controlled, supervised and limited in use across the day. Whether anxiety is increased depends on the individual. Some may "handle it" while others cannot. Another example is recipes. Some can collect, bind and donate them, while others are so preoccupied that they cannot function if the possibility of getting them exists. In many cases the **No Doubt, No Hope, No Disappointment** rubric must be applied to these situations. *Janice Forster, M.D., Neuropsychiatrist and PWS Specialist*

It's funny you should ask this, as we have had several conversations about these very topics. We see a lot of people with PWS living at home and doing well. Though we haven't figured it out, we have the following thoughts. Every person with PWS is different and you have to look at these in light of each person's needs and appetite. One size doesn't fit all.

Some kids and adults with PWS like playing Candy Crush, Cooking Mama for the Wii, and other food programs on iPad. They don't seem to increase anxiety about food more than anxiety about not finishing the activity. They have a hard time stopping these games. Each level leads to the next. Putting time limits or giving them time between activities seems to help contain and a few folks have said that playing these repetitive games keeps their mind off being hungry.

Same thing with the lip balms, some folks have said that [applying lip balm] takes the place of food. If that is the case, I think it's okay in moderation. But if it seems to make them upset, they should not be used. Some parents have had success with them and only a couple have had a problem. Curious what others think.
Elizabeth Roof, M.A., Senior Research Specialist and PWS Specialist

Do you have a question for the experts?
Email it to info@PWCF.org for a chance to have it answered.

Want to meet more experts like this in person?

See page 11 for details on PWCF's Annual State Conference.

Get the newest, cutting-edge knowledge about
supporting the individual with PWS,
meet with other parents, caretakers, and professionals,
and find out what PWCF is doing for YOU
in the state of California.

GADGET TIP: STRIDER BALANCE BIKES

STRIDER balance bikes are industry-leading training bikes that help toddlers, children, and adults of all abilities learn to ride on two wheels. STRIDER balance bikes focus on the fundamentals of balancing, leaning, and steering without the distractions and complications of pedals or training wheels. The STRIDER's simple, no-pedal design builds confidence and eliminates fear by allowing kids to have their feet on the ground and progress at their own pace. This unique design teaches children balance on two wheels right from the start, avoiding developmental delays typical with tricycles and training-wheel bikes.

"I have 8 Striders for my Special Education classroom. Students with a wide variety of disabilities use them, including Down Syndrome, blind, cerebral palsy, intellectual disabilities, and others. They have helped with gross motor, spatial awareness, social skills, self-advocacy, and a whole lot more. We absolutely LOVE our Strider bikes!"

See page 18 for how to transition from a Strider to a pedal bike.

FOOD TIP: STEVIA WATER FLAVOR DROPS

Submitted by Julia Lindstrom (who has PWS)

Does your child have PWS? If so you should get the Stevia flavored drops. You get them at a health food store. I use it in my water.

There are a lot of different kinds: SweetLeaf Water Drops or Stur Water Enhancers. Lots of flavors and very delicious!

OUR KIDS GOT TALENT

Submitted by Lindy Marich

Brooke Marich, age 15, created a beautiful quilt!

Brooke has been learning to sew with her Grandma Sharri over the past few years and has even helped make her very own pajamas to wear! She works with her grandma to sew quilts for needy mothers with new babies and recently made one for her teacher's brand new baby boy.

Executive Director's Column

We are NOT Helecopter Parents… By Choice

by Lisa Graziano, M. A.

hel·i·cop·ter par·ent
noun informal
a parent who takes an overprotective or excessive interest in the life of their child or children.

To the outside, uninformed world, parents of persons who have Prader-Willi syndrome look like Helicopter Parents. This column is *not* for parents. This column is for everyone else.

Dear Outside, Not Yet Informed Enough World:

Please believe us when we tell you we are **not** Helicopter Parents by choice but by sheer necessity.

In our world, if we are not managing and supervising and directing and educating and organizing our child or adult child's life, he no longer has one – or any quality of one.

Please believe us when we tell you that we don't *want* our child to become "dependent" upon his class aide or his house staff or his work coach. *Even more than you*, we *want* our child to be independent, self-regulating, self-sufficient, self-reliant, flexible, productive citizens. Our reality – at least for now – is that supervision or shadowing or aide support or *whatever* you call it is *necessary for our child's survival*.

Please believe us when we tell you we don't *want* to direct who our child plays with, what activities they play, and how they play. We don't *want* to scrutinize our adult child's computer and phone and Facebook account and every nook and cranny of their bedroom. We don't *want* to have to have one ear at the door listening to every interaction, on the ready to intervene or intercede or re-direct. We *want* our child or adult child to have his alone time, his solitude, his privacy.

Please believe us when we tell you we don't *want* to supervise or coordinate or oversee or do our adult child's activities of daily life for him. We *want* him to be able to shower, bathe and groom himself satisfactorily without prompts or reminders or arguments. We *want* him to be able to select the proper attire according to the weather or event he plans to attend. We *want* our adult child to manage his own finances, to shop for and prepare his own meals. Shoot, we'd *love* for him to prepare a meal for us! Please believe us when we tell you our adult child needs 24/7 *awake* residential staff supervision and that securely locking access to food reduces his anxiety. We *want* him to be independent, ride his bike or drive his own car or take public transportation or even walk to where he needs or wants to go all by himself.

> Even more than you, we *want* our child to be independent, self-regulating,
>
> self-suficcient, self-reliant, flexible, productive citizens.

Please believe us when we tell you we don't want to volunteer in our child's classroom *so* often and attend *every* class event, and we don't *want* to be the only adult who stays at the kids' party. We don't *want* to chaperone every work party or school dance (especially the ones with painfully, deafeningly loud music) and station ourselves near the food tables until our bums become as flat and cold as the folding metal chair we're sitting on.

Please believe us when we tell you that the behavior plan you developed may be perfect for someone else but is *not* appropriate for our child, or that our child still needs help wiping his bottom *not* because we haven't been teaching him but because his motor planning skills aren't proficient enough yet or his back brace interferes with his reach.

Please believe us when we tell you that arriving late to pick up our child will *not* teach him to be more flexible and that we are *not* coddling our child when we do not punish him for a temper tantrum. We don't *want* to have eyeballs on at all times and scrutinize and override and argue about our child's food consumption at family parties and reunions and celebrations and holiday gatherings and barbeques. We do want to enjoy *ourselves* at parties and gatherings and barbeques.

Please believe that we *want* our child to make friends on his own, watch and learn from his contemporaries, work out disagreements on his own. We *want* our child to have a girlfriend or a boyfriend, to one day walk elegantly down the aisle under a beautiful wedding veil, or stand secure and confident as he watches the love of his life walk down the aisle toward him.

Please believe us when we tell you we don't *want* to be overly protective or excessively involved in our child's life. *Even more than you* we want our child to be an independent, self-sufficient, mature adult. Until we are absolutely confident that the individuals in our child or adult child's life understand how Prader-Willi syndrome impacts him, we will continue to educate and advocate and supervise and scrutinize and yes, sometimes even "helicopter" because this is what is *necessary* to keep our child safe and secure and happy. This is our job and, like any pilot who is entrusted with the comfort and safety of his passengers, we take our job very, very seriously.

CERTAIN MEDI-CAL WAIVER PAYMENTS MAY BE EXCLUDABLE FROM INCOME

IN HOME
IHSS
SUPPORTIVE SERVICES

On January 3, 2014, the Internal Revenue Service (IRS) issued Notice 2014-7, 2014-4 I.R.B. 445. Notice 2014-7 provides guidance on the federal income tax treatment of certain payments to individual care providers for the care of eligible individuals under the state Medi-Cal Home and Community-Based Services waiver program described in section 1915(c) of the Social Security Act (Medi-Cal Waiver payments). Section 1915(c) enables individuals who otherwise would require care in a hospital, nursing facility, or intermediate care facility to receive care in the individual care provider's home. The notice provides that the IRS will treat these Medi-Cal waiver payments as difficulty of care payments excludable from gross income under § 131 of the Internal Revenue Code.

The following questions and answers clarify the notice and provide guidance on the information reporting requirements, and the employment tax requirements for Medi-Cal waiver payments described in the notice.

I receive payments under the Medi-Cal program other than a Medi-Cal Home and Community-Based Services waiver program for the personal care of my adult disabled son in our home. May I exclude these payments from gross income?

Whether the IRS will treat payments under a state program other than a state Medi-Cal Home and Community-Based Services waiver program as difficulty of care payments excludable from gross income will depend on the nature of the payments and the purpose and design of the program.

I am the parent of a disabled child, and I receive state Medi-Cal Home and Community-Based waiver payments excludable from gross income under Notice 2014-7 for the care of my child in our home. My sister lives with me, and she also receives state Medi-Cal Home and Community-Based waiver payments for the care of my child. May she exclude the Medi-Cal waiver payments from gross income?

Yes. More than one care provider living in the home with the care recipient may exclude state Medi-Cal Home and Community-Based waiver payments from gross income under Notice 2014-7.

I am a respite care provider, and I provide personal care and supportive services to disabled individuals in their homes, or in my home where the care recipient does not live. I receive payments for this care under a state Medi-Cal Home and Community-Based Services waiver program. May I exclude these payments from gross income?

No. The exclusion only applies to payments for care in the individual care provider's home where the care recipient lives under the recipient's plan of care.

I am an individual care provider, and I receive payments under a state Medi-Cal Home and Community-Based Services waiver program for the care of a disabled individual who lives with me in my home under the individual's plan of care. The program has a cost-sharing provision that may require an individual to pay the administrator of the program a portion of the total amount that the administrator pays me for the care of the disabled individual. May I exclude the entire payment that I receive from the administrator for the individual's care?

Yes. You may exclude the entire payment that you receive under the state Medi-Cal waiver program for the care of the disabled individual in your home even though the individual is required to pay the administrator part of the cost of the care. By contrast, an individual care provider may not exclude direct payments from a care recipient who pays part or all of the cost of the recipient's care with the care recipient's private funds.

I am an individual care provider, and I receive vacation pay from the state, as well as Medi-Cal waiver payments for the care that I provide to a disabled individual living in my home under the individual's plan of care. May I exclude the vacation pay from gross income?

No. The only amounts excludable from gross income under Notice 2014-7 are payments for the care of the disabled individual.

IHSS Q&A, continued on page 7

NANCY BARGMANN, DEPUTY DIRECTOR OF DDS COMMUNITY SERVICES DIVISION RESIGNS FOR FAMILY REASONS

Excerpted from CDCAN Disability Rights www.cdcan.us

Nancy Bargmann, deputy director for the Community Services Division under the Department of Developmental Services announced in July that she will resign her position by the end of the month to return to her family home in Long Beach due to family reasons. As of this writing, the position remains vacant.

The Community Services Division of the Department of Developmental Services (DDS) oversees the community based services coordinated by the 21 non-profit regional centers provided by community based organizations and individuals for close to 290,000 children and adults with developmental disabilities across California. Bargmann has played a key role in bringing together diverse and sometimes competing stakeholders to navigate and implement major changes in state and federal policies impacting people with developmental disabilities.

Bargmann served in the position for the past three and half years, serving first under former department director Terri Delgadillo and then under current director Santi Rogers. She is widely respected by persons with developmental disabilities, their families, providers, regional centers and other advocates for her work and in recent years has been a visible presence at numerous budget and other legislative hearings and stakeholder meetings.

Her departure comes at a critical time for people with developmental disabilities, their families and what advocates call an increasingly "fragile" network of community-based services and supports provided by community-based organizations and individuals coordinated through the 21 regional centers, hit by decades of rate freezes, reductions and major changes in state and federal policies.

Bargmann had another focus in what she called her "very special responsibility in my life, my dad". In her brief email announcement, she gave mention to her father "…As an educator he has been a voice in my head about caring and supporting others and as a person who has gracefully managed the challenge of Parkinson's Disease for the past 30 years, he has taught me how to be the best advocate and caregiver possible".

Marty Omoto, of CDCAN and also a member of several stakeholder groups that Bargmann was a part of, including the Self Determination Stakeholder Committee, wrote to Bargmann after the announcement saying that "I am so very sad you are leaving, but understand completely. You have been so extraordinary and remarkable for the tremendous work and advocacy you have always given to all of us and all of our families! For that we can never express enough our deep appreciation, respect and love for what you have done." Omoto continues, "Your transition to focus on your family only underscores what we felt and will always feel about you.... As a father I know how precious a daughter can be – as you must be to your own father. I wanted you to know that you are precious to us too. Your work will never be forgotten, you will always be irreplaceable, and your work will always be our foundation to build even more remarkable lives for our families and everyone in our community…"

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IHSS Q&A, continued from page 6

I received payments described in Notice 2014-7 on or after January 3, 2014, that are excludable from gross income as difficulty of care payments under § 131. May I choose to include those payments in my gross income for 2014 and later years?

No. A taxpayer may not choose to include in gross income difficulty of care payments that are excludable from gross income under § 131 as provided in Notice 2014-7.

If I received payments described in Notice 2014-7 in an earlier year, may I file an amended return to exclude the payments from gross income that I reported as income in the earlier year?

Yes. You may file a Form 1040X, Amended U.S. Individual Income Tax Return, if you received payments described in the notice in an earlier year and the time for claiming a credit or refund has not expired under § 6511 of the Internal Revenue Code. A taxpayer generally may file a claim for refund within three years from the date the return was filed or two years from the date the tax was paid, whichever is later.

For more information, see "When To File" in the instructions to Form 1040X or Tax Topic 308, Amended Returns, available at http://www.irs.gov/taxtopics/tc308.html. In Part III of Form 1040X, you should explain that the payments are excludable under Notice 2014-7.

Excluding payments described in the notice in an earlier year may affect deductions or credits that you claimed for the earlier year, as well as other tax items for the earlier year. To help expedite the processing of your amended return, you should include the following to substantiate your claim: (1) the full name of the individual receiving care (and the care recipient's social security number or other taxpayer identifying number, if available); (2) copies of documents from third parties to show that you and the individual receiving care resided in the same home in the year to which the claim relates (such as a driver's license or other government-issued document, social agency document, bank statement, medical bill, or utility bill); and (3) evidence that the individual is receiving care under a state Medi-Cal waiver program.

PWS BEHAVIOR MANAGEMENT STRATEGIES TOOL KIT

by Lisa Graziano

Prader-Willi syndrome is a spectrum disorder; not everyone with PWS will exhibit the same degree of behavioral symptoms. The following strategies and techniques can, however, help with almost everyone with PWS. Keep in mind that anything that raises anxiety has the potential for a behavior problem, so if you reduce/eliminate the source of anxiety you'll reduce/eliminate the behavior problem!

*For more information about PWS or to or to request a PWS Training, contact PWCF at 310-372-5053 or info@pwcf.org.To order PWCF's **Behavior Management Strategies That Work** DVD go to PWCF.org.*

- **Respond calmly at all times**. Logic and reasoning don't work when the person with PWS is upset. Don't try to talk someone out of their upset because they'll just feel they need to express more upset so that you understand. Listen, repeat their concern. Listen, express your concern. Listen, repeat their concern. After empathy, respond to an escalation or temper tantrum with indifference. Ignore unwanted behaviors as much as possible.

- **Oppositionalism**: The brain's automatic reaction is often to respond with "NO!" This looks like oppositional, defiant, argumentative behavior. Avoid "Yes/No" questions. Allow lots of time to process past the brain's oppositionalism. Build in extra time everywhere you go. Give limited, preferred choices and as much control as possible: "Do you want to wear the red jacket or the blue jacket?" "Wear your jacket or carry it?" "Do you want to clean up in 5 minutes or 8?" Avoid open-ended questions which can be difficult to process and may create anxiety.

- **Egocentrism**: People with PWS generally think about themselves first and foremost: This can also make it difficult for them to see things from someone else's perspective. Don't say, "If we don't hurry, Grandma will be late to her appointment." Do say, "If we get Grandma to her appointment on time you and I will have time to watch the movie!" Don't say, "Your yelling is disturbing the class/residents/workplace." Do say, "When you speak softly we can talk about your concern."

- **Impulsivity**: Persons with PWS generally want what they want, when they want it, which is right now. Before entering a situation or environment, 'paint the picture' of what things will look like, what will happen, your expectations for behavior, what will occur if there is unwanted behavior, etc. Reward for patience/self-control.

- **Inflexibility**: Persons with PWS may have difficulty transitioning, changes in routine, or expectations. Provide verbal and/or visual countdowns, "Five minutes until we leave. Three minutes 'til we go so let's put shoes on. One minute until we leave, good job for getting ready to leave on time." Don't use words to "hurry" individual; instead use excitement, music, natural incentives, praise. Provide advance notice of change when possible. Provide empathy when there is an upset.

- **Frustrators**: Anything that looks, sounds, or smells like a frustrator could lead to a behavior problem. Use "No" as infrequently as possible. Disguise No's: don't say, "No, we can't go outside now." Do say, "I'd love to go outside too! As soon as we finish homework/chores let's go outside!" Provide empathy: repeat individual's words. Observe individual's actions: "You look like you're feeling upset. What's up?"

- **Obsessions**: The brain believes 'if 1 is good, 100 is better.' Collecting, hoarding, picking, sorting, pulling, tearing can be associated with the brain's obsessive or compulsive tendencies. Give limited, preferred choices. Use empathy. Medications may be necessary.

- **Self-Monitoring**: The ability to monitor self and accurately evaluate one's own performance is often impaired. Continuously remind to speak softly; slow down eating, etc.

- **Need to be Seen as Right/Good**: Most people have a strong need to be right at all times and at all costs. Avoid power struggles by allowing for the possibility of the individual's "rightness." Use phrases like, "You might be right" or "That interesting. You think x and I think y."

- **Planning, Prioritizing & Problem Solving**: These skills are typically poor. Continuously provide assistance and guidance. Keep the individual thinking and guide them to solutions rather than solving the problem for them.

- **Low Internal Motivation; Higher External Motivation**: Use external motivators such as praise, token rewards, visual reward system, special time, asking individual to be your 'special helper.'

- **Persons with PWS are generally concrete thinkers**. The concept of time can be especially difficult. Make things as concrete as possible. Use visuals, timers, alarms, etc. Specifically teach metaphors, idioms, slang. Until taught, terms like, "Hop to it!" may not be understood to mean "Begin the task immediately." Teach to reduce anxiety and increase social competence.

- **Don't give in to a temper tantrum**. Stay strong and remember that if you give in today, tomorrow's tantrum will be worse.

CHILD WHISPERERS, EXCERPT

by Lisa Peters, www.onalifelessperfect.blogspot.com

I am the mother of two child diagnosed with special needs. But I am not a parent. Yes, you read that right, I am NOT a parent. At least not in the ordinary sense of the word. To me, parenting is about educating your children and providing them with instruction and social conditioning so that one day they may acclimate into the world and conform to what society expects of them. For a long time that is exactly what I tried to do.

I became a parent like any other and tried to condition my children, to mold them into society. I pounded and pounded on my square pegs trying to fit them into unaccommodating round holes. The end result of all this pounding was nothing more than splintered wood. There was costly damage inflicted upon all of us.

On my journey to raise unique children, I am beginning to believe that I must redefine my ideas about parenting, or at least what this role means to me. Is it my job to mold what is un-moldable? To search for a “place” for my children that does not exist? To send them into a world that does not know them?

It all sounds like madness to me. And so I search to create my own definition of parenthood. What does it mean to be a parent of a child diagnosed with special needs? In this role, when and what am I doing that feels right?

After 16 years of special needs parenting, I can tell you, without a doubt, that it is when I assume the role of an observer, the magic begins. It is when I watch them. I listen instead of lecture. When I really, really study them, noticing the small things that they do or say that seem to speak so loudly. It’s only when I am enlightened and educated that am I helpful to my children. It is when I assume a passive role that I move forward. In this role, I am not the parent or at least not the one doing the educating. It is counter intuitive, feeling a lot like parenting in reverse. But as an observer, I have learned many things from my children.

They seem to know instinctively of life and love and sing of the simple things. They value things like honesty, love and togetherness. They possess warm spirits and pure hearts. Their messages are the medicine the world lacks. I do not believe my children are alone in this knowledge. I believe many parents feel similarly.

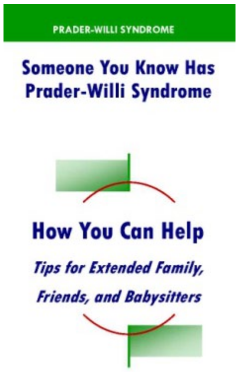
Our children are trying to tell us something.

But how do children diagnosed with special needs, many who cannot express or speak, communicate these powerful lessons?

I have learned that it is through me.

I must not only be an observer of my children, but also a translator. This is my job as a parent.

NEW PWS BROCHURE: HOW YOU CAN HELP



PRADER-WILLI SYNDROME

Someone You Know Has Prader-Willi Syndrome

How You Can Help

Tips for Extended Family, Friends, and Babysitters

Thanks to Board President **Julie Casey** and Board Member **Jennifer Wolkensdorfer** PWCF has a new brochure intended to show extended family, friends, and others just exactly *how* they can be supportive of parents and helpful to someone who has PWS. Quick, easy to read sections cover General Support, Food Support, Social Support, and Behavioral Support.

Examples of General Support include:

- Supportive means **not** saying “you worry too much about food; one little piece won’t hurt.”
- Supportive means **not** telling your friend what they should be doing (what worked for your kids most likely is not going to work for a child with PWS).
- Supportive means educating yourself by visiting knowledgeable PWS sites (there’s a list on our website), not Googling it which often leads to inaccurate or outdated information.

Examples of Behavioral Support include:

- Reasoning with someone when they’re upset generally does not work. Do not tell someone who is upset that “everything will be ok.” Instead, let them know you understand they are upset by repeating their words and showing empathy.
- Do not “punish” or threaten to punish unwanted behavior by taking anything away, especially food.
- If someone with PWS is left in your care be sure to stick to the schedule and follow the parent’s instructions for dealing with any behavioral issues that may arise.

Examples of Food Support include:

- Remove all candy, mints, and nut dishes that you may typically have out.
- To the extent possible remove food from kitchen counters. Out of sight is not necessarily out of mind for the person with PWS, but it definitely helps.
- If someone with PWS is left in your care, follow their food plan exactly.

Available for download at **www.pwcf.org**
or contact the PWCF Office **info@pwcf.org** or **310-372-5053.**

Call for research *participants*

PATIENTS NEEDED PWS RESEARCH

CALIFORNIA STATE UNIVERSITY FULLERTON

UCIRVINE

Energy Expenditure in Children with PWS While Walking on a Treadmill

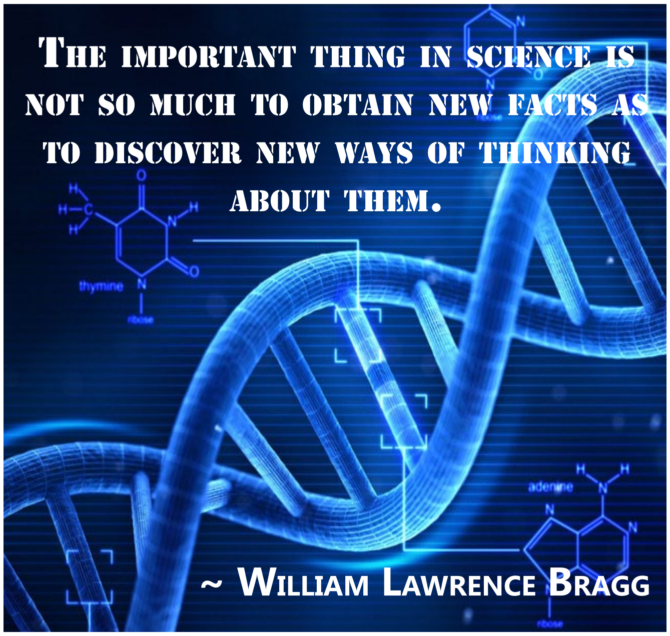
Participants: Children with and without PWS ages 7-12. Must be able to walk continuously for 5 minutes.

Time Commitment: Complete 1 site visit at CSU Fullerton lasting 2.5 hours.

Compensation: Children will receive a $20 gift card for their participation

Contact: For more information or to participate in this study, please contact us or visit our website.

Dr. Daniela Rubin:	drubin@fullerton.edu	657-278-4704
Diobel Castner:	dcastner@fullerton.edu	657-278-8737
Research office:	pwstudy@fullerton.edu	657-278-3671
Website:	http://pws.fullerton.edu	
Languages:	English/Spanish	



Phase 2 Pilot Study to Assess the Effects of RM-493 in Obese Subjects with PWS on Safety, Weight Reduction, and Food-Related Behaviors

Purpose: This is a Phase 2 study that will assess the effects of the drug RM-493 on weight reduction and food-related behaviors and safety on obese patients with PWS. It is a randomized, double-blind, placebo-controlled pilot.

Anticipated Benefits: There may be therapeutic effects for PWS by decreasing symptoms. There are potential side effects associated with this drug that will be discussed in detail with you before beginning the study.

Eligibility:

1) A confirmed diagnosis of PWS
2) Age 16-65 years
3) All race/ethnic backgrounds
4) Male and Female
5) BMI ≥27 kg/m2
6) Receiving and those not receiving growth hormone
7) Are generally healthy based on initial screening exam results.

Study Location(s): University of California, Irvine Institute for Clinical and Translational Science

Time Commitment: This study includes 5 to 7 visits and will last a period of 70 to 163 days. There will be one visit every two weeks for the duration of the study. Each visit will be approximately an hour. The first two visits will be a screening to determine health status. The subsequent 3 to 5 visits will include the drug treatment, physical exam, blood draw, bone scan, and questionnaires.

Compensation: $50 per visit completed plus travel expenses.

Contact:
Abhilasha Surampalli, Study Coordinator
949-824-0521 asurampa@uci.edu

Or contact Virginia Kimonis, M.D., Lead Researcher
949-824-0571 vkimonis@uci.edu

More than ever before, experts recognize how critical movement is to learning. This conference will focus on how to use movement to improve a host of symptoms in persons with PWS of every age. Breakout sessions provide in-depth learning and sharing opportunities. Hear the latest in PWS research. New and experienced parents, extended family, and professionals will learn something that immediately improves the quality of life of their loved one or patient.

Don't miss this conference!

Saturday, November 14, 2015

8:00 am - 5:00 pm
Crowne Plaza Los Angeles Int'l Airport
5985 W Century Boulevard
Los Angeles, CA 90045

Meet & Greet Mixer

Friday, November 13 at 7:00 p.m.
Crowne Plaza Lobby Bar

Youth & Adult Program

Simultaneous conference for persons with PWS and siblings. Give them a day of fun while you enjoy worry-free time at the conference

To Register

Mail registration form (to the right) to PWCF
or go online at www.pwcf.org
or call the PWCF Office 310-372-5053.
Reserve your hotel room at 888-315-3700

2015 Annual State Conference Form

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

PWCF Member:	$70 / $100 per couple
Professional:	$85
Non-PWCF Member:	$85

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

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

Please Print:

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

____
Mailing Address

____
City State Zip

______________________ ______________________
Telephone Email

Number of Vegetarian Lunches Requested: ________________

Youth & Adult Program Registration

PWCF Members	$10/child or adult
Non-PWCF Members	$12/child or adult

Fees may be reduced or waived upon request

Names & Ages of Persons Enrolling in Youth & Adult Program

Name: ________________________ Age: ______ PWS? Yes/No

Name: ________________________ Age: ______ PWS? Yes/No

Name: ________________________ Age: ______ PWS? Yes/No

Name: ________________________ Age: ______ PWS? Yes/No

Fee Calculation

Total Enclosed for General Education Meeting: $ ______

Total Enclosed for Youth & Adult Program: $ ______

Total Tax-Deductible Donation Enclosed: $ ______

Total Amount Enclosed: $______

☐ Check payable to PWCF enclosed ☐ Charge my credit card

Name on Card: ______________________________

Credit Card No: ______________________________

Expiration: ____________________Security Code: ________

Email: ______________________________

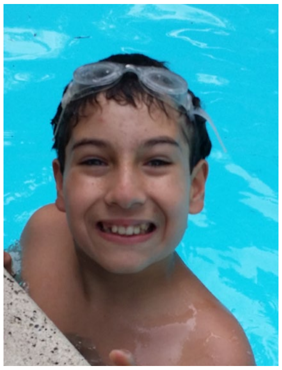
Signature: ______________________________

Return Registration Form to PWCF:

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

5TH ANNUAL PWS CAMP PHOTOS

June 18-23, 2015



More comments from families:

"***We loved the respite***. *We were glad Lisa and Emily were there. There's always some anxiety any time my child is away from home, but minimal at Camp Harmon*"

"*I was nervous about no phone contact until after camp, but looking back I realize this was a blessing*"

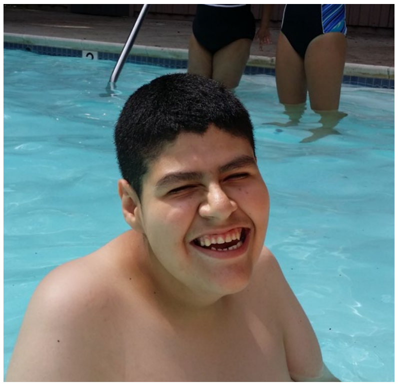
"*I did not have to worry about food.* ***I am so glad this camp exists for my child***"

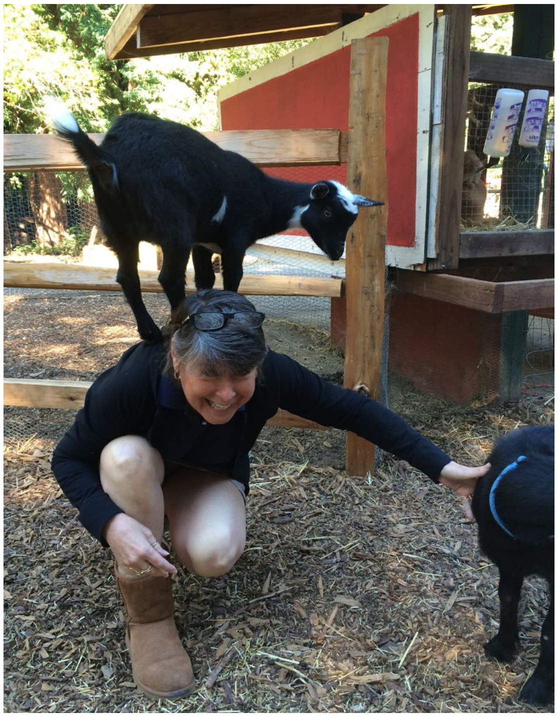
"*It was a nice break.* ***I felt confident in the skills of the counselors to redirect behavior***"

It doesn't get much better when our kids are happy and their families are happy!

Next year's PWS Camp session at Easter Seals' Camp Harmon will be **July 13-18, 2016**. Campers on this year's wait list will have first dibs at registration which will open in January.

Because we know how beneficial camp is to our members, PWCF is working hard to develop another camp in the Southern California area! Stay tuned for details.





PWCF BOARD EMERITUS INDUCTEES 2015

At its January meeting, PWCF's Board of Directors established a new category of Board member known as a **Board Member Emeritus.**

Board Emeritus members shall be nominated and elected by the Board of Directors. They shall be elected from board members who have **served on the Board of Directors with distinction and excellence and considered deserving of recognition for outstanding service**. Board Member Emeritus is a lifetime designation.

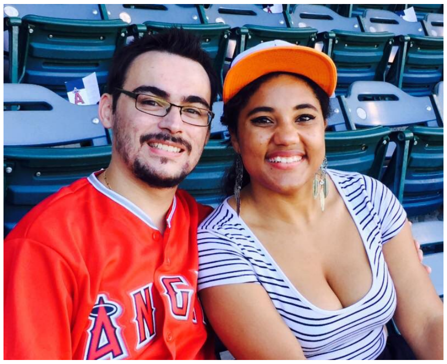
PWCF's Board of Directors extends its congratulations and sincere appreciation to each of the 2015 inductees:

- **Bud Bush**
- **Toni Campoy-Wagonor**
- **Carl Martens**
- **Fran Moss**
- **Anne Scott**
- **Bob Scott**
- **John Shimmen**
- **Janice Shimmen**
- **Renee Tarica**

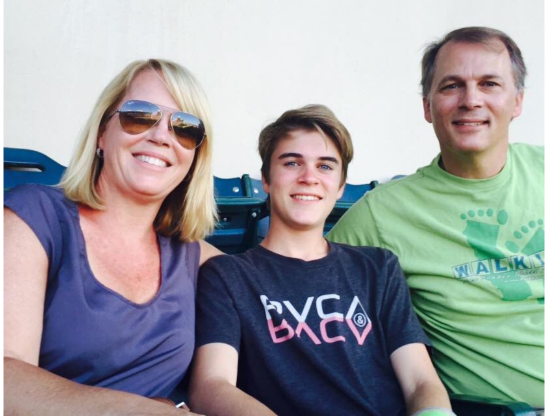
e·mer·i·tus *adj.*

Retired but retaining an honorary title corresponding to that held immediately before retirement.

PWCF FAMILY DAY AT THE ANGELS



PWCF families enjoyed another fun PWS Family Day! Gathering in Anaheim at the Angels stadium, baseball fans watched the Angels battle it out with the Texas Rangers and afterward, were treated to an amazing fireworks show. While the Angels eventually lost to the Rangers (7-6), our families were the big winners!



2016-2018 Board of Directors Candidates

Prader-Willi California Foundation

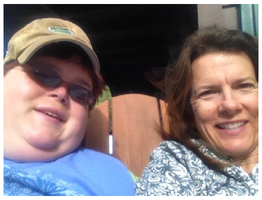
PWCF Members in Good Standing* may cast your vote for the 2016-2018 incoming PWCF Board of Directors by marking the Official Ballot and returning it to the PWCF Office in the Official Ballot Envelope postmarked by November 10, 2015. Ballot Envelopes postmarked after November 10 will not be counted. Or you may present your Official Ballot at the PWCF General Education Meeting on November 14, 2015 at the Crowne Plaza, 5985 W. Century Boulevard, Los Angeles, California CA. Questions? Contact the PWCF Office at 310.372.5053 or 800.400.9994 (toll free within California) or info@pwcf.org.

PWCF maintains an eleven member Board of Directors. Three (3) seats will vacate for the 2016-2018 term.

Please cast your vote for three (3) candidates from the slate of three (3) candidates below:

Rodney Dong: Rodney Dong is a Board Certified Music Therapist and proud dad of Kiran Dong (4yrs, PWS). Born and raised in Vancouver, Canada, he currently lives in sunny Valencia, CA together with his wife Gail and with Kiran. He has served as co-chair of the Board of Touched by an Angel, a non-profit dedicated to providing resources and support to families of children with special needs, and has worked with children with developmental disabilities as a Music Therapist, social skills therapist, and developmental play therapist for over 12 years. Currently he spends most of his days chauffeuring and coaching his son Kiran through his incomprehensibly busy days of school, therapy, and extra-curricular activities. Rodney is (thanks to PWCF) an avid runner and loves to train for half and full marathons, and also enjoys tennis, Badminton, hiking, and every form of winter sport. Rodney feels strongly that it is important to help educate others about PWS and its challenges, and to pay forward the support and guidance that he and his family received from wonderful organizations such as PWCF.

Nisha Mehta (Incumbent): I have served on the Board of PWCF for the past 3 years as Secretary. I live in Redondo Beach, California, with my husband, Minesh, and three incredible kids, Siena (PWS), Melina, and Jaiden. I have spent the majority of my career working in Strategic Planning and Strategy Consulting positions, and have an MBA from the Wharton School of Business. I am very interested in working with the Board to achieve its Strategic Objectives and to help our kids and families reach their fullest potential. I have been a stay-at-home Mom since Siena was born. I am extremely grateful to the PWS community for all of its support and I would like to share my knowledge and experience in every way that I can. Thank you for your consideration



Jacki Lindstrom (Incumbent): My name is Jacki Lindstrom. I am a wife of 37 years to my husband Jeff, and proud parent of Julia (30 with PWS) and son Jake (25, graduate of Chico State). Together, my husband and I own and operate a General Building Contracting firm in Burlingame for over 23 years. I have also worked many years in Special Education Infant Program and ECE. Julia currently lives in a group home about 100 miles from home. She has lived outside our home off and on since she was 11 years old. I am hoping with the experience I have had dealing with group homes, supported living services, school programs, day programs, colleges, and social workers that I will be able to assist the board with a common sense approach to making long term care in a residential setting a positive and happy alternative for families with children and adults with PWS. I have always supported PWCF from afar and have relied on them heavily at times. I am hoping I will be able to give back to the association what they have given to myself and my family. Thank you for your consideration.

***Voting Criteria:** Voting members must be Members in Good Standing with Prader-Willi California Foundation (PWCF). Membership dues must be current and paid in full through 2015 or a dues waiver granted.

Member Types Eligible to Vote:

- Individual Member may cast 1 vote
- Family Members may cast 2 votes
- Professional Member may cast 1 vote

pwcf.org Prader-Willi California Foundation

Supporting People with Prader-Willi Syndrome

Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

2016-2018 OFFICIAL BALLOT

Prader-Willi California Foundation Board of Directors

Voting Instructions:

1. Review the candidates' statements printed on the Slate of Candidates on page 15, prior page.
2. Cast your vote on the Official Ballot and insert it into the Official Ballot Envelope.
3. Print and sign your name on the Official Ballot Envelope. Affix postage. Mail it to PWCF postmarked no later than November 10, 2015.

Or

1. Present your Official Ballot in person at the PWCF General Education Meeting on Nov. 14, 2015 at the Crowne Plaza Hotel, 5985 W. Century Boulevard, Los Angeles, California

Deadlines:

The deadline for voting by **mail** is **November 10, 2015.**
Ballots postmarked after November 10 will not be counted.
The deadline for voting **in person** at the General Education Meeting is **November 14, 2015**.

Confidentiality:

Your vote will be kept confidential. PWCF office staff will verify voter eligibility and separate the Official Ballot from the Ballot Envelope before the Ballots are tallied.

Voting Criteria:

Voting members must be Members in Good Standing with Prader-Willi California Foundation (PWCF).
Membership dues must be current and paid in full through 2015 or a dues waiver granted.

Member Types Eligible to Vote:

- Individual Member in Good Standing may cast 1 vote for three candidates
- Family Members in Good Standing may cast 2 votes for three candidates
- Professional Member in Good Standing may cast 1 vote for three candidates

INSTRUCTIONS FOR INDIVIDUAL MEMBERS AND PROFESSIONAL MEMBERS

Cast your vote for the 2016-2018 Board of Directors. Vote for three (3) of the candidates listed below.

Vote for Three (3) Candidates:

☐ Rodney Dong ☐ Nisha Mehta ☐ Jacki Lindstrom

INSTRUCTIONS FOR FAMILY MEMBERS

Cast your vote for the 2016-2018 Board of Directors. Vote for three (3) of the candidates listed below.

Family Member #1 - **Vote for Three (3) Candidates**:	Family Member #2 - **Vote for Three (3) Candidates**:
☐ Rodney Dong	☐ Rodney Dong
☐ Nisha Mehta	☐ Nisha Mehta
☐ Jacki Lindstrom	☐ Jacki Lindstrom

Prader-Willi California Foundation
An Affiliate of Prader-Willi Syndrome Association (USA)
514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, California 90277
310.372.5053 • 800.400.9994 Toll-free in California • info@pwcf.org • www.PWCF.org

BOARD CORNER

Summary of Board of Directors Meeting on July 14, 2015

Submitted by Tom McRae

Tom McRae

The Board of Directors meeting was held via conference call.

Board members present: Whitney Bras, Julie Casey, Roger Goatcher, June Anne Gold, M.D., Jacki Lindstrom, Tom McRae, Nisha Mehta, Kimberlee Morgan, Daniela Rubin, Ph.D., Renee Tarica

Executive Director present: Lisa Graziano
Board members absent: Diane Kavrell, Jenny Wolkensforder

Fundraising/Awareness –Long Beach Marathon, October 2016

At the last board meeting we decided **not** to submit an application for the 2016 Los Angeles Marathon because the event falls on a major holiday weekend.

Julie Casey researched alternatives and recommended the Long Beach Marathon as the best option in terms of timing (away from other events) and pricing. After discussing the pros and cons, the board passed a motion to apply as an official charity to the 2016 Long Beach Marathon.

Julie Casey will do additional research and try to find an organizer.

Daniela Rubin will have a table at this year's Long Beach Marathon to promote for next year.

2015 Member Give Back Item

The board discussed various possibilities for this year's Member Give Back item, the purpose of which is to acknowledge our members with a useful gift. We narrowed down the choices to a few, some of which will also serve to raise public awareness. I could tell you the choices but I'm not going to because I don't want to ruin the surprise!

Research Committee: PWCF's Recommendations for AMA priorities

Background: The American Medical Association (AMA) designated Obesity as a disorder two years ago. This opens the door for more obesity-related policies to be written.

June-Anne Gold, M.D. made the following weight-related recommendations to the AMA:

- Car seat regulations should include weight as a factor.
- Psychiatric evaluations should be used in approving bariatric surgery.

A group for Obesity has been formed within the AMA given these recent discussions, and **June-Anne** was asked to join the group. She will be able to represent the needs of people with PWS as well as make PWS more visible to doctors. **June-Anne** asked the Board if there was anything else the AMA should be considering for people with PWS. A suggestion was made to identifying proper G-tube protocols. June-Anne will look into getting supporting data.

New PWCF Brochure Review

Julie Casey and **Jenny Wolkensdorfer** have been drafting a new brochure about PWS to distribute to extended family and others. The draft was presented to the Board for review. The Board's initial feedback was very positive. We felt the content is excellent, easy to read, and provides good examples. **Julie** asked all the Board members to review the draft brochure one more time for typos and other suggestions. **June-Anne Gold** will review the brochure for medical accuracy.

Next up, **Julie** wants to create a brochure targeted at medical professionals that captures general information (as opposed to detailed medical information which already exists). The following suggestions were made for potential topics:

- Benefits of Growth Hormone at Birth
- PWS does not have to mean Obesity

Review of Strategic Plan

Julie Casey distributed the spreadsheet of PWCF's Strategic Plan. The Board reviewed goals and progress.

One topic discussed was to consider organizing new and or coordinating existing PWCF events in May given that May has been designated as "Prader-Willi Awareness Month". Some ideas discussed were:

- Move the various PWCF Walks to all occur in May.
- Do our Member Give Back in May
- Sell PWCF's Virtual Walk/Yard Signs to be displayed throughout the month of May

Closing

Those are the highlights of the Board meeting. If you have read this far, well, perhaps I may ask you to read one more paragraph.

Remember, we need your help. Consider running for the Board. If you cannot make that commitment but would like to help, please reach out the PWCF office. Give them a call at: **310-372-5053**. Tell them Tom sent you.

WE GET MAIL

✉ Dear PWCF: Thanks so much for the A's photo...it's great to have the whole family together in a picture. Angela enjoyed seeing Stomper again. We have Angela involved in cheer, dance, bowling, tumbling and Special Olympics swim team... and she just did her first 4th of July parade with dance team...she loves being busy and we're very proud of her. Have a great summer. Take care, *Rhonda and Andy Faust, parents of Angela, age 6*

✉ Dear PWCF: Great newsletter! I love all the dyspraxia info and Lisa's column was wonderful!
xoxo, *Linda Ryan, mother of Trevor, age 25*

✉ Dear PWCF: Thank you for making this [IEP] training happen... This presentation should be mandatory for all parents! The presentation was well paced and so informative and went by quickly. I [had previously] learned some of these things along the way but you gave me a better understanding of WHY the wording is important to parents and the school... At the end of the day, I still believe that it's the relationship with the team and people interacting daily with my child that makes the biggest difference in her quality of life- and you covered that too! Thank you again. P.S. Loved the videos! *Kimberly Pratto Storr, mother of Naomi, age 12.*

✉ Dear PWCF: Thank you so much for sharing your expertise with [our student's] team. We all appreciate your time and support to assist us in keeping him safe so that we can assist him in being the best he can be! Warm regards, *Jay Schwartz, Principal, Special Education Department, Glendale Unified School District*

✉ Dear PWCF: Very warmest thanks to you for the grant for the CHOC Prader-Willi California Foundation Clinic. The ability to have two developmental behavioral pediatricians is of such mportance and value to families. The impact of your support and generosity is so meaningful. Very deepest thanks. Warmly, *Sarah Miyashiro*

* * *

Transition to Pedal Bike, continued from page 4

1. **First, don't rush pedaling**. Striding and practicing balance is fun! Even if your child appears to be striding like a pro, moving to a pedal bike too soon can derail progress and discourage your child. The weight of a pedal bike is significantly more (sometimes two to three times the weight of a STRIDER) and handling that extra weight can be very frustrating to a child. Let them practice, play, and perfect their balance and bike handling skills while having fun on their Strider bike. Be confident that all time spent on a balance bike will only make them more proficient on a pedal bike the day they decide to transition.

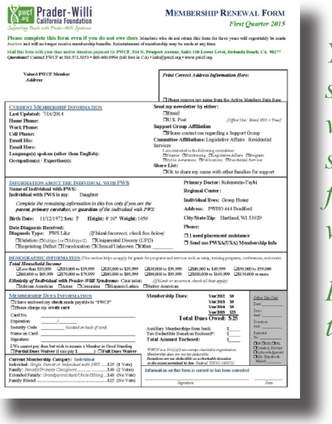
2. **Second, never ever use training wheels!** If you feel your child is ready to pedal, we recommend finding the simplest, lightest bike possible. Avoid "bells and whistles" as they all add weight and distraction. We also recommend that pedal bikes have a free wheel hub and a hand brake. Do not buy a bike for your child to "grow into." A bike that is too large won't fit properly, will be too heavy, will be unsafe, and will ultimately discourage your child. With the seat at its lowest setting your child should be able to touch the ground flat footed. Remember, training wheels are NOT a solution to a bike this is too large.

3. **Third, keep it fun!** Putting kids on a pedal bike too soon will limit where they can go. It is much harder to ride a pedal bike on grass, dirt, or over obstacles than it is on a STRIDER. Keep in mind how important fun and adventure are to a kid. The lightweight simple STRIDER has a "fun factor" simply not available on a heavy pedal bike. We recommend having both the Strider bike and the pedal bike available to the child so they can choose which they prefer on a given day. We recommend this overlap for at least a year. At some point of the child's choosing, as they get taller, stronger, more skilled, and more confident, they will complete their transition to a pedal bike.

For more information visit Strider Sports Int'l, Inc.
www.StriderBikes.com

MEMBER ACTIVITY

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



Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

MEMBERSHIP RENEWAL FORM
First Quarter 2015

Please complete this form even if you do not owe dues. Members who do not return this form for three years will regrettably be made inactive and will no longer receive membership benefits. Reinstatement of membership may be made at any time.

Mail this form with your dues and/or donation payment to: PWCF, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277
Questions? Contact PWCF at 310.372.5053 • 800.400.9994 (toll free in CA) • info@pwcf.org • www.pwcf.org

Valued PWCF Member
Address

Print Correct Address Information Here:
☐ Please remove my name from the Active Members Data Base

CURRENT MEMBERSHIP INFORMATION
Last Updated: 7/16/2014
Home Phone:
Work Phone:
Cell Phone:
Email His:
Email Hers:
Language(s) spoken (other than English):
Occupation(s) / Expertise(s):

Send my newsletter by either:
☐ Email
☐ U.S. Post
Support Group Affiliation
☐ Please contact me regarding a Support Group
Committee Affiliations: Legislative Affairs Residential Services
I am interested in the following committees:
☐ Finance ☐ Fundraising ☐ Legislative Affairs ☐ Program
☐ Public Awareness ☐ Publications ☐ Residential Services
Share List:
☐ Ok to share my name with other families for support

INFORMATION ABOUT THE INDIVIDUAL WITH PWS
Name of Individual with PWS:
Individual with PWS is my: Daughter
Complete the remaining information in this box only if you are the parent, primary caretaker, or guardian of the individual with PWS.
Birth Date: 11/12/1972 Sex: F Height: 4' 10" Weight: 105#
Date Diagnosis Received:
Diagnosis Type: PWS Like (If blank/incorrect, check box below)
☐ Deletion (☐ Subtype I or ☐ Subtype II) ☐ Uniparental Disomy (UPD)
☐ Imprinting Defect ☐ Translocation ☐ Clinical/Unknown ☐ Other

Primary Doctor: Rubinstein-Taybi
Regional Center:
Individual lives: Group Home
Address: PWHO 644 Bradford
City/State/Zip: Hartland, WI 53029
Phone:
☐ I need placement assistance
☐ Send me PWSA(USA) Membership Info

DEMOGRAPHIC INFORMATION (This section helps us apply for grants for programs and services such as camp, training programs, conferences, and more)
Total Household Income
☐ Less than $10,000 ☐ $10,000 to $19,999 ☐ $20,000 to $29,999 ☐ $30,000 to $39,999 ☐ $40,000 to $49,999 ☐ $50,000 to $59,000
☐ $60,000 to $69,999 ☐ $70,000 to $79,999 ☐ $80,000 to $89,999 ☐ $90,000 to $99,999 ☐ $100,000 to $149,999 ☐ $150,000 or more
Ethnicity of Individual with Prader-Willi Syndrome: Caucasian (If blank or incorrect, check all that apply)
☐ African American ☐ Asian ☐ Caucasian ☐ Hispanic/Latino ☐ Native American

MEMBERSHIP DUES INFORMATION
☐ I have enclosed my check made payable to "PWCF"
☐ Please charge my credit card
Card No.
Expiration
Security Code (located on back of card)
Name on Card
Signature
I/We cannot pay dues but wish to remain a Member in Good Standing
☐ Partial Dues Waiver (I can pay $) ☐ Full Dues Waiver

Membership Dues:
Year 2012: $0
Year 2013: $0
Year 2014: $0
Year 2015: $25
Total Dues Owed: $25

Auxiliary Memberships from back: $
Tax Deductible Donation Enclosed*: $
Total Amount Enclosed: $

*PWCF is a 501(c)(3) tax-exempt charitable organization. Membership dues are not tax deductible. Donations are tax deductible as a charitable donation to the extent permitted by law. Federal TIN 95-3480752

Office Use Only
Date
Dues Amt.
Donation Amt.
Payment No.
☐ Ck ☐ Cash ☐ Cr.
☐ Donation Receipt
☐ Acknowledgment
☐ Handbook Mailed

Current Membership Category: Individual
Individual: Single Parent or Individual with PWS ....$25 (1 Vote)
Family: Parents/Primary Caregivers ....$40 (2 Votes)
Extended Family: Grandparent/Aunt/Uncle/Sibling ....$40 (No Vote)
Family Friend ....$25 (No Vote)

Information on this form is correct or has been corrected
Signature
Date

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

Renew your membership today!

New Auxiliary Members

David R. Powers, DDS
David C. Ward, MD

New Family Members

Michael Brunelle
Charles & Carol Huang
Diana & Ryan de la Rosa Galey
Natalie & Steven Inouye
Michelle & Zack Petitt
Timothy Russell

New Extended Family Members

Carolyn & William Rubin

Renewed Extended Family Members

Peri & James Anders
Martha & Gary Girdaukas
Carolyn Meyer
Erin Philips
Joyce & Norman Smith

Renewed Professional Members

Vicki Cox, M.S., LCGC, UCSF Pediatrics/Medical Genetics
Luz Rasco, Talia Vi Homes - Carfax

We Remember

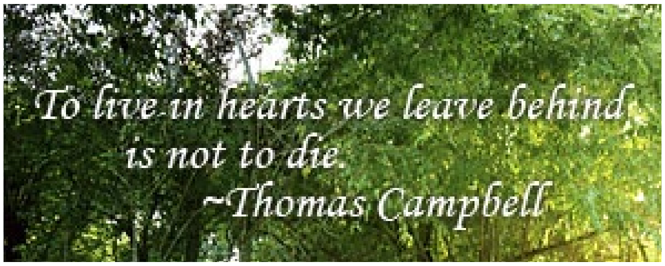
Michael Kugelman

August 15, 1979 – September 2, 2015

PWCF is saddened by the loss of Michael Kugelman who had Prader-Willi syndrome.

Michael is survived by his mother, Kari Burgess, and his former stepfather Mark Lewis, who is a former member of PWCF's Board of Directors. Mark let PWCF know that "Michael passed away after his battle with testicular cancer. His cancer was not diagnosed promptly and had spread... I appreciate all the support Michael received from PWCF over the years."

Michael Kugelman will be missed by his family and all who knew and loved him.



VOLUNTEERS are Priceless

PWCF thanks **Cameron Graziano** for his help to prepare mailings from the PWCF Office.

PWCF thanks **Paula Watney** for staffing the PWSA (USA) Booth at the Combined Federal Campaign Charity Fair in Fresno on September 22 and raising awareness of Prader-Willi syndrome, PWSA (USA) and PWCF.

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

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

DONATIONS

July - September 2015

Shining Star Donations

Canopus ($500 - $999)

Suzanne Privette in honor of Samantha Morgan (monthly donation)

General Donations

Adobe
Amgen Foundation Staff Giving Programs
Hasmukh & Bernard Amarasekera
Ione Bell
Darren Clarke in memory of Christopher Clarke
Lee Elliott
Daryl Keighley
Kaiser Permanente Community Giving Matching Gift Program
Martha & Gary Girdaukas in memory of Lillian Weigand
Kroger Grocery
Patti & Tom McRae (monthly donation)
Anna Montoya
Fran Moss
Patricia Olivarez
Michelle & Mike Raleigh
Joyce Smith
D.L. Sweet
Ron Vogrin in honor of Jim Cahill's 75th birthday

Donations to Support PWS Camp

Suzanne Privette in honor of Samantha Morgan (monthly donation)

PWCF Events Calendar 2015

Date	Day	Event	Location
October 3	Saturday	Behavior Management Training	Redondo Beach, PWCF Office
October 4	Sunday	Brass Golf Tournament	Black Gold Golf Club, Yorba Linda
October 18	Sunday	Family Day at the LA Galaxy	StubHub Center
October 25	Sunday	LA County Support Group Meeting	Redondo Beach, PWCF Office
November 1-7	Sun-Sat	Obesity Week	Los Angeles
November 4-7	Wed-Sat	PWSA Meetings/Conference	Orlando, FL
November 13	Friday	Board Meeting	Crowne Plaza, LA Int'l Airport
November 13	Friday, 7pm	PWCF Meet and Greet	Crowne Plaza, LA Int'l Airport
November 14	Saturday	PWCF Annual State Conference	Crowne Plaza, LA Int'l Airport

Prader-Willi California Foundation is a non-profit 501(c)(3) public charity. Established in 1979, PWCF is the only organization dedicated exclusively to serving the needs of Californians impacted by Prader-Willi syndrome. PWCF is comprised of parents, extended family, friends, dedicated professionals and care providers, and is supported solely by dues and donations.

Prader-Willi California Foundation proudly maintains an affiliation with the national Prader-Willi Syndrome Association (USA)

PWCF OFFICIAL BALLOT ENVELOPE

I am/We are a PWCF Member in Good Standing
- ☐ Individual Membership Status -1 Vote
- ☐ Family Membership Status - 2 Votes
- ☐ Professional Membership Status - 1 Vote

Printed Name #1:_____________________________________

Signature #1:____

Printed Name #2:_____________________________________

Signature #2:____

Address:____

City, State, Zip:______________________________________

Mark your Ballot and insert into Ballot Envelope.
Ballot Envelope must be signed to be counted.
To ensure confidentiality, Ballot will be separated
from Ballot Envelope before being counted.

Please
Place
Your
Stamp
Here

Prader-Willi California Foundation
514 N. Prospect Avenue
Suite 110-Lower Level
Redondo Beach, CA 90277

NEW DVD!

Prader-Willi Syndrome Behavior Management Strategies that Work DVD

Especially for Parents, Extended Family, Babysitters, and All Care Providers

Produced by the Prader-Willi California Foundation, this new DVD provides valuable strategies to better manage the behavior of persons of all ages who have Prader-Willi syndrome

Topics addressed include:

- Understand How the PWS Food Drive Impacts Behavior
- Understand How Children & Adults with PWS Think So You Can Reduce Behaviors Problems
- Reduce Anxiety-Related Behavior Problems
- Avoid Oppositional Behaviors and Power Struggles
- Implement the Principles of Food Security
- Rewards, Incentives, Punishment & Natural Consequences
- Excessive Talking, Questions, Skin Picking
- When Does One Think About Medication?

About the Featured Presenter

Lisa Graziano, M.A., LMFT is the Executive Director of the Prader-Willi California Foundation. Ms. Graziano holds a Masters degree in Clinical Psychology with an Emphasis on Marriage, Family and Child Counseling, and is a Licensed Marriage and Family Therapist. She presents on a variety of aspects of PWS at conferences throughout the country including behavior management and marital and family issues. She is the proud parent of a teenage son who has PWS.

PWS Behavior Management Strategies DVD Order Form

PWCF Members $25 ‖ Non-Members $35

Ship To:

Name(s)____

Facility/Company Name (if applicable) ________________________

Address ________________________ **Phone** __________

City ____________________________**Zip**__________

Total DVD's Ordered: ________

Amount Enclosed/To Be Charged: $_______

☐ Check made payable to PWCF

☐ Credit Card

Name on Card ________________ Signature ______________

Card No.____

Expiration Date __________________ Security Code ________ *(on back of card)*

Email ____

Billing Address ____________________________________
(if different from address above)

Pre-Order your DVD by Phone, Online, Fax or Mail

☎ 800-400-9994 💻 www.pwcf.org Fax 310-372-4329

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Supporting People with Prader-Willi Syndrome

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