PWCF NEWS

pwcf.org Prader-Willi California Foundation

Supporting People with Prader-Willi Syndrome

The Newsletter of Prader-Willi California Foundation

AN AFFILIATE OF PWSA (USA)

July-September, 2013
Volume 24, Number 3

In this issue:

PWCF:

A Full Life

Without Limits

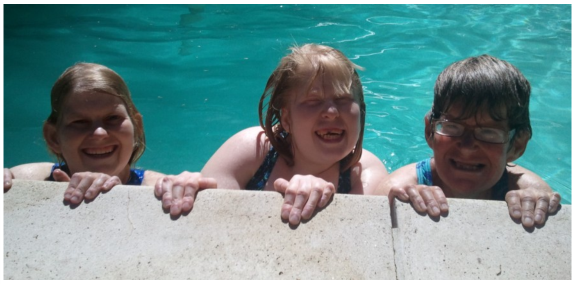
PWCF Holds Another Successful Camp Session

Over sixty campers attended PWCF's third annual PWS Camp session at Easter Seals' Camp Harmon in June. All the planning, coordinating and preparation that goes into making possible California's only PWS Camp (actually, the only PWS Camp on the *entire* West Coast) is completely worth it after seeing campers enjoy themselves reuniting with old friends and making new friends.

PWCF's former Vice-President **Linda Ryan,** Executive Director **Lisa Graziano**, and Family Support Coordinator **Katherine Crawford** arrived at Camp early to provide PWS training to all camp staff and meet Camp Harmon's new director, **Scott Webb.** We are so fortunate that Easter Seals engages truly incredible staff, many of whom are volunteer students who return year after year from all over the country because they love life and love sharing their lives with others.

This year's activities included the kick-off campfire, daily swimming, tie-dying, relay races, indoor and outdoor games, basketball, cabin play and board games, a horse-drawn wagon ride, an absolutely *fantastic* talent show, an end-of-camp dance, and of course the most delicious low-calorie menu created by Mama Deb!

Mark your calendar for next year's camp session June 19-24, 2014. Register early as space fills up fast. See you at Camp next year!



> Some of the most beautiful things in life cannot be seen or touched — they are felt with the Heart. ~ Helen Keller

Fran Moss, Editor, PWCF News

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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, their families and professionals with a state network of information, advocacy and support services.

PWS Support Contacts And Groups

Northern California

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

Central California

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

Southern California

Los Angeles County	Lisa Graziano	310-372-5053	pwcf1@aol.com
	Julie Casey	818-843-7321	julie.casey@att.net
Orange County - Contact	Jenn Paige Casteel	949-735-0472	marchroses@hotmail.com

Inland Region Area

San Bernardino County	Ester Del Real	909-213-5992	esterdelreal@ymail.com
	Maria & Ken Knox	909-421-9821	teachknox@aol.com

Spanish Speaking

Mercedes Rivera (Adults with PWS)	619-822-5742	mercedes_rivera2002@yahoo.com
Maria Knox (Adolescents with PWS)	909-421-9821	teachknox@aol.com
Kilma Carillo (Infants and Children with PWS)	760-427-1100	kilmab@excite.com
Veronica Baez (Infants and Children with PWS)	760-357-8189	vbaez92@yahoo.com

On-Line Support

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

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

PWSA Online eSupport Groups. www.pwsausa.org Click Enter. Click Support.

- for Families of Children Ages Birth-5 Years
- for Families of Children Ages 6-12 Years
- for Families of Teens
- for Families of Adults
- for Siblings
- for Spanish-Speaking Families
- for Military Families
- for PWS + Autistic Symptoms
- for Persons with PWS
- for Grandparents

International PWS Organisation

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

Parent to Parent

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

In my opinion smoking is an unacceptable behavior – just like acting out or hurting oneself or others. I would use a behavior management strategy. Implement a plan with specific goals and rewards. No smoking one day (or half a day) equals a token towards a larger reward, etc. I would insist that the group home only allow smoking in an outside designated area (and make that area unappealing). Don't provide money to purchase cigarettes. The group home should make smoking something that is not fun – perhaps reward the group that stays inside and doesn't smoke with a special game only for non-smokers. *Amy Wissmann, mother of Amanda, age 24.*

* * *

A couple of thoughts about this question: 1) If the smoking is occurring within the home or in areas where others may be exposed, this may be a violation of local regulations. The State or local health department may be able to assist. 2) Individuals with hypotonia or other neuromuscular disability, such as PWS, have an elevated risk for respiratory morbidity and mortality. Inhalation of tobacco smoke or other noxious fumes are known to adversely affect respiratory function and increase the risk for infections and cancer. The operators of this group home, and particularly the medical personnel involved, should be well aware of these risks and should be discouraging tobacco use among the residents. Perhaps the local chapter of the American Cancer Society or American Lung Association can provide assistance with educational programs and/or smoking cessation efforts.

Parents/guardians of individuals in residential group homes or assisted care facilities should not be afraid to approach the facility managers and/or medical personnel with their concerns. Hope this helps! *Phillip D.K. Lee, M.D. [Endocrinologist and PWS specialist]*

* * *

Just tell them straight out you don't want your child smoking. Went through a similar situation with my daughter and her group home. Just be honest and forthright. *Sandra Levine, mother of Caryn, age 37.*

* * *

First off, anytime you have concerns, bring them up just like this, "I have some concerns" and then list them. One parent will actually email me her concerns and the reason behind them. I print it out and address each concern and we come to compromise.

We hate smoking in our group homes. We have a designated smoking area, away from everyone and everything else *and* clients and staff take smoke breaks alone (the client is supervised from distance so staff doesn't get second-hand smoke). Smoking with "friends" makes it a *social event*. We do not promote smoking as social, it's an addiction. We convinced one smoker to use the e-cigarettes, have had physicians discuss stop smoking with our clients, and one conservator limits one client to 4 cigarettes a day and another one to 10 a day at designated times.

I assume the person is purchasing all their cigarettes. It's cost prohibitive and eats into the P&I. Show the resident what they could purchase with the cigarette money. Clients are not allowed to give each other gifts/things so make sure they are following this rule, especially in a house serving adults with PWS.

If the facility administrator is a smoker they may be less open to change. We have also discussed as an agency, due to large number of staff who smoke, to making some of our care homes 'non-smoking campuses.' Also, if the house manager is not the Licensee, go over their head if you get nowhere. The Licensee knows your child is worth $5,000 of income to their home (if this is a Level IV-I house). Hope these ideas help. *Mary Gates, Administrator, Residential Services*

* * *

My son with PWS, Nicholas, is 33. He has been in supportive living for about 4.5 years now. Prior to that, he lived in developmental centers and group homes. He has smoked for a long time. Nick has been able to maintain his weight well. He goes to the gym 3 days a week and attends adult education for his HS diploma. He is on a smoking contract that we have all agreed on. He's allowed 20 cigarettes per day (1per hour), always supervised. If not watched he would sneak or smoke at least 3 in the time that anyone else would smoke one. My son says that smoking helps curb the thinking about food. Nick maintains his diabetic menu and his smoking schedule like clockwork. This way he always has something to look forward to. Behaviorally this works very well and has helped Nick be successful. Nick prepares all his own meals. We have had no food issues for some time. Nick is part of all the decision-making. I know that people have bad feelings about smoking, and for good reason, but we are not working with the same thinking processes as our children. We decided a long time ago that you have to pick your battles. We felt that this is one we could live with. The smoking and eating schedules have worked wonderfully in relieving Nick's anxieties and obsessive thinking about food. The staff keeps the cigarettes as well as the lighter locked in the pantry with other supervised things. He asks to smoke and for the lighter at the correct times. We all know [that persons with PWS] operate best on time schedules so they know when everything is happening. This has helped satiate my son's consumer mentality and allowed him to be able to function well in the rest of his life. Hope this helps out. *Lynda Larsen, mom of Nick.*

Next issue's Parent to Parent question is *"I love attending our local PWS support group and am always surprised that more families don't attend. What keeps parents and grandparents, and aunts and uncles from attending support group meetings?"*

Food Tip

Submitted by Cameron Graziano of Redondo Beach

I love to eat frozen grapes! We put bunches into a bowl and pop them into the freezer for a few hours. Frozen grapes are a refreshing snack when it's hot outside or energizing on a cold, rainy day.

Green grapes have only 2 calories each, only .1g of fat and only .4g total carbs! Plus there are 4.6 mg of potassium, a mineral that helps balance the pH in our body, help keep fluids in balance, and help with muscle growth and brain function. Try a bunch of frozen grapes!

Gadget Tip

Time Timer

The **Time Timer** is a **quiet visual countdown** that helps the whole family make every moment count. Visualize time. Encourage visual learning. The **Time Timer** is totally intuitive. It comforts toddlers, builds independence in youth with learning disabilities, and it isn't just for kids! Adults with special needs can use the **Time Timer** at work to help *everyone* improve productivity. Prices start at $30. To learn more or to order visit http://www.timetimer.com/explore-special_needs.php#sthash.aDmEhXyO.dpuf
View all Time Timer sizes: http://www.timetimer.com/store/category/1/timers#sthash.fx4nFsZX.d

Back to School Snack Ideas

According to certified nutritionist Cheryl Wheeler Duncan, "Eating healthy snacks can provide children with the nutrients they need to 'feed their brain' and gain natural energy to get through their day." In today's busy lifestyle, snacks play a significant nutritional role.

Serve up uncomplicated, fast, easy, affordable and totally yummy snacks. Here are some healthy snack ideas:

Devil-ish Eggs

Nutritionist Trudy Scott recommends a boiled egg: "Boiled eggs are a great source of protein and good fats for growing brains. The choline in the yolk is important for brain health and as a chemical messenger between nerve cells. Eggs also help to keep blood sugar levels stable for better energy and mood." Okay, but just a plain old boiled egg? Maybe, that works some days, but cut that egg open, squirt on some Sriracha sauce (5 cal./tsp), salt and pepper, and you've got a bite o'dynamite. If hot sauce isn't on your kid's hit list, switch it to mustard (9 cal/Tbsp).

Smooth Move

Start with frozen blueberries (packed with antioxidants and brain food), a banana, and a little Greek yogurt.

Go Nuts

What's full of antioxidants, unsaturated fats, and is heart healthy? Nuts and seeds. Mix up raw almonds, sesame seeds, and cashews with some dried cranberries. But don't go nuts on the nuts; watch portion size on these snacks, a 1/4 serving should be about the maximum size. Prepack in sandwich bags so they are easy to grab and go. Or use a little peanut butter on celery or apple slices, a classic snack that everyone loves.

Other Quick Fixes:

- String cheese dipped in mustard
- Whole grain pitas with hummus or bean dip
- Chopped papaya sprinkled with lime juice and nuts (add chili powder for adventurous spice!).
- Edamame with soy sauce
- Dress up carrot sticks, broccoli florets and celery sticks with plain Greek yogurt spiced with a little soy sauce and dill. This snack is a great source of antioxidants, dietary fiber, and complex carbohydrates.

Executive Director's Column

Lisa Graziano, M.A.

PWCF's Board of Directors has been exceptionally busy this year planning how to provide greater support to families, how to increase the public's awareness of PWS, how to bring PWS education to greater numbers of families and professionals, how to better support research efforts and the reporting of it to members, and how to increase member participation in committees and events.

The list of PWS awareness and fund raising activities held just since the printing of the last edition of this newsletter is long. For the second year in a row **Sam and Kristin Cropper** poured their hearts and souls into creating another very successful and fun **Putt for PWS Charity Golf Tournament** that helped raise not only public awareness but a funds to support PWCF (page 7). Read about the grand Ball that **June and Ernie Leitheim** threw for their daughter, **Heather,** in celebration of her 30th birthday which also raised funds (page 13). PWCF applied for and was accepted as an Official Charity of the 2014 **ASICS LA Marathon** which will help raise a lot of public awareness this year and next**.** We are recruiting runners to be a part of Team PWCF so please let us know now if you want to be a part of this extraordinary challenge (page 15). PWCF applied for and was chosen to participate in a project for a Masters level Communications class at USC's Annenberg School of Communications. Graduate students will help us create a strategized campaign to increase the general public's awareness of PWS. Every event in which we participate introduces Prader-Willi syndrome to people who've never before heard of the disorder, bringing us closer to the day when PWS is as widely known as Down syndrome and Autism and families no longer feel so misunderstood and isolated.

In that isn't-it-ironic way, we are fortunate that PWS is such an "interesting" genetic disorder because it draws the interest of world-class researchers including those affiliated with the National Institutes of Health. PWCF's role in the area of research is to keep informed about studies and encourage families to participate in as many research studies as appropriate and comfortable. Every research study brings us closer to unlocking the complex mysteries of PWS and closer to the treatments we so desperately need. Please take a look at page 11 to see if there's a study your family could participate in. And let us know if you'd like to learn more about PWCF's Research Committee.

Meanwhile, families need education and support services *now*.

PWCF's advocacy and support services remain a high demand commodity. As the school year has begun so have the requests for inservice trainings and staff has been working hard to provide them. Our PWS Clinics are working hard to serve individuals with PWS; PWCF remains committed to continuing to fund them *and* establish additional clinics in the State. As medical insurance becomes ever more complicated PWCF is developing a relationship with a Licensed Clinic Social Worker to help families get the answers they need to the complex questions they have. As children born with PWS now have greater access to growth hormone therapy and are exhibiting fewer obvious symptoms, the need for advocacy support to maintain Regional Center eligibility past the age of 3 is increasing and PWCF is working hard to help families secure these services. As the State of California succumbs to instituting shortsighted "care" plans for people with developmental disabilities and has directed Regional Centers to return to California all out-of-state resident consumers, PWCF has been working hard to advocate for and support families as they fight to keep their child in their current successful group home placement. At its May meeting PWCF's Board of Directors resolved to initiate a new Give Back Project to provide additional support to members. This year's Give Back will be a free Medical Alert booklet, an invaluable pocket-size publication that contains life-saving information to provide to physicians. The booklets are being distributed in memory of **Yvette Tarica**, daughter of long-time members **Renee and Henry Tarica**.

Bringing PWS education to families and professionals is an unrelenting fundamental responsibility. Just as schools have requested more inservice trainings this past quarter so have residential providers asked for assistance with in-house training of their staff. As a result of PWSA (USA)'s Wyatt Special Education Advocacy Training course attended last March by Family Support Coordinator **Katherine Crawford** and Board member **Roger Goatcher**, Roger and Katherine created a brand new educational program to help parents understand and navigate the entire school IEP system (page 9). This training program is designed to educate and empower parents as they advocate for appropriate supports and services for their child. I presented a PWS Behavior Management Training Session to inform parents and professionals about how persons with PWS typically think and react so that parents and professionals may develop more successful strategies to reduce unwanted behaviors (page 9). It is our goal that both of these educational training sessions will travel throughout California next year, making it easier for members to benefit from the wealth of information that is presented. Finally, PWCF's 2013 annual state educational conference planning is complete and reveals an incredibly exciting program! **Breaking Through Barriers**, to be held on November 2 at the Crowne Plaza LAX, features keynote speaker is **Nick Daley**, a successful television actor who just happens to have Prader-Willi syndrome. The enclosed/attached flyer reveals an impressive lineup of presenters, all of whom are extremely knowledgeable about PWS. The program contains something for everyone: **Special Needs Trust and Wills, and Conservatorship issues** presented by ***Lisa Thornton, Esq***.; **Endocrine Conditions in Persons with PWS** presented by ***Suparna Jain, MD***; **Physical Activity: Why It's So Important That Your Child/Adult is Physically Active and the Role of Your Family** presented by ***Daniela Rubin, PhD***; and **Successful PWS Behavior Management Strategies** presented by ***Lisa Graziano, LMFT***. Share Sessions will provide support and networking opportunities, and a simultaneous Youth & Adult Program will provide fun activities and programming for persons with PWS and their peers. PWCF's conferences are *always* educationally rewarding and highly rated – don't miss this one!

Please support PWCF so that we may continue to support you. Your Membership renewal keeps us strong. Your dues funds our core programs. Your generous donations enable us to save lives and improve the quality of life of *everyone* impacted by Prader-Willi syndrome. I am proud of the work of PWCF and remain ever hopeful that successful medical interventions are just around the corner and, working together, we will reach them.

In the Trenches

Vol. 12

by Jessica Patay

Dear Sweet Mama (or Papa or Caregiver):

You have been given an incredible, amazing, and heartbreaking gift.

You have been given a child with "special needs."

The needs could range from severe allergies to severe handicaps and/or anything in between. Not that there is a spectrum and your story is worse than another mom's story. Or her story is worse than your story. You just each have a story. And a journey that has been difficult. It may get easier. It may get harder. BUT you are all "special mamas" together. You are all in this TOGETHER.

And it's not the road you asked to travel down. You were hoping for the road that leads to Italy, Fiji, or Santorini. Yet instead your travel stop landed you in the middle of a war-torn country you've never been in. There are landmines to baby-step around. There are well-meaning but insensitive people there. And there are downright nasty, unjust humans there, too, who make your struggle to provide everything your child needs all that more challenging.

It is TRUE, though, that in this distant land of life with disability there are ***angels.*** There are lovely souls who care and whose patience and compassion are as vast as the universe sky. There are angels each step of the journey if you look for them, in the smallest cracks of your day. YES.

Sweet Special Mama, do not think for one second that your experiences in Motherhood are in any way on par with families who have *not* encountered disability.

Do not think for one second you should be like THAT MOM, wife or family.

Do not expect that you will cherish motherhood and parenting in the same way.

Do not expect that you will not need breaks. Lots of them.

Do not expect to never fantasize what life would be like if your child was born perfectly healthy in every single possible way.

Do not condemn yourself for wishing, hoping, praying, and pleading for a re-do.

You, Mama, carry heartache.

You carry loss.

You carry an on-again off-again grief. And it comes in waves. And in your everyday life, it's there underneath the surface, threatening to come up.

It takes some of your joy. It makes you tense. It makes you more snappy and less carefree-and-happy.
You have become more tender and you have become tougher as a result of this terrific trial in caring for your disabled child.

And it's ok.

You are ok.

You are very ok.

You can do hard. You already have.

I know there are moments you absolutely want to curse and cry, "Why me? Why us?" You want to pull your hair out after a day of dealing with illness, or medical specialists, or anxiety or behavioral issues. That is normal. You are normal.

You need to vent.

You need to cry.

You need to share, with raw intensity and honesty, with other moms. Just be WITH.

You absolutely must exhale or your soul and spirit and body will implode.

That cannot happen because your precious child needs you, mama-bear-advocate-extraordinaire. So find, seek, and chase after moments or days of respite.

In your brighter moments, you completely recognize that you are deeper, richer, more compassionate and more sensitive to the needs and crises of others because of what you have been through. Because of what you go through every day.

Continued on page 7 ...

Awareness

Putt for PWS Charity Golf Tournament

An extraordinarily HUGE thank you to PWCF members **Sam and Kristin Cropper** who organized from beginning to end the second **Putt for PWS Charity Golf Tournament** awareness and fund-raising event held in June in Windsor. Thirty six golfers, seventy dinner guests, and twenty children enjoyed the event that netted over $8,000 to support PWCF's programs and services!

Sam and Kristin poured their hearts and souls into the event to raise awareness of PWS in their community and raise the quality of life of their beautiful daughter, Chloe, who has PWS. Thank you to all of our family members who attended the event, including Board members **Paula Watney** and her husband **Mike**, and **Tom McRae** and his wife **Patti**.

Fashion Supports PWS

On August 17 at the home of PWCF **member Jessica Patay** a group of women gathered to sip a little wine, shop the CAbi Fall 2013 collection of beautiful clothing, and raise some funds to support PWCF. Jessica will donate a portion of the event's proceeds to help fund childcare for the L.A. County Support Groups. **Thank you, Jessica!**

PWCF Member Angela Lucero Honored by Global Engagement Solutions

The Global Engagement Solutions Team spotlights certain individuals who deserve to be recognized for their immense efforts in volunteering and philanthropy. Through associate suggestion Global Engagement Solutions shined the spotlight on ADP associate and PWCF member **Angela Lucero** for her many years of dedication in fundraising and participating in The Prader-Willi California Foundation and Walkathons. The GES Team noted "She is passionate about finding a cure and continues her efforts in supporting the foundation. Angela works diligently to grow Prader-Willi awareness throughout the year. With her vigilance and dedication to finding a cure, she has helped to grow the Walk year after year."

In The Trenches continued from page 6 ...

Yet, it is VALID to wish that this unique opportunity for major emotional, spiritual, and intellectual growth was not given to you. That personal growth could have come, *should have come*, in a different vehicle altogether. No mother, however excellent and mature she is at having wise perspective, wishes for their child to be disabled. No mother.

So again, do not place unrealistic expectations on yourself, your heart, your mind, and your day-to-day dealings with disability. It is hard. It is maddening.

And when the sweet moments and small victories come, inhale them, deep into your soul. Because of these, you will survive.

Sweet Special-Needs Mama, you will survive, and the sun will still shine.

I love you,

Jessica

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

Peanut Butter and Lollipops: A Curious Test for Speech Problems

by Katherine Crawford, Family Support Coordinator

The test is a strange one. As a parent, you may be used to exercise balls, theraputty, and balance games from the OT/PT, and blowing bubbles, or repeating syllables from the speech therapist. But this test involves peanut butter and lollipops and has implications beyond just speech production. For this first test, the speech-language pathologist (SLP) puts a dab of peanut butter just above the upper lip of the child.

"Lick the peanut butter off with just your tongue", the SLP says. The child scrunches up their face with focus, opens their mouth, and tries to stick out their tongue. But the tongue is "stuck". It looks like the tongue can move, but somehow can't get out of the mouth on-demand.

"Alright then, next try!" The SLP gives the parent a napkin to wipe of their frustrated child's mouth. Then, the SLP puts peanut butter on the corners of the child's lips. "Now let's see if you can get *this* peanut butter off with just your tongue." Once again, the child focuses intently on the task. With every ounce of focus, they try to get the peanut butter. But just like the first test, their tongue is stuck, unable to reach the peanut butter just outside the corners of their mouth.

"We're done with the peanut butter for now, but good try! Are you ready for the next test?" The child squirms as their parent wipes their mouth clean with the napkin, but then straightens back up when they see the SLP pull out a lollipop. "See this? I'm going to hold this lollipop right here for you." The speech therapist holds the lollipop just in front of the child's mouth. "See if you can lick the lollipop." Just like the other tests before, the child opens their mouth and tries as hard as they can, but the tip of their tongue just won't leave their mouth. "Good try!" The SLP hands the child the lollipop, and goes on with the rest of the testing. The other tests seem fairly dull by comparison: making an inventory of sounds the child is capable of making, challenging the child to repeat words of increasing difficulty (things like this are called a "motor speech exam"). The speech-language pathologist will also check the inside of the child's mouth to make sure there isn't a physical problem interfering with articulation.

"Well, just from today's tests, I suspect that your child may have Childhood Apraxia of Speech." *Oh no,* thinks the parent. *Another diagnosis?* But take heart: CAS is one of many things that occasionally show up in the PWS population that can be improved through therapy.

Apraxia means that there's nothing physically wrong with the mouth preventing your child from saying words clearly; it's considered a motor speech disorder. Speech affected by apraxia is notable for the "random" distribution of speech mistakes being made. The child can say a word one day, but not another. They may also have limited vowels. They have difficulty rapidly and accurately moving between sound sequences - a difficulty which becomes more apparent in longer words. Something is interfering with the child's speech.

That "something" is a breakdown in communication between the brain and the muscles of the mouth, and/or there is trouble sequencing the motor movements needed for clear speech. Research is still being done in this field to figure out the precise mechanism. But how is this different from other common speech difficulties? In a normal speech delay, language the child understands and language the child uses are equally delayed. In CAS, the child will be able to understand a *lot* more language than the child is able to use verbally. For a child with PWS, hypotonia can also have an impact on speech, since low muscle tone affects the muscles in the tongue and mouth. Speech difficulty caused by low muscle tone is called *dysarthria*. But don't worry, this complexity is exactly why you are going to a speech-language pathologist trained in differentiating these issues. Now let's get back to apraxia.

Imagine two kids are playing an old video game. They are both an equal "match" for one another. But imagine that one of them has a video game controller that has a cable that isn't quite connected properly to the console, and who doesn't have all the combo-moves memorized. Even though he has access to all the same buttons as his friend, his video game character just isn't fully under his control. The child understands the game but can't make the character move properly. But, if we jiggle the cable to make sure that connection is solid and *explicitly* teach him all the game's combo moves, all of a sudden he can play the game competitively.

In apraxia, the brain is the child holding the game controller, the video game character is the muscles in the body (who wait to be "told" what to do by the brain), and the cable is the neurological connection between the two and "combos" are the speech sequencing. Treatments for apraxia involve "jiggling the cable": giving those neurons that connect the tip of the tongue to the brain lots of stimulation and exercise to strengthen those pathways and practicing tricky sequencing directly with exercises.

After some time in therapy, the child in the story above goes back to the SLP. "Lick the peanut butter off with just your tongue" the SLP says. This time, the peanut butter gets licked off the corners of their mouth and their upper lip. "Lick the lollipop that I'm holding." The child is able to lick the lollipop. It is empowering for the child, no longer trapped by their own faulty "cables", and it is uplifting for the parents who watch their child grow and prosper. The specific tests done to check for apraxia will vary from SLP to SLP, and they may or may not include peanut butter or lollipops. This should go without saying, but treatments aimed at solving other speech problems (such as a general delay, or dysarthria) don't necessarily address the causes of *apraxia*. Children with apraxia need therapy designed *for* apraxia. Children with undiagnosed apraxia generally do not make progress in speech therapy.

For information about the diagnosis and treatment of Childhood Apraxia of Speech visit **http://www.apraxia-kids.org**

Training Programs

PWCF has been busy preparing educational training programs to support families and professionals. Our goal is to travel these and other training programs throughout California.

IEP S.O.S.

In July PWCF Board member **Roger Goatcher** and Family Support Coordinator **Katherine Crawford** presented to parents the information they learned as participants of PWSA's Wyatt Special Education Training course. The training was held at the PWCF Offices in Redondo Beach.

Roger and Katherine compiled a *tremendous* amount of educational tips and guidelines and placed them into a 3" binder designed to help families understand the entire daunting process of their child's Individualized Educational Plan (IEP). Each attendee received a free binder. Stay tuned to attend an IEP S.O.S. coming to your area!

PWS Behavior Management Training Session

PWCF Executive Director **Lisa Graziano** presented a training session in August to help parents and professionals better manage the behavior of persons of all ages who have PWS. The packed agenda included such topics as *Understanding the PWS Food Drive – Hyperphagia; Understanding How Children & Adults with PWS Think; The ABC's of PWS Behavior Management; The Principles of Food Security; Collaborative Problem Solving; Rewards, Incentives, Punishment & Natural Consequences*; and *Excessive Talking, Questions, Skin Picking & other Obsessive-Compulsive Behaviors.* We hope to bring the next PWS Behavior Management Training Session to your neighborhood.

VOLUNTEERS
are
Priceless

Thanks to **Trevor Ryan** for his help with multiple mailing projects, New Member Binder creation, and office organization. His upbeat attitude and determination made quick work out of many projects. Thank you!

Thanks to **Carina Chaij** for her quick work to translate an important project into Spanish. Always willing to help. Thank you, Carina!

Thanks to **Cameron Graziano** for helping to prepare the mailing of educational training flyers!

Rosa's Law Eliminates "Mental Retardation"

In October, 2010 President Obama signed a federal statute (Public Law 111-256 Rosa's Law) that required the federal government to stop using the term "mental retardation" and begin using "intellectual disability" instead. The Social Security Administration (SSA) will become the latest federal agency to implement Rosa's Law. By the end of 2013 the SSA will eliminate all such references and replace them with the term "intellectual disability."

The American Psychiatric Association's 2013 classification of disorders likewise replaces the term "mental retardation" with "intellectual disability" and "intellectual developmental disorder." IQ scores will continue to be one factor in the determination of the severity of intellectual disability, assessed as Mild, Moderate, Severe, or Profound.

To read the Act visit http://www.gpo.gov/fdsys/pkg/BILLS-111s2781enr/pdf/BILLS-111s2781enr.pdf

Covered California: California's New Insurance Marketplace


COVERED CALIFORNIA

Visit Covered California's consumer-friendly homepage
www.CoveredCA.com
or call us, toll-free:
800-300-1506

Because the 2014 enrollment period begins this October, it's a good time to start talking about what Covered California is and how it could potentially be useful for you.

Chances are you've heard a little about it over the radio, on TV, or online. Covered California is California's new insurance exchange platform. The goal of this program is to provide a place for Californians who don't have health insurance (or who are struggling to pay insurance premiums) to shop for and purchase insurance. But it's no secret that buying health insurance can be expensive, so starting in January 2014 there are a number of things that are going to be put into place to help offset these costs. Each of these options is based on your income. You and your family may be eligible for more than one of the following options.

- **Tax Credits** are available for individuals and families that meet income requirements and do not have affordable health insurance that meets minimum coverage requirements through their employer or government program. Tax credits are available when you pay the premium; you do not have to pay the entire premium up-front and then wait for reimbursement. These tax credits can only be used for Covered California Insurance.

- **Cost-Sharing Subsidies** reduce out-of-pocket expenses, such as co-payments. Subsidies are based on income level and family size. You may be eligible if your income is less than around $27,936 (for an individual) or less than $57,636 (for a family of four).

- **Medi-Cal Assistance** will be expanded to include people *under* 65 with an income of less than $15,856 (for an individual) or $32,499 (for a family of four). For those eligible, this coverage is free.

Another consistent barrier has been the ability to compare one insurance plan to another, since insurance plans are complicated. Originally, Covered California had planned to have a rating system starting at its launch date, however this will be delayed until Covered California can review performance of the new plans offered. After all, you can't judge performance until it happens. But all's not lost: there is another place you can compare insurance companies. The Office of the Patient Advocate has an up-to-date ranking of California insurance providers and HMOs. They even have an app for quick comparisons, so check out the website at the bottom of this article.

There are other changes that will also take effect. For one thing, you and your family will not be denied insurance for a pre-existing condition, nor will you be charged more because of a pre-existing condition. This had been a concern for families with an individual with PWS.

One final change to be aware of is even if you are staying with the *exact same* insurance company, the exact network of covered providers may change. You'll want to check to make sure your doctor is under the network if you're buying it under Covered California's marketplace.

Plans offered in the individual and small group markets must also now provide a comprehensive package of items and services. These are known as "Essential Health Benefits". These services include most vaccines and a wide swath of preventative health care, aimed at reducing the cost of preventable illness.

Covered California's website also includes a helpful calculator to allow you to get an idea of what you and your family might be eligible for. For more information, look at the links below:

Covered California 800-300-1506
www.coveredca.com

Office of the Patient Advocate (for comparing insurance companies and HMOs)
http://www.opa.ca.gov/

Research

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

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

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

PWS and Early-Onset Morbid Obesity Natural History Study – All Persons with PWS Conducted by Virginia Kimonis, M.D., Chief, Division of Genetics and Metabolism, UCI Med Ctr. The purpose of this study is to collect natural history information on PWS and early onset morbid (severe) obesity.

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

WHERE: UCI Medical Center and General Research Centers at UCI Med Ctr. and Children's Hospital, Orange County in Orange, CA. CONTACT: Virginia Kimonis, M.D. at 714-456-5791 or email at vkimonis@uci.edu or Marie Wencel, research coordinator at 949-824-0521 or email at mwencel@uci.edu.

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

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

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

Symptoms of Prader-Willi Syndrome Associated with Interference in Circadian, Metabolic Genes

Researchers with the UC Davis MIND Institute and Agilent Laboratories have found that Prader-Willi syndrome is associated with the loss of non-coding RNAs, resulting in the dysregulation of circadian and metabolic genes, accelerated energy expenditure and metabolic differences during sleep.

The research was led by Janine LaSalle, a professor in the UC Davis Department of Medical Microbiology and Immunology who is affiliated with the MIND Institute. It is published online in *Human Molecular Genetics*.

"[Children with] Prader-Willi syndrome do not sleep as well at night and have daytime sleepiness," LaSalle said.

The study found that these behaviors are rooted in the loss of a long non-coding RNA that functions to balance energy expenditure in the brain during sleep. The finding could have a profound effect on how clinicians treat children with Prader-Willi, as well as point the way to new, innovative therapies, LaSalle said.

The leading cause of morbid obesity among children in the United States, Prader-Willi involves a complex, and sometimes contradictory, array of symptoms. Shortly after birth children with Prader-Willi experience failure to thrive. Yet after they begin to feed themselves, they have difficulty sleeping and insatiable appetites that lead to obesity if their diets are not carefully monitored.

The current study was conducted in a mouse model of Prader-Willi syndrome. It found that mice engineered with the loss of a long non-coding RNA showed altered energy use and metabolic differences during sleep.

Prader-Willi has been traced to a specific region on chromosome 15 (SNORD116), which produces RNAs that regulate gene expression, rather than coding for proteins. When functioning normally, SNORD116 produces small nucleolar (sno) RNAs and a long non-coding RNA (116HG), as well as a third non-coding RNA implicated in a related disorder, Angelman syndrome. The 116HG long non-coding RNA forms a cloud inside neuronal nuclei that associates with proteins and genes regulating diurnal metabolism in the brain, LaSalle said. "These novel molecular insights into the energy imbalance in PWS should lead to improved therapies and understanding of lncRNA roles in complex neurodevelopmental and metabolic disorders."

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Florence K. Crary[1],
Spencer S. Wong[1],
Robert A. Ach[2],
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Did you know that you can help PWCF earn money just by doing things you do every day?

If you search the web (and who doesn't?), you can use www.goodsearch.com instead of Google or yahoo and every time you click search it's a penny earned for PWCF. To get started go to goodsearch.com and click on "sign up" in the upper right hand corner and follow the directions to get started.

Help Ralph's support PWCF by registering your Ralph's Reward Card online in the Community Contribution Program. Once you register, every time you shop for groceries with our Ralph's Reward Card, a donation will automatically be made to PWCF at no additional cost to you! **You must re-register every year; the new year starts on September 1st, so even if you registered before you need to re-sign up each year:**

1) Go to www.ralphs.com
2) Click on "services" along the top red bar then select "Community Contributions"
3) At the bottom of the page click on "enroll"
4) Follow the directions to establish your online account or sign-in to your existing account
5) Designate Prader-Willi California Foundation – Organization #93694 – then whenever you use your Rewards Card a portion of your purchases will be donated to PWCF

Sign up for eScrip which encompasses three ways to support PWCF

- Sign-up and register your reward cards, credit cards and debit cards then whenever you shop at participating merchants a portion of your purchase amount will be given to PWCF
- Visit www.escrip.com to sign up
- Click on "about the program" along the top then click on "sign-up"
- Search for Prader-Willi California Foundation or enter group ID# 500042750
- Once our name appears you can select it and then continue your enrollment
- Once your cards are registered a portion of purchases made at participating merchants will automatically be donated to PWCF
- Shop at the eScrip online mall
- Once you set up your eScrip account you can shop lots of merchants including amazon right from your personal eScrip page or install the AutoEarn program to make sure participating online merchants are redirected to your eScrip page to ensure a portion of your purchase is donated to PWCF
- Alternatively you can shop through this link: https://secure.escrip.com/jsp/group/onlinemall/groupmallredir.jsp?gid=500042750
- Participate in eScrip Dining by Rewards Network
- Once you enroll in the eScrip program and register your cards, a portion of purchases made at participating restart aunts will be automatically donated to PWCF

Note: Safeway/Vons limit their contributions to K-12 schools therefore PWCF is not eligible to receive donations for purchases made at their stores; however purchases at all other participating merchants are eligible.

Heather Leitheim Shines as the Belle of the Ball

It was a perfect evening. The ballroom glittered from floor to ceiling with tiny white lights tucked within lavender balloons. Ladies in flowing gowns and sparkling jewelry whirled about the room with elegance. The gentlemen were sharply dressed in crisp tuxedos. Even an infant guest wore his tuxedo bib.

On each round dining table was a sprinkling of shimmering diamonds of all sizes that surrounded long-stemmed glass roses that glowed in tones of pink, then purple, then blue, changing colors like magic.

This wasn't just *any* ball. It was the 30th birthday celebration of **Heather Leitheim**, who has PWS, daughter of **June and Ernie Leitheim**. The belle of the ball was dressed in a stunning beaded chiffon gown that glittered as she danced. June was dressed in an equally beautiful gown and Ernie cut an impressive figure in his black tuxedo. Heather and her parents absolutely beamed throughout the evening.

A plated dinner of vegetable lasagna was served, followed by fancy sorbet a delicious birthday cake just perfect for wish-making. A professional photographer took gorgeous photos of ball's gorgeous guests. Heather's cousin wowed the audience with her extraordinary voice, singing two songs she chose to honor Heather. Raffle items donated from the Leitheim's community thrilled guests who eagerly purchased tickets for a chance to win and raised hundreds of dollars. The Leitheim's planned the ball to honor Heather and to raise funds for the Prader-Willi California Foundation because, said June, "The Foundation has given our family so much support we just want to give some back."

By the end of the evening the Leitheims had collected over $2,600 in donations. Many thanks to June and Ernie for organizing and hosting such a beautiful and poignant ball. And a very Happy Birthday to you, Heather. May all your wishes come true!

2013 Membership Renewal

Don't forget to renew your PWCF membership! Reminder Renewal Forms were recently mailed.

Renewing your membership keeps PWCF strong and vital and keeps you informed of all educational and support activities.

If you haven't already, please renew your membership today!

Board Corner

Summary of the Board Meeting/Retreat May 16-18, 2013

Submitted by Julie Tauscher

Prader Willi California Foundation held the Board meeting/annual retreat in Marina Del Rey. Board Members present: Julie Casey, Nisha Mehta, Kemberlee Morgan, Paula Watney, June-Anne Gold, MD, Julie Tauscher, Renee Tarica and Roger Goatcher. Fran Moss, Katherine Crawford and Lisa Graziano were also there to help tackle our agenda.

Group Home for Children Update

Whitney Bras and Lisa Graziano updated the Board about their progress working with a residential service provider who is interested in developing a group home to serve children with PWS. PWCF family members living in Orange County have been queried about their interest in residential support. They will also reach out to non-member families who attend the PWS Clinic at Children's Hospital Orange County.

Research Committee Update:

- June-Anne wishes to add committee members to assist her with research planning and support. Katherine Crawford, Nisha Mehta and Kimberlee Morgan volunteered for the committee.
- June-Anne followed up on the Oxytocin study and is starting to recruit participants to work with Dr. Jennifer Miller who is the Primary Investigator.
- June-Ann and the Board were excited to discuss a new opportunity for a possible newborn screening for PWS.

PWSA (USA) Wyatt Educational Training Report

Roger Goatcher and Katherine Crawford shared a pilot manual they put together after they attended the Wyatt Educational Training Program designed to help parents navigate through the IEP process. It was obvious the amount of time and effort both have put forth to create this manual and provide information, suggestions and resources for families. The Board was very happy with the depth of information included. Next a series of training sessions educating families will begin at the July 7th Support Group Meeting held in Redondo Beach.

Executive Director's Report

- Lisa discussed with the Board potential candidates to fill future board members vacancies. Several names were suggested and will be given the nominating committee. The Board saw a need to try and include someone with a child with PWS between the ages of birth to 5 years, an area where we are currently lacking.
- The PWS Camp session in June is full and there are currently 11 individuals on the waiting list for this awesome camp opportunity. There is a new camp director this year. Lisa, Katherine and Linda Ryan are geared up and will be training camp staff. There was discussion on how to coordinate carpooling for parents transporting to camp. This may be something the camp committee can assist with for next year.
- **General Education Meeting (GEM)** Planning continues for the GEM. Date is set for November 2nd. Lisa is currently working to finalize the contract with a hotel near LAX and has contacted potential speakers for this year's Southern California GEM.
- ***Walking for PWS* Awareness Event Updates** Lisa handed out a report detailing financials for all three Walk locations. Over $47,000 has been collected so far. It was noted that at the Southern and Northern *Walks* Lisa asked everyone in attendance for a moment of silence to remember Yvette Tarica, the daughter of *Walk* organizer and long-time PWCF members Renee and Henry Tarica. This was an extremely touching moment for many walkers, their families and Board members who were touched by their interactions with Yvette. Yvette attended Northern and Southern California *Walks* with her family and friends each year.

Strategic Planning

The Board spent some time redefining Short Term and Long Term Strategic Planning.
Board members agreed that short term goals should fall within the 1 to 2 year timeframe, with 3+ years for long term goals.

Identified Short Term Goals:
1) Walk awareness events; 2) Camp; 3) Putt for PWS; 4) Race for PWS; 5) Galaxy Event; 6) Cut A Thon; 7) Birthday Ball Celebration; 8) Information booth at Levitt Pavilion; 9) Parent Information Fair; 10) Behavior Training Sessions; 11) IEP Training Sessions; 12) General Education Meeting; 13) quarterly newsletters.

Membership Board members agreed that **current "Membership**" status is based on and defined as members who renew their annual membership with a dues payment or a waiver request.

Giving Back Board members discussed the introduction of a "give back" program to support members. Board members identified several give away options and chose the **Medical Alert Booklet** as this year's give away item. This booklet is a very helpful tool parents and providers can carry with them and share with doctors to give answers to vital medical questions.

Continued on page 16 ...

Board Corner

Summary of July 23, 2013 Teleconference
Submitted by Roger Goatcher

Board members present: Whitney Bras, Julie Casey, Roger Goatcher, Jackie Lindstrom, Tom McRae, Nisha Mehta, Kimberlee Morgan, Paula Watney, Renee Tarica. Board members absent: Julie Tauscher, June-Anne Gold. Others present: Lisa Graziano, Executive Director; Katherine Crawford, Family Support Coordinator

A Family Day at the Oakland A's event was discussed and options for holding this year's event, but a decision was made to hold off this year because of the tight timelines and the amount of tickets that would need to be sold to break even. There was interest in exploring the event for next year.

The Board discussed the recent death of a young adult with PWS who became morbidly obese while living at the group home and the removal of that group home from PWCF's Residential Facilities Referral List. The Board discussed how to communicate with the group home and the Regional Center about the care and wellbeing of current residents.

A Member Outreach Project will be implemented prior to the General Education Meeting. Board members will contact each of our members to personally invite them to the conference and discuss any items the member may wish to explore.

A Give Back Program will be launched starting this year to provide yet more support to members. This year's Give Back item will be in memory and honor of Yvette Tarica and will be a Medical Alert Booklet. We look forward to mailing these booklets to our members as quickly possible.

We are still pursuing the creation of a group home to serve children with PWS. We are coordinating efforts with a provider who has agreed to open a home, a Regional Center, and a local PWS Clinic.

The Board discussed creating a new vision statement for the organization. Many great ideas have been discussed and considered. We will finalize a final vision statement at our next Board meeting.

During new business Julie proposed creating a new brochure targeted toward Medical professional and Friends that would educate about the new generation of children with PWS so that the public knows that PWS does NOT automatically mean children will be obese.

Julie also proposed that we create a new development committee for fundraising and networking that would be made up of non-board members (outgoing or former ok) in order to reach out to members who want to get more involved.

PWCF is proud to announce that we are an Official Charity of the ASICS LA Marathon!

Run with Team PWCF and help raise awareness of Prader-Willi syndrome! Help us provide education, support, research opportunities, and advocacy services to families and professionals. For more information visit www.PWCF.org or like our Facebook page www.facebook.com/PWCF1

Tell us NOW if you want to run with Team PWCF!
pwcfoffice@aol.com or **(310) 372-5053**

Date: Sunday, March 9, 2014
Starting Line: Dodger Stadium, Los Angeles
Finish Line: Santa Monica

Board Corner May 16-18 continued from page 14 ...

Member Outreach Helping families stay connected, informed, and supported is an important part of the work of PWCF. Board members discussed ways to improve communications with PWCF members and how to reach out to inactive members.

Mission Statement Review Following a recent leadership training program attended by PWCF's President Julie Casey, Vice President Kim Morgan, and Executive Director Lisa Graziano, the Board reviewed PWCF current mission statement. After a long brainstorming session, the Board came up with the following revisions:

> *"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. Prader-Willi California Foundation provides individuals with PWS, their families, and the professionals who serve them with a state network of information, advocacy, and support services."*

Vision Statement Board members are also looking at revising the current vision statement of PWCF. Homework assignments have been given to each member to come up with a revised vision statement.

Elevator Speeches, brief descriptions designed to quickly convey information about Prader-Willi syndrome and the Prader-Willi California Foundation continue to be reviewed by the Board. The Board is looking to find that one statement that will have to most impact on substantial financial donors.

Social Worker Resource PWCF has identified a social worker to consult with families on social services matters such as medical insurance reimbursement, Medi-Cal, and Medicare issues. She will be invited to the next Board Meeting to introduce herself and explore a more formal association with PWCF.

Health Bridge PWS Inpatient Unit Update Progress is being made on the creation of a PWS inpatient unit at HealthBridge Hospital in Orange County. PWCF is involved in the connection of PWS specialists with the hospital's director to ensure they are able to provide quality services for those in need.

And may you always remember that obstacles in the path are not obstacles, they ARE the path.

~ Jane Catherine Lotter

Consider the ways friends make life better. Authentic friends…

1) Encourage us. Friends believe in us. As a result, they offer both the words and the support we need to become better people in all aspects of life.

2) Challenge us. Friends recognize deficiencies in our life. They challenge us to embrace and succeed in making these healthy, life-giving changes.

3) Motivate us. In every regard, it is highly motivating to know that someone loves you, believes in you, and is cheering for you.

4) Listen to us. Friends open their ears and hearts to our words. A listening ear communicates value, trust, and openness. And a listening ear provides the opportunity for our thoughts to disentangle themselves.

5) Celebrate with us. Full joy is never realized until it has been shared with others – that's why we immediately call our friends when something good happens. Friends celebrate with us in victory and make our joy complete.

6) Grieve with us. Life is full of ups and downs. Friends make the high points higher and the low points bearable.

7) Support our contributions. Friends recognize the value we contribute to the world and the beauty we offer to it. They look forward to our contributions and promote them to others.

8) Keep us honest. Friends know us best. They know our strengths… and they recognize our weaknesses. Because of their intimate knowledge of who we are, they keep us honest with each other and with ourselves.

9) Add joy to our lives. According to a study from the Harvard Medical School, the more friends a women had, the more likely they were to be leading a joyful life. There is likely some correlation between being joyful and having friends… but clearly the inverse is also true.

10) Improve our health. Studies also indicate that authentic friendships actually result in better health. These relationships make healthy habits easier to adopt and the body more likely to heal itself.

11) Provide opportunity for influence. Trust always precedes influence. Sometimes trust can be earned quickly (books, experts, studies), but other times it can take years of living life together. Friendships – life lived in relationship with others – offers trust and influence.

12) Provide opportunity for sacrifice. Giving always benefits the receiver and the giver. True friendships require sacrifice. And in that sacrifice, both lives are improved.

Author Unknown

We Remember

Christopher Ashwin Clarke-Gujral

April 5, 1979 – July 6, 2013

Christopher Ashwin Clarke-Gujral departed this life in the evening of Saturday, July 6 surrounded by family and friends.

Although he left us at much too young of an age, Christopher made a lasting and positive impression with those who were lucky to have known him. Despite the daily challenges he faced while dealing with Prader-Willi Syndrome, Christopher never passed up an opportunity to make a friend, and never forget your birthday or phone number.

His humor and cleverness, his smile and laughter, and his genuine warmth and thoughtfulness will be greatly missed, but never forgotten.

PWCF continues to receive donations in memory of Christopher, which are acknowledged on our donations page in this newsletter.

The Mom Switch

by Lisa Peters, Massachusetts

I believe there is a "Mom Switch" located somewhere in the brain of all young boys, a switch that when kept on, enables these growing children to love their mothers unconditionally.

In the early years, a young boy's mother is his everything. She represents beauty, warmth, shelter and love. Her female energy gives her a kind of magical superwoman power in the eyes of her adoring son.

But as her child starts to grow, there is a time in each boy's life when his Mom Switch is abruptly clicked off. Mom's female energy is now embarrassing and unwelcome. She is annoying, nagging and old. The family leadership baton is passed to Dad as he assumes the position of the infallible figurehead and new household champion.

Exiting mother goes from super hero to super hopeless with the sudden flick of a switch.

Weston's Mom Switch flicked early, but dear loving Nicholas seemed to be missing the mother reject button and I thought, just maybe, I was going to get lucky. Perhaps some of Nick's missing genes included a missing Mom Switch. I basked in the sunshine of his stuck button and unconditional love for the past 11 years.

But alas, it was wishful thinking and all good things must come to an end.

Today, I was startled by the very loud ***SNAP*** of Nick's Mom Switch turning undeniable **off.**

It was morning and I was making coffee and toasting an English muffin. Nicholas was in his usual place beside me, helping me pour the water into our Mr. Coffee machine.

"POP" went the muffin as it jumped out of its slot in the toaster.

I grabbed the golden brown muffin and dropped it quickly to the counter.

"Ouch, that's hot," I said to no one in particular.

Well-versed in the smart aleck language of his older brother, the budding new mother repeller replied with a sarcastic tone,"Well, yeah Mom! It came out of the toaster, duh!"

I froze for a few seconds, stunned by my son's new found ability to zing his poor mother.

Yes, mild mannered Nicholas has learned the art of smart assness.

I thought about the mental skill required to effectively needle a person and realized that perhaps Nick's recent neuropsychology test failed to accurately measure this skill.

While I am sad to have lost the only Mom supporter in the family, I realize that like Weston, dear hearted Nicholas is on his way to becoming a young man.

I hope my self esteem survives.

Do you think our dog, Muffy, has a Mom Switch?

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

PWCF: Leadership, Mission and Vision

by Julie Casey, Board President

In January I, along with Board Vice President **Kimberlee Morgan**, and Executive Director **Lisa Graziano** had the privilege of attending the Annenberg Alchemy Leadership Seminar at the Annenberg Foundation.

One of the things the Leadership Seminar teaches is how to develop a compelling mission statement. They emphasize that an organization's mission statement should clearly demonstrate the "why" behind the organization - what is the fundamental belief or driving force of the organization? Once that is stated, then explain what the organization is doing to address the issue. Many organizations actually have a mission statement that is either more appropriate as a vision statement (the ultimate desired outcome) or is actually the organization's goals or objectives.

Kim, Lisa and I brought back what we learned at class to the Board which has since spent a good amount of time discussing and revising the mission and vision statements.

The existing mission statement was…

> *Our mission is to provide parents and professionals with a state network of information, advocacy and support services to expressly meet the needs of people with Prader-Willi syndrome, their families and the professionals who support them.*

And the existing vision statement was…

> *Our vision is that people with Prader-Willi syndrome may pursue their individual hopes and dreams to the full extent of their talents and capabilities…and that we will help them achieve their goals.*

The Board felt that the existing content was still applicable, but based on the current thinking of emphasizing why an organization exists first, that the mission needed some tweaking. We also realized that the vision statement was really part of our mission. Therefore the Board happily announces our new mission statement…

> ***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, their families and professionals with a state network of information, advocacy and support services.***

We believe that this will serve as our over-riding purpose in the years to come and lets the world know why Prader-Willi California Foundation exists. All of our objectives and goals will continue to fall under the umbrella of helping individuals with PWS achieve success either by direct benefit to the individual, or more-often, indirectly by educating parents, teachers, doctors, therapists, etc. with appropriate information to properly assist their loved one, patient, student, or client.

Coming up with a vision statement was a little harder. We wanted something that would succinctly capture what we strive to accomplish for our children, but how do you do that in one line? After much discussion we are happy to present our new vision statement…

> ***A Full Life Without Limits***

We liked incorporating the word "full" for its double meaning – we all want complete lives for our children and of course we wish those with PWS didn't lack the ability to feel full. We incorporated "without limits" because so often people who have PWS are left out, told they can't do something, are perceived by others as unable to achieve, or face a variety of other limits. It is PWCF's ultimate desire that all people who have PWS will lead ***A Full Life Without Limits*** and our mission is to help them achieve this ultimate vision.

We Get Mail

Dear PWCF: As I've told my boss and several other co-workers, [PWCF Executive Director Lisa Graziano, who testified on behalf of an individual with PWS] were FABULOUS! Once we get the decision, I thought I'd send out your contact info to all of the Office of Clients' Rights Advocacy branch offices. You are a really welcome addition to our list of experts. And, even aside from potential expert testimony, just a very valuable resource… *Kimberlee Candela, Attorney, Clients' Rights Advocate, Office of Clients' Rights Advocacy, Disability Rights California*

Dear PWCF: Nick had a fabulous time at Camp. He said it was wonderful yet again. Thank you to all at the PWCF who put their time and energy into making the camp happen again this year. This is a fabulous resource and really, really beneficial for us. *Jennifer Paige-Casteel, mom of Nick, age 13*

Dear PWCF: I have been utilizing this [Food, Behavior & Beyond: Practical Management for the Child and Adult with PWS] home study for training my staff for one of my dependent adult consumers with Prader-Willi syndrome. I feel the information provided in the DVD is very useful in assisting persons with Prader-Willi. *Thank you, Tanna Robertson*

Dear PWCF: I finally worked my way through the aging stack of mail on my desk and read the April-June newsletter, with Katherine's great piece on her brother's experiences in Pittsburgh. Katherine, well done. Thank you for your honest, bracing writing. I felt my own gut wrenching when Michael managed to get out of TCI and landed in a psychiatric ward. I was sweating it out, hoping for a happy ending, and was relieved to read that he did eventually get back to TCI. I'm looking forward to an update (or maybe it's already buried in my new mail stack...) *John Storr, dad of Naomi, age 12*

MEMBERSHIP ACTIVITY

July-September 2013

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

New Family Members
Annie Fricke & Andrew Smyth
Kristen Widdifield

Renewed Family Friend Members
Dolores Horn & Mel Goldberg
Jan & Steve Grogan
Patrick Maxon
Ronnie Raffaniello

Renewed Extended Family Members
Dolores Albaugh
Carina Chaij
Judy & Nick Cropper
Gail Morgan
Nancy & Christopher Rohan
Sharri & George Marich
Frances & Dave Sim
Joyce & Norman Smith
Billy Vitro
Ron Vogrin
Celeste & Tom Von Der Ahe
Carol Williams

New Extended Family Members
Rosary Osuna

Renewed Professional Members
Zylnna Andaya Oliva,
Mary Lane Carlson, EdD, MPH, RD, CDE
Suzanne B. Cassidy, M.D.
Vicki Cox, M.S.
Gayle Anne Cronic
Lynn W. DeFreece, North Valley Services
Department of Genetics, Kaiser Hospital Sacramento
Jaime Fisher, M.S.
Michael Gottschalk, M.D., Children's Hospital, San Diego
Linda Hamilton, Lee Street Homes
Laura Larson, Far Northern Regional Center
Phillip D.K. Lee, M.D.
Lota Mitchell
Rosary Oliva
Kwaj Overton, BSN, RN, The Children's Institute PWS Program
Cynthia R. Pollock, Esq.
Melanie Silverman, MS, RD, IBCLC
Julie Tauscher, PRIDE Industries

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

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

We work hard to recognize all donors who wish to be recognized. If you don't see your name listed, please accept our sincere apologies and allow us the opportunity to include your name in the next issue by contacting us at 310.372.5053 or PWCF1@aol.com

DONATIONS ~ July-September, 2013

SHINING STAR DONATIONS

Canopus ($500 - $999)

Suzanne Privette in honor of Samantha Morgan

Donations in Memory of William E. Breeden on behalf of his grandson Makoa Breeden

Pulani & Alan Cumpston
A. Sonia Faust
Janet Foytich
Paula Harris
Floria Komer
Henry Rice
Karen Sakihama & Jerome Dowling
Randall Shibuya

Donations in Memory of Christopher Clarke-Gujral

Karen Aitken-Bernosky
Blue Turtle Spa
Michelle & Kevin Donaldson
James Hamlin
Michael Nakamura
Patrick O'Donnell
Carol Oushani

Donations in Memory of Yvette Tarica collected by Julie Tauscher

Leannette Isom
Hoover Electric
Fran Moss
Renee & Henry Tarica

Donations in Honor of Heather Leitheim's Birthday Ball

Lauren Becker
Renee Bionci
Michelle Bush
Care-Rite Vocational Service, Inc.
Leann Csonka
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Katherine Dupuis
Lisa Graziano
James Juge
Jacki & Jeff Lindstrom
Sandra & Jerry Martin
Patrick OKeefe
Richard Rust
Vicki & Ronald Schlickenmeyer
Ami Stonebraker
Dorothy & Raymond Turnbull
Tiffany & Bob Weidlein
Sharon & William Workman

General Donations

Dolores Albaugh
Zylnna Andaya Oliva
April L. Bennett in honor of Julie Casey's Birthday
Whitney Bras
Nenita Mona Bubuli
Anonymous Donor via Cars 4 Causes
Anonymous Donors via Kroger
Julie & Dan Casey in honor of Ryan Casey for Judy Ray's 50th Birthday
Julie & Dan Casey in honor of Ryan Casey for Marie-Claire Leon's 50th Birthday
Suzanne B. Cassidy, M.D.
Peter Chiang
Joe DiFilippo
Julia Feldman in honor of the "Wonderful, beautiful, charming Chloe Cropper"
Foothill Civitan Club in honor of Tony and Sylvia Pusateri's grandchild
Dolores Horn & Mel Goldberg
Jan & Steve Grogan
Maggie Gutierrez
Susan & Daniel Hedstrom
Jason A. Huck via HSBC Philanthropic Programs
Georgene & Ralph Lowe
Sharri & George Marich
Drew Marich in honor of Brooke Marich for raising PWS awareness
Pat Noland
Rosary Oliva
Grady Robbins via Enterprise Rent-A-Car via United Way
Diane Scott in honor of Emma Fluhr-Resendes
Pankaj Shah
Joyce & Norman Smith
Billy Vitro

Donations to Support Residential Staff Training

Michelle & Mike Raleigh

Donations to Support the IEP S.O.S. Program

Andrea Barraza
Hilda & Martin Hernandez

Donations to Support PWS Camp

Suzanne Privette in honor of Samantha Morgan

Donations to Support Putt for Prader-Willi Syndrome Charity Golf Event

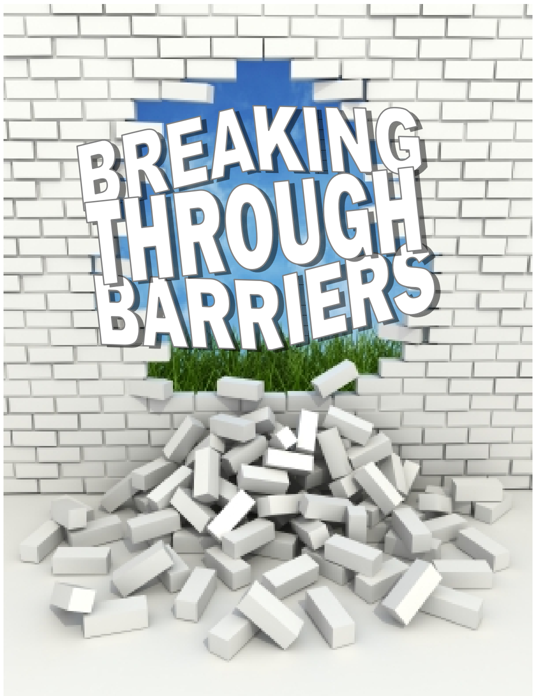
Kristina Fallon
Dan Halsey
Jacob Hawkes
Jeannie Koby
Raafia Mazhar
Karen Meyer
Austin Milliken
Allyson Stewart
Jeff Stewart
Martin Sychowski

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).

Prader-Willi California Foundation

2013 General Education Meeting



Meet & Greet Mixer
Friday, November 1 at 7:00 p.m.

General Conference
Saturday, November 2, 2013
8:00 am - 5:00 pm

Crowne Plaza
Los Angeles Int'l Airport
5985 W Century Boulevard
Los Angeles, CA 90045

Contact PWCF by October 20 for a Spanish Interpreter
Ponte en contacto PWCF antes del 20 de Octubre
por un intérprete Español

See Back for Topic and Speaker Details!

LEARN HOW to break through the barriers that stand in the way of your loved one, client or patient with Prader-Willi syndrome. New and experienced caretakers alike will learn new ways to improve the overall quality of life of *everyone* impacted by the syndrome.

Reserve your hotel room by October 14 for a reduced room rate of only $109 (plus taxes). For hotel reservations call 888-315-3700 and use Group Rate Code PW1.

Register for the conference by mail, fax, or online at www.pwcf.org.

PWCF 2013 GEM REGISTRATION FORM

Register online at www.PWCF.org or use this form

Early Bird Discount: Register by 10/14 and deduct $10!

PWCF Member: $60 / $90 per couple
Non-Member Family: $75
Non-Member Professional: $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	$15/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.______________________________________
Email ______________________________________
Expiration ______________ Security Code ______________
Signature ______________________________________

Return Registration Form to PWCF:
514 N. Prospect Avenue
Suite 110-Lower Level
Redondo Beach, CA 90277
Fax 310.372.4329

Office Use Only
Date: __________
Reg. $_________
Don.: $_________
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PWCF 2013 GENERAL EDUCATION MEETING OVERVIEW

Keynote Speaker — Nicholas Daley

Nick Daley is a 33 year old man with Prader-Willi syndrome. He has a richly rewarding family and personal life, as well as a successful career as an actor on stage and screen. Nick moves through life with grace and confidence, and never lets anything stand in the way of his goals. His is defined more by his determination than his diagnosis.

Special Needs Trusts & Wills — Lisa Thornton, Esq.

Spend an hour and a half with attorney Lisa Thornton and walk away with a lifetime of all the tools you'll need to set your loved one's legal affairs in order. Ms. Thornton will outline the legal documents you need to protect your family and will provide you access to those forms, for which most attorneys charge thousands. Also, learn about legal guardianships and why they are essential for your adult with PWS. This session is not to be missed!

Lisa Thornton is first and foremost "Mom" to her daughter Kate who has Prader-Willi Syndrome. Lisa has four other children (her oldest daughter currently serving an LDS church mission in Mozambique, Africa) and a wonderfully supportive husband, Sid. Lisa has served as the president of the Utah Prader-Willi Syndrome Association for the last eight years. She also serves as a board member of PWSA (USA). Lisa has been an attorney for the past 25 years, currently practicing in the areas of estate planning and special needs legal planning. She has helped hundreds of families secure the legal planning needed to protect themselves and their child with special needs. You can contact Lisa at lisa@lisathorntonlaw.com. View her webinar on special needs legal planning at http://www.utahparentcenter.org/training/webinars/.

Endocrine Conditions in Persons with Prader-Willi Syndrome — Suparna Jain, M.D.

This presentation will review endocrine manifestation in PWS including hypogonadism (lack of normal puberty), hypothyroidism, cortisol deficiency, and growth hormone deficiency. The lecture will also discuss benefits of growth hormone therapy for individuals who have reached their maximum adult height.

Suparna Jain received her medical degree from University of California at San Francisco and did her pediatric residency training at the University of Minnesota. She moved to Los Angeles in 1994 and completed fellowship training in pediatric endocrinology at UCLA where she first started working with children with Prader-Willi syndrome. She had been in private practice for 16 years, the last 11 at Tenth Street Pediatrics. She is also a staff pediatric endocrinologist at Cedars-Sinai Medical Center and participates in resident teaching.

Physical Activity: Why It's So Important that Your Child/Adult is Physically Active and the Role of Your Family — Daniela Rubin, Ph.D.

This presentation will provide you with physical activity recommendations for your child or adult with Prader-Willi syndrome as well as for your whole family. You will learn what we've begun to discover in our study "Active Play at Home," a home-based physical activity program. You will learn how physical activity in persons with PWS is related to quality of life, motor competency, self-esteem and bone density. You will also learn how to create a physical activity routine for your child/adult and family, get around barriers that interfere with schedules, and learn how to sustain motivation.

Dr. Daniela Rubin is an Associate Professor in the Department of Kinesiology at California State University Fullerton. She obtained her Teaching Degree in Physical Education in her home-country Argentina and graduated from the University of North Carolina at Chapel Hill in 2005. Dr. Rubin is interested in the promotion of an active lifestyle in children and adolescents. While at UNC, she was involved as a co-investigator in a diabetes prevention trial in middle school children. Since she has been at CSUF, she has worked in community-based physical activity interventions for youth. Currently she is conducting a study on a physical activity program for children with and without Prader-Willi syndrome: *"Active Play at Home"* and has finished the study titled "*Exercise Aspect of Prader-Willi Syndrome and Childhood Obesity.*" She is also interested in the role of physical activity and exercise not only in the treatment but also in the prevention of obesity and its associated conditions. She strongly advocates for the vital role of physical activity in the lives of individuals with Prader-Willi syndrome.

Successful PWS Behavior Management Strategies — Lisa Graziano, M.A., LMFT

Learn important strategies that will help you reduce unwanted behaviors in persons with PWS of all ages. Topics to be covered include understanding how persons with PWS think, how the hyperphagia food drive influences behavior, and how you can employ successful strategies to reduce anxiety, reduce unwanted behaviors, and improve *everyone's* overall flow of the day. If you love, live, or work with someone with PWS you don't want to miss this session.

Lisa Graziano received her Masters degree in Clinical Psychology from Pepperdine University. She was licensed in 1997 as a Marriage and Family Therapist and maintains a small private practice. After her son's birth and diagnosis in 1999 she organized the L.A. County PWS Support Group. She is a past member of PWSA (USA)'s Board of Directors and has served as PWCF's Executive Director for the past 10 years. She has written dozens of articles and presents locally and nationally on such topics as behavior and food management strategies, parenting, and couple and family issues. She provides trainings at group homes, vocational work sites, day programs, and schools. Most importantly, she is the proud wife of 26 years of TJ and the proud mother of their 14 year old son, Cameron.

Share Sessions will provide families and professionals the opportunity to share insights, strategies, and experience in a supportive environment.

Youth & Adult Program allows care providers to learn more about the syndrome and symptom management all the while knowing their child or adult is safe and having fun!

PWCF Business Meeting will provide attendees the opportunity to learn more about what the PWCF is doing to improve the quality of life of individuals with Prader-Willi syndrome, their family members, and the professionals who serve them.

Spanish Translation Contact PWCF by October 20 for a Spanish Interpreter. Ponte en contacto PWCF antes del 20 de Octubre por un intérprete Español.