PWCF NEWS

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

The Newsletter of Prader-Willi California Foundation

AN AFFILIATE OF PWSA (USA)

Oct. - Dec. 2015
Volume 27, Number 4

In this issue:

PWCF IS RINGING IN THE NEW YEAR WITH TWO PWS CAMPS COMING UP IN 2016!

Registration opens
Early January
See page 7 for details!

PWCF ANNUAL STATE CONFERENCE: PROGRESS MADE!

The day's first speaker, **Daniela Rubin, Ph.D**., provided a hopeful overview of current PWS research. A promising medication to reduce the hyperphagia food drive symptom is RM-493 which appears to successfully decrease food intake, increase energy expenditure, decrease body mass, and improve metabolism and fat oxidation. Beloranib is a new drug in Phase III trials that shows promising results so far to reduce the food drive and behavior symptoms but has been temporarily halted while researchers consult with the FDA regarding the death of a study participant. [Researchers are working to determe whether the now two deaths were due to complications of PWS or the drug.] Another drug, Diazoxide, appears to increase fat oxidation and energy expenditure and normalize GABA receptors, all the while decreasing the hyperphagia food drive and significantly reducing aggressive behaviors. There is a great deal of research on Oxytocin, a "feel good" hormone that plays a role in behavior, metabolism, and the reproductive systems. The number and size of oxytocin-producing neurons in the brain is reduced in persons with PWS. Research has shown that increasing oxytocin levels reduces PWS temper outbursts, improves social interactions and bonding, and has a protective and reparative role in the central nervous system. May 2016 be the year for major PWS breakthroughs!

Daniela Rubin, Ph.D.

Tom Kavanaugh, M.A. kept the audience on its toes… literally! He taught attendees about the Brain Gym, a specific set of movements, exercises and activities that help improve concentration, focus, memory, academics, physical coordination, attitude, and even relationships. Employing volunteers from the audience, he demonstrated how to activate parts of the brain using various body movements. Tom's presentation was not only enlightening but entertaining and energizing!

Tom Kavanaugh, M.A.

Janice Agarwal, P.T. shared her wealth of experience and insights about how to improve the physical movements of persons of all ages with PWS. Janice reported that all children with PWS are born with abnormal muscle tone and have physical and sensory deficiencies. As a result, it is common to see upper and lower extremity weakness, skeletal issues including scoliosis and hip dysplasia, sensory integration problems, and oral-motor dyspraxia (difficulty making and coordinating movements which are used in the production of spoken language). Today, many infants and children now receive growth hormone therapy, so the degree of low muscle tone has improved. However many still face physical and sensory issues that require therapy and ongoing attention. Janice presented a multitude of strategies that parents can employ to improve the vestibular, proprioceptive, tactile, and oral motor systems of the body.

Janice Agarwal, P.T.

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PRADER-WILLI CALIFORNIA FOUNDATION
A Full Life Without Limits

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Web address: www.PWCF.org
Facebook: www.facebook.com/pwcf1

Supporting families in California

and beyond

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	pattimcrae@sbcglobal.net
SF Bay Area (teen to adult)	Michelle Donaldson	415-290-6282	md@michelledonaldson.com
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 Gutierrez (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) Facebook Support Groups
for Families of Children Ages Birth-3 Years
for Families of Children Ages 3-5 Years
for Families of Children Ages 6-12 Years
for Families of Teens
for Families of Adults

International PWS Organization, **IPWSO** offers information about PWS in other languages. Go to www.ipwso.org

PWS Share & Support Groups Meeting Calendar 2016

Southern California

Beach Cities Health District
514 N. Prospect Avenue, Redondo Beach CA
0-5 Years: Redondo Room (Lower Level/Basement)
6+ Years: Beach Cities Room (Lower Level/Basement)

Sundays: February 7, May 1, September 11
Time: 1:30 p.m. - 4:00 p.m.

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

Northern California

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

Saturdays: Jan. 23, April 30, Sept. 24
Time: Check-in 10:15 a.m.
Meeting 10:30 a.m. - 1:30 p.m.

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

PARENT TO PARENT

If you could go back in time and give yourself any advice about the PWS diagnosis what would you say?

Breathe… and breathe again. Milestones will be delayed, but only delayed. Participate in as many of the early interventions as you can. Call the hippotherapy [therapeutic horseback riding] program and ask how soon she can get in! Don't try to do this alone; involve your family from the start. Find another parent to talk to (a PWS parent).

Lastly, don't read farther than the age your child is at. ***Be in the moment with your child.***
Diana M. de la Rosa Galey, mother of Jenna, age 9

Keep calm. Follow what the PT and OT therapists assign. Tummy time is important, don't over cuddle learn to love the floor. It's ok to lie to coworkers, friends and family you don't have to tell anyone anything. Get on the same page as your partner in regards to treatment. Your child will amaze you.
Shell Pititt, mother of Dylan, age 1 ½

I would not feel sorry for the individual and I would train himor her in the social skills they will need for the rest of their lives. They need to be educated like other [typical] individuals and not give up on them when it takes longer to learn. They are [very clever at getting food] and need to be watched constantly. The food must be out of reach and locked. Left to their own devices, they will eat themselves to death. What may seem cruel is only good parenting. Weight control is a must and exercise should be not only encouraged but demanded.
Tom Von Der Ahe, brother of Steve, age 55

We were advised to not read anything online, to only look at PWSA's website. And, I was put in touch with Lisa Graziano [who ran PWCF's South Bay Support Group at the time]. All very helpful! To this day, I choose not to read anything unless it is from PWSA or PWCF. There is no need!!
Elizabeth Greskovics, mother of GiGi, age 15

We have a different story than most people with a child who has PWS. Even though our daughter had been born in a major California hospital and we had every test available at the time of her birth to figure out what was "wrong" with her, in 1986 the year she was born on Christmas Day, 6 weeks early, her diagnosis fell through the cracks. It wasn't until she was 25 years old (after years of tutors, therapists, exercise classes, treadmill work outs, etc) that a stranger who had a 41 year old daughter with PWS suggested to me that my daughter might have it.

The irony of this story is that finding out that she has PWS was the best thing that ever happened to her and us. We have studied the syndrome, attended a few conferences and our daughter is now normal weight (lost 75 pounds), lives in a group home, has a good volunteer job and is in a "Day Program." She is happy, beautiful, well-adjusted and we feel very blessed. She is 28 years old now almost 29.

Today we had her "IPP" and she had glowing reports from all concerned. It was SO DIFFERENT from the first 16 years of her life when I cried myself to sleep many nights. We do EVERYTHING recommended, from having locks on the cabinet doors and refrigerators. We aim for 800 calories per day maximum and she walks, swims, does yoga, walks dogs and as much exercise as we can squeeze in. She has adjusted beautifully to her new way of life (people with PWS like predictability and routine) and she is a joy to have around.

The STRICT LIFESTYLE for a person with PWS is not a curse, it is a life affirming way to live. Our daughter is HAPPY to have a dessert of sugarless jello when the rest of us have ice cream or cake. TOUGH LOVE is the way to go and your child will thrive. Take heart. It works and it isn't terrible.
Kathleen Meeker, mother of Anne Meeker, age 28

Our next Parent to Parent:

My loved one with PWS is hyper-sensitive to clothing tags. Will he grew out of it?
What sensory sensitivities do other people with PWS have and how do you treat or manage them?

Gadget Tip: If I Need Help Products

If I Need Help products are for loved ones who may wander or need assistance. Founders Bruce and Erin Wilson are the proud parents of a fun loving and overly energetic 13-year-old son, Jay, who has moderate to severe Autism. Jay has very limited language ability and has been known to quickly "bolt into danger." *If I Need Help* was created out of their concern and love for their son. There are a number of products including patches, shoe tags, dog tags, pins, clips, ID cards, bumper stickers, and clothing. Here's how the system works:

- Become a free member
- Create a profile which can be changed in real time when needed
- Have your special person wear or carry the iD patch, pins, clips, iD cards, shoe tags, or other iD products
- When lost, the code can be scanned by a smartphone/tablet or the number associated with the code can be entered manually into the home page of *If I Need Help* to access the contact information
- In a situation the profile can be emailed to you and forwarded to searchers
- Password protected secure site can be used to keep important personal information

Prices are reasonable. For example, shoe tags for tie and tieless shoes are $15; shoe tags for Velcro are $10; ID patches are $15; ID pins are $2. For more information or to order go to www.ifineedhelp.org

Food Tip: Ella's Kitchen Organic Juice Blends

Submitted by Julie Casey

Ella's Kitchen organic juice blend drinks are deeelicious drinks that are made from real fruit juice and purees, not from concentrates. Unsweetened and unsalted and never made with artificial colors, flavors, sweeteners, preservatives or concentrates.

Each 8 oz. box is packed with 1 full serving of fruit. Yummy flavors include strawberry Lemonade Juice blend drink; blueberry apple juice blend; mmmighty strawberry + red beet smoothie drink; amaaaazing apple + zucchini smoothie drink; superrrr sweet potato + mango smoothie drink.

Available at Sprouts, Farmers Market, Whole Foods, Target, Walgreens, Ralphs, and Wal Mart or order online at www.ellaskitchen.com

Our Kids Got Talent

Submitted by Lisa Graziano

Cameron Graziano has been practicing karate since age 9. When he first began taking lessons, he could not stand on one leg for any length of time. He has remained dedicated to the sport, progressing through six belts to his current brown belt. Now, at age 16, Cameron can not only stand on one leg, he can break a board with one swift kick! He has begun to participate in regional Tai Kwon Do competitions and was recently awarded a second place medal in the Forms competition. Way to go, Cameron!

EXECUTIVE DIRECTOR'S COLUMN

by Lisa Graziano, M. A.

At the end of each year I like to reflect on where we we've been and what we've accomplished. This year my first thought is really a question: *How did this year pass so quickly?* If PWCF had a dollar for every one *else* who has a similar thought, I bet we'd have a bunch of like-minded dollars making their way to us!

In 2015, PWCF served over 850 active members who live in California as well as live or work in other parts of the country. To keep up with PWCF's growing programs and services, PWCF is fortunate to have three dedicated individuals work in the office. In addition to me, we have **Gloria Burns**, who keeps PWCF's office and finances humming as our Office Manager. **Emily Dame, M.Ed.** was hired in June to bring education and training services wherever they are needed in California. We contract with awesome specialists including **Jill Nowak, R.D.,** who provides nutrition consultation services; **Sheila Umeda, MSW,** who provides social work consultation support; and **Katherine Crawford** who does our graphic design, including for this awesome newsletter. We have a number of members who generously provide consultative services throughout the year when we have need for legal consultation, grant writing services, regional center consulting, educational consulting, and more.

PWCF's vision is that all persons with PWS live a full life without limits. Each of our programs and services supports our vision and each of our goals. Let's take a look at what we accomplished this year:

Educational Activities --- PWCF produced a brand new DVD to educate and empower families and professionals on how to manage behavioral symptoms often associated with PWS. We produced a quarterly newsletter, providing important medical information, research-related information, educational articles, and stories of support and hope written by and for parents. We produced Behavior Management training sessions and an IEP training session to empower families. We updated our website to make it even easier to navigate and download critical educational, awareness, and support-related information for families, professionals, and the general public;

Annual State Conference --- PWCF takes great pride in the consistent quality of speakers, topics, information, and support we bring to our members. Our simultaneous Youth & Adult Conference not only provides a safe day for kids and adults with PWS, it was an awful lot of fun this year featuring a photo booth, a DJ dance, even a therapy dog. We raised awareness of PWS by recruiting 40+ enthusiastic university students in such fields as nursing, special education, PT and OT, medicine, psychology and social work to help with the program;

PWS Camp --- PWCF hosted our fifth annual summer camp with Easter Seals, serving 59 campers at Camp Harmon and granting over $13,000 in scholarships. Because the demand for camp now exceeds our capacity to serve everyone at one camp session, we sought out and reached agreement with Ability First and will open a second PWS Camp at Camp Paivika in 2016 in Southern California;

School Trainings --- Knowing how PWS impacts the student with PWS informs teachers and related staff about how to improve the quality of support they provide their student. We provided dozens and dozens of in-person and telephone training to schools throughout the entire state, gifting our school DVD when needed;

Dear PWCF: Great newsletter! I love all the dyspraxia info and [the Executive Director's] column was wonderful! *Linda Ryan, mother of Trevor, age 25*

Dear PWCF: Thank you for the Healthy Life materials I just received from your organization. How clever and how useful! Up here at Far Northern we are working on a number of small projects to increase the health status of those we serve. Your materials are very useful for everyone as well as the population you focus on. Thank you so much for the resources… Thank you again for the gifts. *Laura Larson, Executive Director, Far Northern Regional Center*

Dear PWCF: [The Northern CA Walk] was the most beautiful experience ever! So emotional. I loved it. My six year old told me, 'This is the happiest day of my life! I'm going to wear my t-shirt to school' and he did. Both he and his big brother, Carlos, who has PWS, wore their PWS t-shirts to school on Monday." *Maria Berber, mother of Carlos, age 11*

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.*

Executive Director's Column continued on page 6

Executive Director's Column, continued from page 5

Dear PWCF: Very warmest thanks to you for the grant for the CHOC Prader-Willi Syndrome Clinic. The ability to have two developmental behavioral pediatricians is of such importance and value to families. The impact of your support and generosity is so meaningful. Very deepest thanks. Warmly, *Sarah Miyashiro, Children's Hospital Orange County*

Dear PWCF: I want to thank you for all your help. I just spoke with the [In-Home Support Services] Social Worker and although she did not approve for 24 hour protective care, she is approving 30 hours a week. She did take the time to read all your information, which aided in her decision for more hours. She said the State of California just does not approve a lot of services for minors and expects the parents to provide that, even though I am not the parent. But I am very grateful for your help. Without that, Lilly would not even be approved for squat. Thank you Thank you! *Stephanie Lawson, grandmother of Lilly, age 6*

Dear PWCF: Thanks for your past information and support. Big win today for our IEP meeting... got 1:1 [aide support] till she is in 2nd grade… presently in Kindergarten. I was coached by all your "lingo" and all the info from PWCF. Our hearts are thankful. We stood our ground and won today. Yeah for the Home Team. I will help others in the future to achieve as well. Great New Year! Always Thankful!!! *Love, Rhonda Faust, mother of Angela, age 6*

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! *Jay Schwartz, Principal, Special Education Department, Glendale Unified School District*

Dear PWCF: …I'm excited about all of the new experiments they are doing with the "new" drug. I'm so thankful for [PWCF] as they have been so into getting PWS out into the news and information that was not available 30 years ago! Keep up the great work!! Thanks and kind regards, *Pat Noland, mother of Brent, age 51*

Multidisciplinary Clinics --- PWCF supports three PWS Clinics that provide state-of-the-art multidisciplinary treatment to children. Now, through the new PWS Clinic at UC Irvine that opened this year, we are serving the needs of adults with PWS;

Residential Support --- We provided dozens of in-person, individualized training programs to group home staff, supported living staff, Regional Center case workers, Day Program staff, and vocational work staff;

Individualized Advocacy Services --- PWCF's advocacy assistance helped families obtain the supports and services they need including Regional Center eligibility, group home placement, school aide support and other educational services, behavioral intervention services, in home supports, inpatient hospitalization support, and advocacy for growth hormone medication prescription and insurance coverage. "Casual" telephone conversations with many more families and professionals provided information that helped them advocate for themselves with greater success;

Family Support --- PWCF continues to maintain our 24-hour PWS-related Medical Crisis Line and our statewide toll-free 800 line. We continue to host Support Group meetings in both Northern and Southern California. We spoke with every newly diagnosed family, sent each a personalized Information & Membership Packet and a Member Handbook & Records Keeper binder when they joined. Each new family who desired one was connected with an experienced Parent Mentor for ongoing information and support. We hosted PWS Family Day events with the L.A. Galaxy, Anaheim Angels, Oakland A's, and We Rock the Spectrum Kids Gym where families gathered, networked, and just had fun together. We maintained our Social Work and Dietitian consulting services;

Public Awareness --- Community awareness of PWS is increased through our website which received another significant facelift this year. Our statewide walk-a-thon event generated the largest participation in its fifteen year history with over 700 attendees. We participated in the ASICS LA Marathon and LA Big 5K, hosted awareness booths at children's concerts and at other local venues. We distributed public service announcements and press releases which reached a potential audience in excess of 13 million! We maintain active Facebook and Twitter pages;

PWS Research --- PWCF supported state and national research by working with local universities, teaching hospitals, researchers, and scientists to help recruit subjects and disseminate research materials. PWCF supported the new Oxytocin research with a matching grant of $10,000. We are fortunate to have wonderfully collaborative relationships with researchers who are active in the study of PWS.

As you bid farewell to 2015, I encourage you to take a moment to reflect on the wonderful parts of what happened in your life this year and recognize the strength you have that got you through the tough parts. On behalf of everyone at PWCF, I wish you and your loved ones a safe and extraordinarily memorable New Year.

> What counts in life is not the mere fact that we have lived. It is what difference we have made to the lives of others that will determine the significance of the life we lead. *~ Nelson Mandela*

PWCF CREATES SECOND PWS CAMP!
REGISTRATION OPENS EARLY JANUARY 2016

What's more fun than PWS Camp?

TWO PWS Camps!

Now, in addition to our PWS Camp at Easter Seals Camp Harmon located in **Boulder Creek**, PWCF will collaborate with Ability First's Camp Paivika located in Crestline, Southern California. Both camps will exclusively serve campers with PWS!

Campers now have their choice to attend camp in the northern or southern part of the state – and we absolutely welcome attendance at both!

Both camps will receive PWS Training prior to camp from PWCF staff and volunteers **Lisa Graziano, Emily Dame,** and **Linda Ryan**. Lisa and Emily will remain at both camps throughout their duration.

Programming for both camps is similar and will include activities such as campfire fun, daily swimming, arts & crafts, hikes, basketball and tetherball, rap/share sessions, horseback riding, movie night, a dance, and of course awesome camp counselors! Male and female nurses are onsite to administer all medications. Staff to camper ratio is 3:1, with 1:1 available. Access to food is strictly secured with daily menus healthy, low calorie and low carb.

Here's your opportunity to recieve six glorious days of respite knowing your child or adult with PWS is safe, having a wonderful time, and making friends.

PWCF's Board of Directors has not yet established the amount of scholarship funding we are able to provide to members for the 2016 season. Stay tuned!

Online registration for both camps will open in January at www.pwcf.org. Space will be limited. For more information about programming, menu, or if you need help registering contact PWCF at 310.372.5053.

See You at Camp!

Northern California PWS Camp

Location:	Easter Seals Camp Harmon Boulder Creek, CA
Dates:	Wed. July 13 - Mon. July 18 2016
Cost:	$726 plus $75 Registration Fee

Southern California PWS Camp

Location:	Ability First's Camp Paivika Crestline, CA
Dates:	Thur. Aug. 4 - Tue. Aug. 9 2016
Cost:	$850

Would you like to help a wonderful person with PWS make memories of a lifetime?
Would you like to give a PWS family a week of respite?

Sponsor a PWS Camper!

Any donation - large or small - will help make our campers' dreams come true!
Donate today to support PWCF's PWS Camp Scholarship Fund www.PWCF.org

Annual State Conference, continued from page 1

Diobel Castner, M.S.

Diobel Castner, M.S. presented research-based information about movement, play and exercise needs for persons with PWS. We all know that physical activity contributes to better weight management, increased metabolism and energy expenditure, improved heart function, improved bone mineralization, improved sleep, stamina, self esteem, and ultimately improved overall quality of life. But few of us know *how* to help our kids and adults to be more physically active. This was the focus of this fantastic presentation. Ms. Castner provided great examples of movement activities and muscle and bone-strengthening activities. She provided recommendations for time durations and intensity for both for preschoolers, school-aged kids, and adults with PWS. Helpful videos illustrated exactly how to make physical activity and exercise fun.

A lively Residential Services Breakout Learning Session panel, led by **Paula Watney** (parent representative), **Joe Tontodonato** (group home representative), and **Paul Wurst** (supported living services representative) was standing room only, which illustrates the critical importance of addressing the residential needs of our increasing population. A list of very helpful suggestions was provided to families, including "Create a Fact Sheet for Your Family Member," "Set Communication Expectations," and maintain a "Community Perspective." Most persons with PWS require a higher level of service than persons with other developmental disabilities, a Level 4-I being appropriate for most. Attendees learned not only from the panel of speakers but also shared experiences and wisdom with each other.

Roger Goatcher led the School Age Breakout Learning Session where attendees learned how to answer important questions such as, "How can I support my child during his/her journey through education?" and "What can I expect from the school academically, behaviorally, socially and emotionally, physically, and in regard to transportation?" Parents of the young child were treated to detailed information from **Janice Agarwal, PT** at the Early Intervention Breakout Learning Session, and **Daniela Rubin, Ph.D.** presented a terrific Meal Planning Breakout Learning Session for Spanish speaking families. Always a favorite at every conference, attendees attended age-specific Sharing Sessions to learn from some of the most informed and knowledgeable… each other!

Golden Ticket winners throughout the day won PWCF's new *Behavior Management Strategies That Work* DVD.

Conference Packets, including all handouts, may be purchased for $25. Call the PWCF office or order at www.pwcf.org.

The **Youth & Adult Program**, *Meet Me At the Circus!,* was a huge hit. Programming was written and overseen by **Emily Dame, M.Ed**. and directed by our amazing Program Directors **Barbara Nguyen, Nanny Sanchez, Kristen Amarasekera, Kevin Amarasekera, and Ben Romero** who kept it all fun and safe. We had a cool photo booth, a Dance Party with DJ "G" (featuring our very own Gloria Burns), calming Yoga provided by DL Sweet, Movie Time featuring the hit Inside Out, and even a visit from Sofia the therapy dog!

Kevin Amarasekera & Emily Dame

To raise awareness of PWS amongst future professionals, we recruit volunteers from local universities. This year we had 40 extraordinarily enthusiastic volunteers. We thought you might like to read some of their comments about their experiences, so we included them in We Get Mail on page 18.

PWCF works hard to produce a safe, fun, high quality Youth & Adult Program. This mom's words encapsulate why PWCF works so hard to produce a stellar Youth & Adult Program: "I didn't feel like I had to worry at all about Averie, and that was a FIRST for me!"

Don't Miss Next Year's Annual State Conference!

Next year's ASC will feature **Jennifer Miller, M.D.** who will focus on all things endocrine related, **Harold von Bosse, M.D.** who will address all things orthopedic and scoliosis-related, and other great speakers.

Mark your calendar now to arrive at the Meet & Greet on Friday evening, **November 4** with the conference starting on Saturday, **November 5, 2016**. Northern California hotel site to be announced soon. Watch PWCF's website for updates!

2015 PRESIDENT'S AWARD RECIPIENTS & PHOTOS

Duane Shewaga & Delene Waltrip in recognition and appreciation of their significant support of the *Walking for Prader-Willi Syndrome* event including raising public awareness, funds, and producing an amazing video.

Estavan Policarpo in recognition and appreciation of his extraordinary support of Team PWCF at the ASICS LA Marathon and at PWCF's Cheer Squad.

Maggie, Molly and **Juan Gutierrez** in recognition and appreciation of their extraordinary support of Team PWCF at the ASICS LA Marathon and at PWCF's Cheer Squad.

Erin Phillips in recognition and appreciation of her extraordinary enthusiasm as a member of PWCF's Cheer Squad at the ASICS LA Marathon.

Petra, Munawwar & Aiden Ali-Martinez in recognition and appreciation of their remarkable leadership of Team PWCF's Cheer Squad at the ASICS LA Marathon.

Jessica Patay in recognition and appreciation of her continuous efforts to inspire her fellow PWS mom warriors and for organizing opportunities for mothers to come together for much-needed fellowship. Husband **Chris** accepted the award for her.

Virginia Kimonis, **M.D.** in recognition and appreciation of her many years of dedication to the PWS community through her work in PWS-related research.

Kristin Amarasekera in recognition and appreciation of her long-standing and passionate commitment to providing a safe and exciting environment for children and adults with PWS at PWCF's awareness and educational events.

Kevin Amarasekera in recognition and appreciation of his long-standing enthusiastic commitment to providing a safe and exciting environment for children and adults with PWS at PWCF's awareness events, educational events, and at PWCF's Camp.

Jacki Lindstrom in recognition and appreciation of her service on the PWCF Board of Directors from 2013 through 2015.

Julie Casey

Nisha Mehta in recognition and appreciation of her service on the PWCF Board of Directors and her work as Secretary from 2013 through 2015.

Outgoing Board member **Julie Casey** was recognized by the Board for her outstanding service as President from 2010-2015.

GENERAL CONFERENCE

YOUTH AND ADULT PROGRAM

YOUTH AND ADULT PROGRAM: COMMENTS AND HIGHLIGHTS

To raise awareness of PWS amongst future professionals, we recruit volunteers from local universities for our Youth and Adult Program during the annual conferences. This year we had some absolutely *amazing* volunteers play with our kids and adults. We thought you might like to read some of their comments:

I was impressed with the hard work and commitment of the parents and foundation. I felt I learned so much. I totally felt that day to be one of the most rewarding days I have experienced in a long time. The opportunity was a gift to me. Thank you for taking our students and giving us an opportunity to learn more about Prader-Willi syndrome. I loved the individuals we worked with – they made our day special. The added gift of being able to attend part of the conference was more rewarding. *Belinda Bickley, MSN Associate Dean of Nursing at West Coast University*

It was a pleasure. I hope to stay current with PWCF and would love to volunteer again in the future. *Jack Hale*

Thank you so much for the opportunity! It was an experience I will never forget! *Crystal Peralta*

It was such a pleasure being of service for such a great cause. Kierra and I could not stop talking about our wonderful experience at dinner time with our family. Felix, Jesse, and Ignacio were the best. We truly enjoyed our time spent volunteering with your organization and we look forward to future events to volunteer. Thanks again for the opportunity. *Keisha & Kierra*

Thank you for giving me a wonderful opportunity to have a great time with [persons with] Prader-Willi and other volunteers. You [Emily] were awesome! *Sarah Son*

Thank you so much for letting me volunteer! I had a blast! I would actually love to keep in touch with you and try to become involved. Do you do other kinds of meetings or fun nights for people with PWS because I would love to help with something like that. People with PWS are so much fun to be around :) Let me know! *Kari Burns*

Thank you so much for the opportunity!! I had so much fun and learned a lot. *Melissa Wenzel*

Thank you for your kind words and I really appreciate this great opportunity that I had. It was a new experience to me to actually interact with the people who have Prader-Willi syndrome. I enjoyed the time in the conference more than I expected and absolutely want to volunteer again next time. Please let me know if there is another volunteer work or event to staff around the area that I can join. Thank you again and hope you have wonderful holidays :) *MJ Cho*

2015 MEMBER GIVE BACK: FOCUS ON RAISING AWARENESS

This year's Member Give Back is an **Eco Tote Bag**, designed to help lighten your load while increasing public awareness of Prader-Willi syndrome.

Use your tote bag at the grocery store, use it to take home restaurant leftovers, take home library books, use it as a gym bag, pack your daily lunch – *everywhere* you go, use the PWCF Tote Bag to carry your goodies and help inform everyone around you about Prader-Willi syndrome. Watch your mailbox for your PWCF Eco Tote Bag.

PWCF works hard for you and your family. We hope our Tote makes your life a little easier to carry!

HANDCRAFTED LAP DESK FUNDS CONFERENCE SCHOLARSHIPS


Roger Goatcher & Diane Kavrell

Made with Black Walnut, Oak, and whole lot of dedication, PWCF Board member **Roger Goatcher** created a beautiful wooden lap desk that raised $500 for educational scholarships.

The desk was filled with goodies including desk supplies, a PWCF pen, a PWS bumper sticker, and a PWS wooden puzzle made by **Noah Thorner**, a young man who has PWS and his own website www.puzzlesntoysnwood.com. The winning bid of $250 was made by **Leo Bennett-Cauchon** who generously donated his new desk — keeping the wooden puzzle! — to the second place bidder, **Jason Messer**. Jason promptly matched Leo's donation, raising even more funds that helped pay for the registration fees of 5 families and 6 children so that they could attend PWCF's Annual State Conference.

"I am very happy that the desk has found a good home and even happier that we were able to raise $500 for scholarships for our families," said Roger.

PWCF expresses its deepest appreciation to Roger for creating and donating this beautiful item to PWCF, and to our top bidders, Leo and Jason, for their generous support.


Leo Bennett-Cauchon

RENEW YOUR PWCF MEMBERSHIP

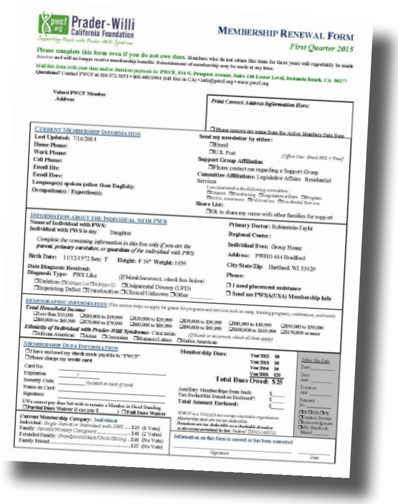
Fourth Quarter **Membership Renewal Forms** were mailed in October. If you haven't yet renewed your membership we urge you to do so today! If you didn't receive your Form in the mail please let us know so that we may mail or email you another.

Dues may be paid by check or credit card. If you can't afford all or part of your dues, simply check the box requesting a waiver. Please return your form even if you don't owe dues so we keep our Database current. Call the PWCF office at **310.372.5053** to renew your membership by phone.

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. Membership dues are not tax deductible, but donations are tax deductible to the extent permitted by law.

When you add a donation to your membership dues, you are supporting myriad wonderful programs like our PWS Camps, family support and advocacy services, our annual state conference, awareness-raising activites, our PWS clinics, our residential trainings, our school trainings, and professional outreach.

Renew your PWCF membership today!


Prader-Willi California Foundation

MEMBERSHIP RENEWAL FORM

First Quarter 2015

Please complete this form even if you do not owe dues.

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
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
Birth Date: 11/12/1972 Sex: F Height: 4' 10" Weight: 105#
Date Diagnosis Received:
Diagnosis Type: PWS Like
☐ Deletion ☐ 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

Total Household Income

Ethnicity of Individual with Prader-Willi Syndrome: Caucasian
☐ 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
Name on Card
Signature

Membership Dues:
Total Dues Owed: $25
Total Amount Enclosed:

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

Call for research participants

PATIENTS NEEDED FOR PWS RESEARCH

CALIFORNIA STATE UNIVERSITY FULLERTON

Parent-Led Physical Activity Program

Study investigating a parent-led physical activity program for children ages 4 to 7 years old with and without PWS. A child ages 4-7 years with or without PWS and one parent per family are invited to participate.

We will train your family how to do a **12-week home-based program** with activities and games that stimulate the development of motor skills. Your family will receive **all play materials and our curriculum of games at no cost.** The study will require three short visits at CSUF and two playdates (one at CSUF and one at a location of the parent's choosing). During the visits at CSUF your child will have their height and weight measured and will complete movement-related tests. Parents will complete questionnaires and a recorded interview. Children and parents will also track their physical activity.

Your child will receive a bag of toys ($10 value) following the first and last visits to CSUF. Parents/guardians will receive a $20 gift card at the same visits. Parents will also be reimbursed for mileage (up to $40 round trip) for the visits to CSUF and will be provided with free parking. For non-local families interested in participating, arrangements for travel expenses may be available (please inquire with our study staff). **Families may keep the all the materials when the program is over.**

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	

* * *

PWCF Expresses Our Sincere Appreciation to the Following Organizations for their Generous Support of the Annual State Conference

Zafgen

Essentialis Therapeutics

* * *

UCIRVINE

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: $100 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
24 Hour Telephone: 714-506-2063 (Pager)

PATIENTS NEEDED FOR PWS RESEARCH

CALIFORNIA STATE UNIVERSITY FULLERTON

Energy Balance in Adults with PWS

Research study investigating energy balance (calories consumed and spent) in adults with PWS.

Purpose: This study will find out how many calories adults with Prader-Willi syndrome (PWS) spend while walking on a treadmill at different speeds in comparison to adults without PWS. Also, we will evaluate the amount of calories consumed versus spent during a normal week at home.

Requirements:

- Adults with and without PWS ages 18-35 years old.
- Must currently use growth hormone replacement therapy for a minimum of 2 years.
- Ability to walk continuously for 5 minutes.
- Complete one visit to California State University, Fullerton lasting 3.0 hours.

Compensation: Participants will receive a $10 Target gift card and a copy of their body composition scan ($50 retail) for their participation!

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	

InterfaceAnalysis ASSOCIATES

Study Assessing Medical Delivery Device

Interface Analysis Associates, a San Francisco Bay Area healthcare research firm, would like your help to evaluate and provide feedback on the kit and instructions for a next generation drug delivery system for the treatment of Prader-Willi syndrome.

In January 2016 IAA is conducting a paid usability research study for family caregivers of children diagnosed with Prader-Willi syndrome. This is a great opportunity for parents to have a voice in future products they may use to deliver beneficial medication to their children or other family members.

Please note that no participants give or take any actual medication during our studies and therefore there is no risk to the participant. Participants are simply simulating the use of the product and providing us feedback about their experience. We want to improve patient safety and at-home health care through research. This is your opportunity to make a difference in the future of a device that you may use, and get paid for your feedback! Below are the details and qualifications specific to this study.

Study Qualifications:

- Must care for a child, adult, or family member diagnosed with Prader-Willi syndrome
- Is the person who is or would be responsible for giving the prescribed medication to the PWS patient

Study Duration: 1-2 appointments (45 – 60 minutes) (we have both available)
Compensation: $150 (1 session) - $200 (2 sessions) Cash
Study Dates: January 18-20, 2016
Location: San Jose/Saratoga Border (Near Westgate Mall)
Study Details: You will be introduced to a new medication delivery device and its instructions and will be asked to provide your feedback on the design and usability.

How to Participate: If you are interested in participating please contact our recruiter Clarissa at **(408) 907-6866** or email **iaa_research@yahoo.com** and mention the "Prader-Willi Study."

Control What You Can Control

By Jon Gordon

If you watched the U.S. Open Golf Championship this year you heard a number of golfers complain about the conditions of the course. This created a lot of buzz on social media. Many agreed with their complaints and many others called them whiners and babies.

The truth is they had every right to complain. The course was horrible and the greens were like concrete. But the bigger question is should they?

For me, the answer is as simple as the No Complaining Rule which says you are not allowed to complain unless you have a solution. No mindless toxic complaining and any complaints should serve as a catalyst for innovations and improvements.

So if you were a golfer who finished your final round and you complained about the course with the intention of improving the USGA's decisions and actions for future championships, then you had every right to complain.

However, if you complained while playing during the tournament, you were engaging in toxic complaining and only hurting yourself.

On ESPN radio, a golf writer said the golfers who complained the most seemed to be doing the worst while those who complained the least were doing the best. I wasn't surprised.

Toxic complaining causes you to focus on everything but being your best. It sabotages you and your performance. Complaining about something you can't control is a waste of energy, focus and time.

We saw a similar situation play out during the Great Recession. When it hit, many complained about the economy, feared the worst, stopped growing and ultimately saw their businesses crumble. On the other hand, those that embraced the challenges and change worked hard, stayed positive, innovated and actually thrived.

Whether it's the U.S. Open or the U.S. Economy, challenges are going to arise. There will always be something to complain about. But you have a choice. You can complain about things you can't control or you can control what you can control and let go of what you can't. You can focus on your problems or focus on getting better. You can look for an excuse or you can look within and find your best.

Westside Regional Center Looking for New Director

The Department of Developmental Services, following an informal meeting with the Westside Regional Center board of directors Monday evening, October 19th, will not intervene in their action made in a special board meeting held October 12th, to fire its executive director, Kevin MacDonald.

Department of Developmental Services Director Santi Rogers and senior staff also met in October with the Westside Regional Center's Consumer Advisory Committee, made up of members who are adults with developmental disabilities who receive regional center funded services and supports.

The department gave them assurances of support, including support to help the regional center move forward after months of growing turmoil and controversy. That meeting on Tuesday evening, held at the regional center, also included board members, family members, other advocates, and regional center staff – though was not attended by any board members who supported MacDonald. MacDonald was not present at either meeting.

Raising Public Awareness of PWS

Human Growth Foundation Event: PWCF's President **Julie Casey** and Vice President **Kim Morgan** worked PWCF's Awareness Booth at the Human Growth Foundation's walkathon in December. They met with a number of people who asked questions about PWS and PWCF.

Evite Pledge to PWCF: Evite now has a link you can include on your Evites so your invitees can make a pledge to PWCF right on your invitation!

Global Genes RARE Foundation Alliance: PWCF is now among over 300 disease foundations that have committed to collaborating with Global Genes and other nonprofit foundations in order to create a stronger, collective voice in the rare disease community.

Heidi Watney, daughter of former Board Member **Paula Watney**, raised awareness with her bPositive Project's t-shirt campaign which raised not only public awareness of PWS but $400 for PWCF! Way to go, Heidi!

RAISE YOUR RESILIENCE AS YOU RING IN THE NEW YEAR

By Emily Dame, M.Ed., Education & Training Coordinator

Everyone has experienced the feeling of stress. Even the act of being born is stressful on an infant, so in a sense, we are stressed from day one. Stress can come from small things (my low fuel light just came on) to large (the death of a loved one). Stress can be an isolated incident (I ran out of T.P.!) or it can accumulate like that pile of dishes that only gets larger the longer you put off washing them. So what do we know about stress, how does it affect our body and mind, and what can we do to become more resilient when stress seems overwhelming?

The definition of stress is very broad because it is a varied and subjective phenomenon. According to the American Institute of Stress, the most common definition is: “physical, mental, or emotional strain or tension” or “a condition or feeling experienced when a person perceives that demands exceed the personal and social resources the individual is able to mobilize.” Science has taught us that the definition of stress should also include ‘eustress’ and ‘distress.’ Eustress is stress that has good connotations such as getting married or having a baby. Distress is stress that has negative connotations such as getting divorced or having financial problems. Good or bad, it’s all stress on your mind and body.

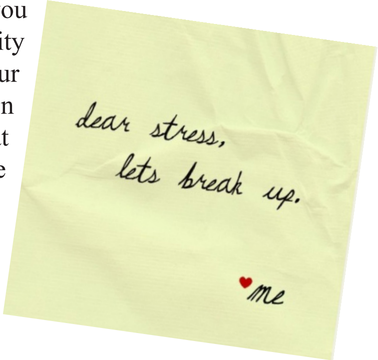
It is important to keep in mind that stress is a physiological and psychological response. When we encounter a stressor, good or bad, our brain responds by activating the ‘fight or flight’ alarm response, causing hormones such as adrenaline and cortisol to surge through the body increasing heart rate, slowing digestion, and increasing respiration. This response is the brain’s way of keeping us safe in dangerous situations. So, in small amounts, stress can be helpful in keeping us alert and on task to stay safe while we get the job done. After the initial release of hormones, our body begins to adapt to the stress and can start to resist the challenge of the current stressor. This part of the response takes energy. Our body can resist the stress and rise to meet the challenge, but it needs time to recover from this response. When unrelenting stressors occur and the body must respond over and over again this is called chronic stress. Chronic stress can affect the immune system and cause myriad problems if not attended to because the body is not able to replenish its energy sources before the next stress response occurs.

So when does “stress” become “stressed out”? Most research agrees that we experience the detrimental effects of stress when we feel less control over the stressful situation. So, the less control we feel over the environment and circumstances around us, the more likely we are to become stressed. Next time you’re in the midst of a stressful situation ask yourself what aspects of this are in or out of my personal control? Most often the only thing we have control over is our own actions. We cannot always control or prevent the stressors in the world around us, but we can control our reaction to them.

How do we know if we are experiencing chronic stress? Look closely at your past experiences of stress. Any behavioral response can become a pattern. Therefore, how you have reacted in the past should give you a good idea of how you might react in the future. In the past did you lose sleep, gain weight, or kick the dog? Did you take the time to exercise, eat healthy food, or get support from a loved one? Many of us know the common signs of stress such as headaches, anxiety, or irritability, but there are many common signs of stress that are less obvious such as upset stomach, panic attacks, anger, forgetfulness, muscle tension, a sore jaw from teeth grinding, an inability to make decisions, or a lack of interest in things that typically excite us.

Next, take a look at what triggers typically activate your stress response and what coping skills you prefer to use. We all know that money, work, and family can cause stress for everyone, but what really activates *your* personal fight or flight response? Recognizing your triggers will enable you to introduce thought between the stressful stimulus and your reaction to it. Once you see it, break your pattern of responses that are no longer productive and practice new ways to respond that are more helpful to you. Thinking positively, getting enough sleep, exercising, and eating healthy are the basics. Then take it from there by prioritizing your tasks and not being afraid to say ‘no’ or asking for help getting things done. Make time for activities that are relaxing to you such as meditation, reading, walking your pet, or listening to music. Use setbacks as learning opportunities and be ready to admit when you’ve goofed. Eliminate sources of stress such as clutter or loud music. Remember that it’s OK to cry. Remember your posture when you’re sitting, and stand up and stretch your body or go for a short walk when you’ve been sitting for too long. Most importantly, breathe. Like muscle memory, practicing deep breathing when you’re calm allows you to get back into a calm state of mind more easily by taking a breath during a stressful situation.

Now that you recognize that stress is a response relative to your perceived control over a situation, you may be concerned that the majority of things in life are out of your control. We cannot anticipate when our car breaks down or when that extra bill arrives in the mail. The key to controlling our responses to these acute stress episodes is to build resilience. The definition of resilience is the ability of a body to regain its original shape



Resilience, continued on page 16

PWCF WELCOMES NEWLY ELECTED BOARD MEMBERS

The three candidates who ran for a seat on PWCF's Board of Directors were elected on November 14, 2015. Each will begin serving their three year term effective January 1, 2016.

Rodney Dong

Nisha Mehta

Jacki Lindstrom

The remaining members of the 11 member Board include Whitney Bras, Roger Goatcher, June-Anne Gold, M.D., Diane Kavrell, Kim Morgan, Nisha Mehta, Daniela Rubin, Ph.D., and Jennifer Wolkensdorfer.

At its November 13 meeting, the Board of Directors elected its officers: Roger Goatcher, President; Kim Morgan, Vice-President; Nisha Mehta, Secretary; and Renee Tarica, Treasurer

PWCF SENDS OUR CONDOLENCES TO ALL AFFECTED BY THE INLAND REGIONAL CENTER SHOOTING

In December two gunmen entered the Inland Regional Center and opened fire, killing 14 people and injuring 21 more. Inland Regional Center is one of California's 21 regional centers that provides assessment, case management, and other direct services to over 280,000 people with developmental disabilities, including persons with Prader-Willi syndrome and their families.

As noted by ARCA, "Regional centers connect families and people with developmental disabilities to services and supports. They are places of connection and community. Any act of violence is a tragedy. But in a place focused on service to people with developmental disabilities, it is even harder to comprehend."

PWCF joins the entire developmental disabilities community as we send our heartfelt condolences to each of the victims' families, employees of the Department of Public Health and their families, Inland Regional Center's employees, their families, the individuals with developmental disabilities they serve, and all those affected by this senseless tragedy.

Resilience, continued from page 15

after circumstances have pulled, bent, stretched, or changed it. In life, resilience is the ability to adapt to adversity; to roll with the punches. Resiliency also means that we have a store of energy ready for when we begin to feel the familiar symptoms of chronic stress.

When stressful things happen that are beyond our control we will still experience stress, anger, grief, and pain. However, by examining our past relationship with stress, noticing how we typically respond to it, and improving our coping strategies, we have the power to control our own responses to stress. As the holiday season comes to a close many of us will reflect on both the eustress and distress we experienced in the past year. As we move into the New Year let's break up with our old responses to stress and build up our relationship with resiliency by taking care of ourselves. Ring in the New Year with resiliency to keep functioning physiologically and psychologically at your best!

For more information visit: http://www.stress.org/

WALKING FOR DUNCAN

Reprinted from the Santa Clara District Attorney's Office newsletter, The West Wing, Volume 2, 2015

Every year, a crowd clad in neon green shirts walk around Crissy Field in Golden Gate Park to raise awareness and money for the Prader-Willi California Foundation. A special group, among the sea of green, walk for **Duncan**.

Duncan McRae, 16, son of the District Attorney's Consumer Mediation Director, **Patti McRae** and her husband **Tom**, lives with Prader-Willi syndrome (PWS), a rare genetic disorder.

"At the walk, I like meeting other people with PWS," Duncan said. "There are games that people with PWS can play easily. I always do the raffle with fun prizes. The best thing is that family and friends come and support the walk and PWS."

The McRaes, along with **Duane Shewaga**, Coordinator for the DA's Real Estate Fraud Unit, and his wife **Delene Waltrip**, a former Senior Paralegal for this office, walked the trail around Crissy Field this April. Duane and Delene, who have supported Duncan since his birth, raised $1,500 from family, friends, and fellow DA employees.

"Our hope is to convey our thanks to Delene and Duane for their consistent support, "Patti said. "We also want to thank the District Attorney family, some who we do not even know, who donate to support our family and other families dealing with the challenges of PWS."

More than $70,000 was raised at three area walks, $2,300 in honor of Duncan.

If you would like to donate to the Prader-Willi California Foundation or would like more information on PWS, please visit www.pwcf.org."

PICTURING A WORLD WHERE EVERYONE UNDERSTANDS PWS...

Picture a world where everyone understands Prader-Willi syndrome, where everyone touched by PWS receives the education, supports and services they need. Your tax-deductible donation will help make this a reality in California.

Since 1979 PWCF has been the only organization in California to solely focus on serving the needs of persons diagnosed with PWS, their families, and the professionals who serve them.

This year PWCF provided support to newly diagnosed parents; funded PWS Multidisciplinary Clinics; provided critical advocacy services to families; brought invaluable education and training to families and professionals including residential providers, teachers, and Regional Center staff; raised the public's awareness of PWS; and helped researchers progress PWS research. Donate online at PWCF.org or call the office as 310.372.5053.

Be a Shining Star! Make a Shining Star donation today in honor of someone special.

WE GET MAIL

Dear PWCF: I'm so impressed with this newsletter! I know this must have taken so much time, but it was well worth it. I love the expert column! Keep up the great work. This is so informative and helpful to so many families in California. Thank you! *Melanie Silverman, M.S., RD*

Dear PWCF: Thank you so much for sending some of your educational materials to include in the silent auction [at the national PWSA-USA) conference! Your support in this, and the MANY other things you help with is much appreciated. With your help we were able to raise over $13,000 for the auction! All the best to you and your families! *Leanne Gilliland, Development Specialist and your PWSA (USA) family*

About PWCF's Annual State Conference:

Dear PWCF: First, thank you very much for the opportunity to present at the [Annual State] conference. It was a wonderful day and a memorable experience. Second, thank you for the chocolates. Of course, my father-in-law halfway opened the box when I got home before I could even offer him some. =) Lastly, I would be honored to help again in anyway. It was a great conference. In fact, I already did some deep massages with both my children (suggestions from Janice) and breathing exercises with my husband! Take care! *Diobel M. Castner, M.S., Project Manager, Prader-Willi Syndrome, Childhood Obesity, and Physical Activity Studies*

Dear PWCF: Thanks for the opportunity [to attend the Annual State Conference]... The conference was unbelievable... *Kilma Bournigal*

Dear PWCF: We had a wonderful and amazing time this year at the PWS Annual Conference! We took lots of wonderful pictures and will be sharing them soon! Thank you and have a wonderful day! *Barbara Nguyen and Nanny Sanchez of People's Care and two of this year's Youth & Adult Program Directors*

Dear PWCF: Thank you for an awesome [annual State] conference! I'm so thankful for every one of you! I'd like to add that I was really impressed with the Youth & Adult Program. I didn't feel like I had to worry at all about Averie, and that was a FIRST for me! *Jenny Wolkensdorfer, Member, PWCF Board of Directors*

From the Youth & Adult Program Volunteers who are our future professionals:

Dear PWCF: I was impressed with the hard work and commitment of the parents and foundation. I felt I learned so much I totally felt that day to be one of the most rewarding days I have experienced in a long time. The opportunity was a gift to me. Thank you for taking our students and giving us an opportunity to learn more about Prader-Willi syndrome. I loved the individuals we worked with - they made our day special. The added gift of being able to attend part of the conference was more rewarding. *Belinda Bickley, MSN Associate Dean of Nursing at West Coast University*

Dear PWCF: It was a pleasure. I hope to stay current with PWCF and would love to volunteer again in the future. *Jack Hale*

Dear PWCF: Thank you so much for the opportunity! It was an experience I will never forget! *Crystal Peralta*

Dear PWCF: It was such a pleasure being of service for such a great cause. Kierra and I could not stop talking about our wonderful experience at dinner time with our family. Felix, Jesse, and Ignacio were the best. We truly enjoyed our time spent volunteering with your organization and we look forward to future events to volunteer. Emily, thanks again for the opportunity. *Keisha & Kierra*

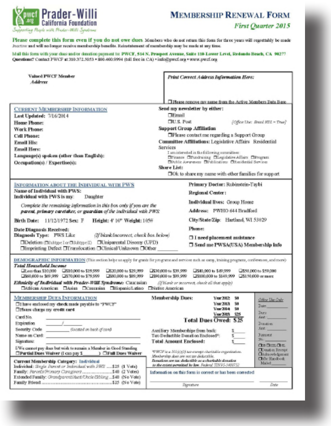
Dear PWCF: Thank you to Emily for giving me a wonderful opportunity to have a great time with [people who have Prader-Willi syndrome] and other volunteers. You were awesome! *Sarah Son*

Dear PWCF: Thank you so much for letting me volunteer! I had a blast! I would actually love to keep in touch with you and try to become involved. Do you do other kinds of meetings or fun nights for people with PWS because I would love to help with something like that. People with PWS are so much fun to be around :) Let me know! *Kari Burns*

We Get Mail, continued on page 19

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.


pwcf .org 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 *(Office Use: Email NSL = True)*
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 95-3480751*

Office Use Only
Date______
Dues Amt.:______
Donation Amt.:______
Payment No.:______
☐[illegible]
☐Donation Receipt
☐Acknowledgement
☐Info 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!

Renewed Professional Members

Gayle Cronic, Puckett Residential Services
June-Anne Gold, M.D.
Babak Hakimisefat, D.O.
Department of Genetics, Kaiser Permanente
Rosary Oliva, Lucky Homes Inc.
People's Care, Inc.
Phillip D.K. Lee, M. D., Univ of Texas Medical Branch

New Family Members

Maria & Jose Berber
Jocelyn Garibay
Lisa & Neil Greer
Bahghi Keflezighi & Layne Tedesfe
Leila Lindsey & Manny Enriquez

New Extended Family Members

Sylvia Boyle
Jamie & Justin Burns
Judy & Nick Cropper
Erin Phillips
Catherine Soden

Renewed Extended Family Members

Judy & Nick Cropper
Nancy & Christopher Rohan
Catherine Soden

VOLUNTEERS are Priceless

PWCF thanks **J.B. Jones** for helping to write a grant that would support PWS Camp. Thanks, J.B.! Fingers crossed!

PWCF thanks **Angela Lucero** and **Karin Boresoff** for their volunteer help mailing the Shining Star holiday greeting cards!

We Get Mail, continued from page 18

Dear PWCF: Thank you so much for the opportunity!! I had so much fun and learned a lot. *Melissa Wenzel*

Dear PWCF: Thank you for your kind words and I really appreciate this great opportunity that I had. It was a new experience to me to actually interact with the people who have Prader-Willi Syndrome. I enjoyed the time in the conference more than I expected and absolutely want to volunteer again next time. Please let me know if there is another volunteer work or even as a staff around the area that I can join. Thank you again and hope you have wonderful holidays :) *MJ Cho*

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

October - December 2015

Shining Star Donations

Sirius ($1,000 or more)

Judith Flanders in honor of Cerridwyn Donaldson
Fusion
Dennis Martino in honor of Lilli Moore
Ashish Mehta in honor of Siena Mehta
Dorothy & John Sirman in honor of Mike, Paula and Dustin Watney

Canopus ($500 - $999)

Gillian Gray in honor of Brooke Marich
Suzanne Privette in honor of Samantha Morgan (monthly donation)

Alpha Centauri ($250 - $499)

Evelyn Chaleki
Rory Hunter Trust in honor of Ryan Patay
Karen & Tim Jobe in honor of Austin Jobe
Diane & Brandon Kavrell in honor of Haley Kavrell
Marie-Claire Leon in honor of Ryan Casey
Shawnee Telephone Company in memory of Robert D. Johnson and in honor of Craig Winters
Sharon & Richard Willis in honor of Ryan Casey
The Graziano Family Trust in honor of Cameron Graziano

Arcturus ($100 - $249)

Judy & Bill Castle in honor of Jason Castle
Michele Boucher in honor of Trevor Ryan
Mary & Holger Bracht in honor of Kean Bracht
Beverly & Harvey Bush in honor of Jeff Bush
Jo & Floyd Hatcher in honor of Tristan Hatcher
Lucy Jao & Bie Chuan Ong
Irene & Kyle Kaiser in honor of Cameron Graziano
Margot & Gerry Lawrence in honor of Lisa Lawrence
Miriam & Elias Liberman in memory of Yvette Tarica
Jacki & Jeffrey Lindstrom in honor of Julia Lindstrom
Rose Sakurai in memory of Richard Sakurai
Liang-Yu Tai

Vega ($1 - $99)

Marilyn & John Bintz in memory of Page Bintz
Bunny Bloch in memory of Yvette Tarica
Jacki & Dale Delanders in honor of Trevor Ryan
William Duggan in memory of Shawn Duggan
Vivian & Raymond Edelman in memory of Yvette Tarica
Lee Elliott in honor of Cameron Graziano
Lisa & T.J Graziano in honor of Cameron Graziano
Barabara & Larry Gunter in honor of Brandi Sherman
Carole Kearney in honor of Katelyn Barcellos
Maria and Kenneth Knox in honor of Jamilet Knox
Isabelle Matos in memory of Manuel & Maria Resendes
Kathleen Minor in honor of Michelle & Kevin Donaldson
Margaret & Bill Spinelli in honor of Cameron Graziano
Plonneke & Martin Thoolen in honor of Lauren Thoolen
Kathleen & William Turley

Annual State Conference Grant Support

Zafgen
Essentialis Therapeutics

Annual State Conference Donations Support

James Bickley
Leo Bennett-Cauchon
Roger Goatcher
Jason Messer

General Donations

Dolores Adams
Adobe matching Tom & Pattie McRae's donation
Ione Bell via Local Independent Charities of America
Vicki & Terry Biswell in memory of Scarlett Meade
Tim Applegate in honor of Nolan Bonk
Sylvia Boyle
Wanda and Steven Faivre
Patricia Grey
Nancy Guerrera
Jacki & Jeffrey Lindstrom
Lucky Homes
Lucky Homes, Inc.
Patti & Tom McRae (monthly donation)
Ted C. Meadows in honor of Peyton Gregg
Anna Montoya via Local Independent Charities of America
Jerry Novotny in honor of Mavis Steffan
National Mah Jongg League, Inc.
Ruchita Parat
Joyce Stio in memory of Olga Tarquinio
Renee & Henry Tarica in honor of Elias Liberman's birthday
Matthew Taylor
Dr. Terrance D. Wardinsky

Donations to Support PWS Camp

Jacki & Jeffrey Lindstrom
Suzanne Privette in honor of Samantha Morgan (monthly donation)

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)