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)

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In this issue:

Walking for Prader-Willi Syndrome 2014

It's amazing how time flies - this year PWCF held our **14th Annual Walking for Prader-Willi Syndrome event**! With sites in Northern, Central, and Southern California, families throughout the state came together to meet old friends and make new ones, watch their kids play games and activities, have their faces painted, and raise awareness of PWS.

Central California held their Walking for PWS event on April 26th with the Clovis Rodeo Parade, followed by a picnic at Dry Creek Park. Strollers and wagons glittered with streamers, metallic flower bunches, and spinning pinwheels that Walk Coordinator and former Board member **Paula Watney** and Family Support Coordinator **Katherine Crawford** decorated earlier. We all held our breath about the weather; rain and hail came down just one day before. Fortunately, the weather brought clouds that kept our participants cool and comfortable during the parade and cleared up in time for the picnic.

The Rodeo Parade lived up to its name! Cowboys on horses, ladies in fancy southwestern dress, and everything else you could imagine rode with our group of fifty people with PWS and their families. Two intrepid Walkers, **Dustin Watney** and **Andrew Martinez**, held the PWCF banner high for the entire parade route. Everyone's spirits were high as we waved to onlookers on each street. We were all uplifted by the crowd's supporting cheers.

The parade was an incredible opportunity for awareness-raising. Every ten minutes an announcer introduced our group with a brief summary written by Paula about Prader-Willi syndrome and PWCF allowing us to raise awareness of PWS on each new stretch of the parade route. With each new person we inform about PWS comes greater understanding of persons with PWS and a broader network of support for families.

After a full morning of walking in the Clovis Rodeo Parade, PWCF members met up for a picnic at Dry Creek Park. We were all happy to kick our feet up after the energy of the parade. After the picnic some kids played on the extravagant playground next to the picnic area while others joined Paula's grandchildren, **Emma & Paige Winter**, who taught them how to make bracelets with their elastic looms.

Though there are fewer families who live in Central California and therefore participate in the Central California Walk event, our message was mighty and we raised a great deal of public awareness of PWS!

Continued on page 8

PRADER-WILLI
CALIFORNIA FOUNDATION

A Full Life Without Limits

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Facebook: www.facebook.com/pwcf1

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 Groups and Contacts

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	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
	Maria & Ken Knox	909-421-9821	teachknox@aol.com

Spanish Speaking

Mercedes Hernandez (Adults with PWS)	619-822-5742	mercedes.hernandez711@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 (USA) Online eSupport Groups **www.pwsausa.org Click Enter. Click "Support"**

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

International PWS Organisation

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

PWS Share & Support Groups Meeting Calendar 2014

Southern California	**Northern California**
Beach Cities Health District 514 N. Prospect Avenue Redondo Room (Lower Level/Bottom Floor) Redondo Beach	Support for Families of Children with Disabilities 1663 Mission Street, 7th Floor San Francisco
2:00 p.m. – 4:30 p.m.	10:30 a.m. – 1:30 p.m.
Sunday, April 6 Saturday, July 26 Sunday, October 26	Saturday, April 19 Saturday, September 20 Saturday, November 15
Childcare available ONLY for children under age 12. RSVP to PWCF 310-372-5053	Childcare available. RSVP to SFCD 415-920-5040 x 135

Parent to Parent

"What tips or advice do people have for healthy and successful visits to restaurants, whether they be fast food or nicer restaurants?"

I am not a parent, but maybe this would help. Whenever I go to a restaurant with my sister Lauren, I talk to her rationally about what she wants to eat and what she thinks is healthy. We decide together that if we all enjoy a healthy meal, maybe we can share a dessert together. I then suggest maybe we could share a meal together, since the portions are big. Sometimes the thought of sharing a meal with me is exciting, and it's a smooth event. If it's one of those days were she is stubborn and persistent, I ask the waiter to bring a takeaway container with the meal. I then put it in front of her and let her decide how much she is putting in the box, and how much she thinks she is able to eat.

Having her make the decision for herself, and thus determining the rest of the family's outcome (dessert) makes her feel more in control of the situation, and then she feels like she was as well in control of her feelings.

We also "play a game" where I am insisting on eating the most unhealthy of meals, and then she will pipe up and tell me how bad that food is for me, and then she'll help me choose a more appropriate meal.

Again... there are good days and bad days, but I have always thought doing it for her without her input has never ended nicely for either of us. *Kristen, sister of Lauren, 26*

When we go out to dinner with our daughter Sarah, we usually go to an Applebee's Restaurant. They have a Weight Watchers menu that she knows she can choose from. They have a variety so everyone else can order what they want and everyone seems to be happy. *Carolyn, mother of Sarah, 24*

On the restaurant question we would always download the menu and discuss what was going to be ordered and how much was going to be brought home as leftovers for the next day. This would take all of the stress and uncertainty out of the outing. *Mark, father of Eric, 30*

[When we order] fast food [or] kids' meals [we] always [order] with diet Sprite or 7-Up. Sometimes I will bring two cherries with me and tell her it is a Shirley Temple. [I] always keep her busy [playing] tic-tac-toe while we are waiting.

Once Ashley sees her plate of food, it's too late [and] I cannot get her share the plate or [save] half for later. In places like Denny's I speak to the waitress privately and have her box half the meal and give it to me later with the check.

I request they bring the food all at the same time, because she eats so fast, she may finish before we start ours. I tell everyone to play along and put their forks down between bites, the one with the most bites wins. *Angela, mother of Ashley, 26*

Next issue's Parent to Parent question is: *"How do you make exercise fun?"*

Mothers hold their child's
hand for a moment
and their heart for a lifetime

Happy Mother's Day!

Some superheroes
don't have capes...
they are called Dad.

Happy Father's Day!

In The Trenches

Vol. 15

by Jessica Patay

First Day of Summer Break and…

I am off to a brilliant beginning! *No really.*

I've already had a "mommie dearest" moment. No need to repeat but it involved a box of Fruit Loops, (which I never buy and never will again…) and a trash can. Someone will be in therapy for that one.

I'm a lame mom because I won't let kids put spray paint in toy water guns and shoot it at each other. I'm so conservative and square. My kids are destitute for no joyful adventures whatsoever.

When I said you get only two hours of electronics/screen time today, I got the "Well, can I watch tv on the iPad cuz all I have to do is push and it goes on, and with the tv, well, you know…" Because. It's so exhausting to use a remote control.

The only box of Ritz kid-crackers was raided and clots of soccer field mud made it into the car and house and in between toes. Which means it is now everywhere. I guess it's ok because it joins the sand from last night's dinner party at the beach. The two can keep each other company.

I've proactively purchased paper cups, plates and plastic spoons to help cut down on dish duty. However, I have still cleaned the kitchen fully. Twice. Today.

And I have already uttered the words, "Could you please NOT BE SO LOUD?!" five times today as I was trying to write or do some work. Yeah, it worked effectively. They totally quieted down.

It's gonna be a long summer. Thanks for letting me vent. I know I am not alone. My attitude will shift soon when we draw up our Summer Bucket List 2014, which truly turns my poor-me-what-will-I-do-with-them attitude into an I-am-destined-for-a-fun-and-vivacious-summer!! attitude.

Continued on page 5

Food Tip

Thanks to Albertson's supermarkets for introducing us to this cool food tip when they donated **Hawaiian Punch Water Enhancers** to Southern California's Walk event.

Hawaiian Punch Water Enhancers are sugar free and have zero calories.

Convenient to take on the road or into an amusement park. Just a little squirt turns plain water into a hydrating beverage! There are four delicious flavors including Fruit Juicy, Crush Grape, Crush Orange, and Juicy Red.

Enjoy!

Gadget Tip

This Gadget Tip is submitted by Shandra, Mother of Emile, age 11, who writes, "We have a new sensory fidget that my daughter loves for taking a calming break (mostly at school). They are water beads, sold in the floral department at JoAnn's craft store. We put some in a Tupperware-type container. She just likes the feel of the wet squishy little balls. They have been a favorite of hers for a few months when she gets stressed at school."

Water Beads are non-toxic polymer beads that typically are packaged dry. Soak in water for about four hours. If you soak them overnight, they can expand so much they're prone to pop… which might be fun for a sensory experience, though a bit messy in a Jello-like way. Each bead absorbs over 100 times its weight in water, so a little goes a long way.

Executive Director's Column

by Lisa Graziano, M.A.

I ruined my own birthday. It started out great and was heading into a lovely evening alone with my husband at a romantic restaurant by the beach. All was perfect. And then I started talking and it all went downhill from there.

Our conversation began innocently enough, reminiscing about past celebrations, vacations, sharing thoughts that we hadn't had the luxury to share since our last date many moons before. And then it happened. A slow but inescapable nosedive. We began to contemplate The Future and our mortality (which birthdays ironically tend to do) and headed straight smack into the dreaded territory of, "What will happen to our son when we're gone?" It was a conversation too serious for the occasion and definitely one that should not have followed a martini (ok, two). What escaped from my mouth in response to my husband's sincere question about what additional planning I thought we need to do for our son was, "We can never die." And before dessert could even be pondered, we had crashed.

"We can never die" sounded like a pretty good plan inside my head. Heck, I've heard it a thousand times from lots of other parents. But when argued by a 52 year old woman who's not exactly the pillar of health, it really is a ridiculous statement.

In my defense, The Future is my nemesis. When it comes to my son, thoughts of The Future can obliterate me, annihilate all semblance of rational thought, leaving me feeling overwhelming, crushing, irrational fear. You know the feeling.

Actually, maybe it's less The Future that is my arch enemy than Denial. Because even after my husband looked at me with stunned, disbelieving eyes and uttered, "Whaaat?" I still argued the "We can never die" plan, forgetting *everything* I know about the supports he and I have already created and forgetting the supports that PWCF has to offer. What I was focused on in that moment were the tasks we *haven't* yet completed, namely creating a Letter of Intent, a task I've put off for… well, frankly, years.

As we all know, PWS is a complex developmental disability unlike any other. It is not enough for parents of a child with PWS to just have a Will. It is not enough to have a Special Needs Trust, or even to obtain legal conservatorship at adulthood. No, in order for our children to live safe, healthy, happy, fulfilling lives we must do more. We must make sure our child or adult is *always* surrounded by adults who *fully* understand not only their unique characteristics, wants, and needs, but who also know the syndrome, from the hyperphagic food drive, to the slow emptying stomach and bowel challenges, to the temperature regulating goofiness, to the story-telling and stealing propensities, to the oppositional thinking and sometimes extraordinary behavioral obstacles.

I worry about what we've not yet done to prepare for our son's future, as does every parent of a child with PWS. And, I can assure you, as does PWCF's Board of Directors. On the Board's Agenda at each meeting are target areas in need of further supports and services. Always paramount is the need to identify and train more professionals who will support our children and adults now as well as after we're gone. This is no easy task as there are many obstacles to identifying and keeping well-informed support staff – the financial state of California and the rarity PWS, just to name two.

PWCF has many tools to keep families and professionals informed and knowledgeable. In the area of residential support, there is our *Residential Staff Training* DVD, augmented nicely with PWSA's book, Supporting Adults with PWS in the Residential Setting, our professional residential staff inservice training program (which continues to be kept *very* busy), ongoing educational and training programs, this newsletter which consistently provides state-of-the-art information, and our Residential Services Committee. **Fran Moss**, the committee's long-time chair, passes the torch to **Linda Ryan** who will accelerate the committee's annual visits to every PWS group homes and supported living site, making PWCF even more accessible to staff and residents. If you are interested in serving on this committee please contact the PWCF office.

Is there more to be done? Absolutely. Is PWCF involved in the doing? Extremely. It's easy not to know how much information and supports are already available, especially when not well connected with PWCF. Or, as in my case, *forgetting* what supports are available because we get sidetracked by the roaring fear of The Future (...maybe age has a *little* to do with the forgetting).

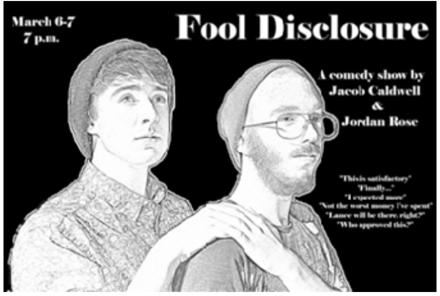
My goal this summer is to break through Denial's bliss and finally finish our son's Letter of Intent so that it doesn't interfere with *next* year's celebrating. I'll keep you posted. And if you finish a long-overdue project this summer, please let me know!

In The Trenches, continued from page 4

Until then... I think I will start a Mamas Surviving Summer support group. Call me. You are welcome to join. But you cannot be creative, crafty, laid back, or love tidy houses. Those types excluded. *Maybe.*

Read more of Jessica Patay's *Truth Telling in Motherhood* on her new website http://jessicapatay.com

Jacob Caldwell is No Fool



"You don't really know how much you can do until you stand up and decide to try."
~ from the movie *Dave*

Jacob Caldwell did just that on March 6-7 when he stood up, took his passion for acting and produced *Fool Disclosure*, an event that raised over $1,000 for PWCF. More importantly, Jacob used his talent to stand up for his brother, **Brett Bernhardt,** who has PWS.

Jacob just wrapped up his senior year at Yosemite High School. As part of his graduation requirements, he was required to complete a senior project. He chose to host an improv-comedy show in which he could flex his acting muscles noting, "Making it a fundraiser was a way to give back where I could." Jacob and his partner, **Jordan Rose**, produced and performed in the show with fifteen of their friends and fellow classmates from their Advanced Theatre Arts class. The show consisted of multiple improv games, skits, musical performances and digital shorts. It ran for two nights and raised $1,038!

Jacob applied to numerous colleges and was accepted at UC Santa Cruz, CSU Long Beach, Cal Poly San Luis Obispo, UC Santa Barbara, and Fresno State. He plans to attend UC Santa Cruz to obtain his Bachelor's Degree and double major in the fields of Theatre Arts and Marine Biology. Jacob graduated on June 6 and was one of the senior Valedictorians at Yosemite High School.

PWCF is proud of Jacob Caldwell and grateful to him for sharing his talent to benefit his brother and PWCF.

PWCF Brings IEP Info to Northern California Families

by Maddy Fluhr-Resendes

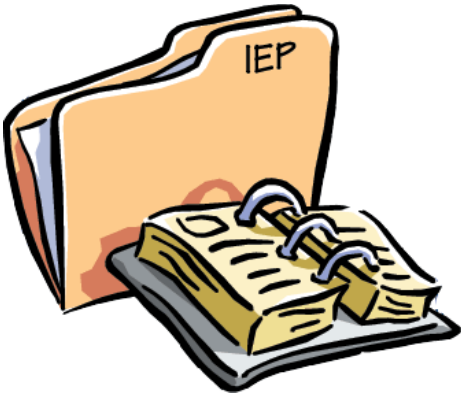
At our PWS Support Group Meeting in San Francisco on April 18, 2014 we were privileged to have PWCF Board Member, **Roger Goatcher**, present on IEPs. As head of Student Services in a California public school district as well as a parent of two children with Prader-Willi syndrome, Roger's dual perspective was invaluable.

Roger stressed the importance of asking for what you want in a non-adversarial manner and working as a team to develop the best plan and placement for your individual child. Roger reminded us that PWS is a spectrum disorder and a one-size-fits-all solutions will not be appropriate. Asking "What" questions is preferable to asking "Why" questions. E.g., "What can the team implement to provide the support my child needs to handle transitions smoothly so that he/she can achieve educational benefit?" as opposed to "Why aren't you helping my child with transitions?!!!"

He also conceded, however, that "the squeaky wheel gets the grease". He emphasized that it is preferable to set the bar high as our children can be very capable and teachable if services are appropriately identified and necessary supports are in place. It was clear that Food Security (which is a health and safety issue) will likely be on everyone's list of issues to address.

Roger provided each participant with a comprehensive organizational binder called "Supporting Parents in Education" covering 25 topics relevant to a successful school experience. Topics covered in the binder range from Resources of Support Prior to IEP Meeting, to Behavior, to Food Management. It was not in the scope of a 2.5 hour workshop to cover each topic comprehensively. However, the binder provided by Roger is not only an excellent organizational tool but an excellent springboard for study on how to become the best advocate for your child that you can be.

PWCF will continue to sponsor these valuable IEP S.O.S. training sessions throughout California. Watch this newsletter or visit our website for the next training date.



PWS and Theft

by Katherine Crawford, Lisa Graziano, M.A.

with input from Elizabeth Roof, Ph.D., Janice Forster, M.D., Evan Farrar

Megan stole a bag of chips from another student's lunch.
Kirk took money out of his father's wallet to buy candy from a vending machine.
Walter went into his brother's back pack and took one of his comic books to trade for food on the bus.
Eloise went into her mother's room and took some jewelry to sell at school to get money for a candy bar.
Isabelle was given recess detention after she took a star eraser from her teacher's desk.

There are many reasons for theft amongst children and adults with PWS. Like all things in the spectrum-world of PWS, not everyone with the syndrome has the same degree of symptoms including the theft of food and non-food items. For those who are impacted by this challenge, this article is for you.

Food-Related Theft

Food-related theft is a well documented challenge with Prader-Willi syndrome. Parents and care providers who live with a high food drive individual know that theft can be a recurring concern. Within food-related thefts, there are differing levels of complexity.

One-Step: Megan
Acquire Food

The simplest form of food-related theft is one-step food acquisition. Such individuals are at risk of stealing food - from other's lunches, from the school or work cafeteria, or even shoplifting from the gas station down the street. Megan's story is a good example of simple, one-step food acquisition to gain access to food: just taking it.

Two-Step: Kirk
Acquire Money, Buy Food

Two-step food acquisition – stealing money to purchase food – can occur as well. Kirk's story (where he took money out of his father's wallet in order to buy food) is a classic example. When an individual is known to steal money to acquire food, it becomes necessary to lock away purses, wallets, and bedrooms to keep the individual safe.

But money isn't the only thing that gets food.

Two-step: Walter
Barter possessions for Food

Another form of two step food acquisition is bartering - trading an object for food. Walter knew that the boys on the school bus were interested in comics, so he took one out of his brother's collection to barter for food. There can be a delay in the discovery of this kind of behavior, and restitution is difficult because it involves both the brother and another child.

Three-Step: Eloise
Acquire Object, Exchange Object for Money, Buy Food

Next we move on to three-step food acquisition: stealing an item which can be exchanged for cash which then is used to buy food. Eloise's story highlights the potential emotional repercussions that such thefts can cause; her mother could be deeply hurt by theft of her jewelry. Unfortunately, potential emotional repercussions may not enter into Eloise's thinking. She doesn't intend to hurt her mother; she simply intends to obtain food.

Each of these examples is food-related theft, no matter how many steps we add. Each also involves a breach of boundaries to acquire food.

Managing Food-Related Theft

When managing food-related theft it is important to remember that the underlying *drive* of the theft is outside the control of the person with PWS. The individual with PWS wants to be "good" in your eyes and do the "right" thing, but the drive to obtain food is too strong. It is up to the family, care providers, and the community around them to provide the compassionate supports they need.

Restrict one-step food theft by preventing access to all food sources with a lock (i.e., refrigerator, food pantry, etc). Human supervision alone is inherently fallible. Lock down sources of money to prevent "two-step theft." Reinforce personal boundaries by locking bedrooms, especially older siblings. For "three-step" acquirers, lock jewelry boxes or keep valuables behind locked doors. In addition to locking access to food wherever possible, provide continuous supervision. When the hope or chance to acquire food is not possible, the person's mind is free to think about other important things.

Sometimes people, especially extended family members, are resistant to the idea of locking up food or keeping food in a restricted area. In this case it may be helpful to describe PWS's hyperphagia food drive like this: think of having a good friend who was just diagnosed with diabetes. Would you have rich desserts or candy bars out on your counter tops or on the table, even though you know they are trying not to eat such foods? Of course not. It wouldn't be the compassionate thing to do. It would just increase your friend's anxiety, suffering, and daily struggle. More than most of us, when someone with

Continued on page 12

Walk, continued from page 1

Southern California's Walk in Griffith Park took place the next day on April 27th. Hundreds of families and professionals came together for the 2.5 mile Walk. The same banner used in Central California travelled back south to be held by walkers including **Samantha Morgan**, **Christie Nguyen** and **Lauren Amarasekera**. It was an incredible sight watching the endless line of over 350 hundred bright yellow t-shirts walk boldly through Griffith Park to raise awareness of PWS. A number of walkers brought along their new family dog, adopted that day from the **Helpful Honda Pet Adoption** with **What's Up Dog L.A.** and **Much Love Animal Rescue.**

Upon return to the picnic area, PWCF hosted a delicious lunch consisting of **Subway** sandwiches, healthy fruit, and yogurt, while **Jimmy "The DJ" Rudon** entertained with fun music. Kids went back and forth between having their faces painted to running in the games. Cool raffle prizes were won by every attendee. The giant bounce castle was a hit. Kids lined up, took off their shoes, and got quite a workout bouncing happily within the inflatable castle. Everyone loved the arts and crafts table which offered an array of activities including glittering window sun catchers, beaded jewelry, and our now-famous Sand Art area which has a gravitational pull on artists of all ages. To take their artwork home, everyone received their own I'm Walking for PWS bag.

Before the start of the event **Melanie Cross, RN, PhN, MSN** presented an informational talk about PWS to the over 30 nursing students who volunteered all day long. These nursing students were an enormous help throughout the event, from set up to tear down. They put up our Walk Information signs, manned booths, sorted and distributed t-shirts, handed out lunches, and cheered our Walkers on the Walk path.

Thanks to outreach from Ms. Cross and others within the medical and research community like PWCF Board members **June-Anne Gold, MD** and **Daniela Rubin, PhD** PWCF is spreading critical knowledge about PWS to professionals.

Northern California's Walk took place the following weekend on May 4th. The weather was glorious in San Francisco, and the Golden Gate Bridge played peek-a-boo with the clouds throughout the day. The first visitor on our site was a graceful heron who gave our grounds a thorough inspection before family volunteers arrived early to set up. Over 250 families from all across Northern California came to experience a fun day at a great location with a group of truly wonderful people.

Executive Director **Lisa Graziano** held the parade banner alongside **Teresa Sharpan**, **Nolan Bonk, Nathan Arellano**, and **Brent Noland**. All of the Banner Bearers started lively cheers: "Give me a P! Give me a W! Give me an S! *What's that spell?* PWS!" Our Banner Bearers were so charismatic we even got cheers from people outside of the event.

A soon as we arrived back at the main grounds the party began! Our beloved **PWS Noisemakers Band**, under the (although absent for the first time in 12 years because he had another gig to play) coordination of PWCF member **Austin de Lone**, delivered a lively musical atmosphere to the grounds as families mingled, chatted, and shared stories with each other. Kids loved getting their faces decorated with swirling designs, superheroes, and animals at the Face Painting booth. The Arts and Crafts area definitely brought out everyone's inner artist.

Patti McRae and **Maddy and Eddie Resendes** led the Games and Activities. In one relay, kids ran around picking up Frisbees that were scattered around the grounds… but with one challenge: they had to use plungers! Another popular game was the tug-of-war which attracted parents as well as kids, and everyone gained some extra muscle!

As the day wound down, 15-year-old **Duncan McRae** called out numbers for the Raffle. Several lucky kids won prizes and two big winners won kites – perfect to use next year when they return to windy San Francisco for Walking for Prader-Willi Syndrome 2015.

See you next year!

WALKING FOR PWS

Special Thanks

PWCF thanks all of the volunteers who made our Walk events fun and successful! So far almost $50,000 has been raised for PWCF's programs and services. With the help of some incredible and dedicated individuals, PWCF's Walk events raised public awareness as they brought families together. PWCF extends our heartfelt gratitude to the following individuals who helped make this year's events truly extraordinary:

Central California: Thanks to **Paula Watney** for her extraordinary efforts planning and organizing the entire Walk event, with gratitude to her family for their support as well! Thanks to **Monte McAbee** of **Pfizer Endocrine Care** for providing water and his wonderful sense of humor.

Southern California: Thanks to **Renee Tarica** for all of her work to ensure the success of the event. Thanks to **Fran Moss** for working the registration tables. Thanks to **Melanie Cross** and all of her **Nursing Students** for their invaluable help throughout the day. Thanks to **Kathleen O'Connell** of **Pfizer Endocrine Care** for her help to secure water. Thanks to **Julie Casey** for coordinating the **Helpful So Cal Honda Dealers,** the **Helpful Honda Pet Adoption** with **What's Up Dog L.A**. and **Much Love Animal Rescue.** Thanks to **Kevin Amarasekera** and his friends for enthusiastically helping with the kids' games. Thanks to **Albertson's** for donating fruit, waters, and water enhancers. Thanks to **Ricky Garcia** for donating yogurts. Thanks to **Subway Tarzana** for making delicious sandwiches. Thanks to **John Storr** for volunteering at the information booth. Thanks to **Petra & Munawwar Martinez** and **Ester Del Real and her family** for their help with set-up.

Northern California: Thanks to **Patti & Tom McRae** for coordinating the event. Thanks to **Diana Vega** and **Sara, Barry and Kelsey Formslag, Maddy and Eddy Resendes**, and **Diane and Brandon Kavrell** for all of their work throughout the day. Thanks to **Michael Moore** for his help to secure the site, set up, and post directional signage. Thanks to **Monte McAbee** of **Pfizer Endocrine Care** for his support and humor at his second Walk event.

Thanks to **Pfizer Endocrine Care** for their support of all three Walks! Finally, thanks to PWCF's staff, **Katherine Crawford** and **Lisa Graziano**, for their hard work and commitment to ensuring that *everyone* who attended a Walk event felt special.

Special Thanks to Our Major Walk Donors and Fundraisers

Central California

Nancy & Steven Fox in honor of Dustin Watney
Mysti Medina in honor of everyone with PWS
Paula & Mike Watney in honor of Dustin Watney

Southern California

Albertsons
Hasmukh & Bernard Amarasekera in honor of Lauren Amarasekera
Maria Barraza in honor of Andrea Marie Barraza
Whitney Bras in honor of Ryan Ramirez
Joanna Brasso in honor of Trevor Ryan
Julie & Dan Casey in honor of Ryan Casey
Michael Change in honor of Trevor Ryan
Karen Crawford in honor of Melissa Moss
Melanie Cross, RN, PhN, MSN of Mt. St Mary's College Dept of Nursing
Marisa Franco in honor of Landon Shea
Libby & Rob Fuller in honor of Allison Mahan
Ricky Garcia & Daniela Rubin, PhD
Mel Goldberg in memory of Yvette Tarica
Bonnie Gowing in honor of Trevor Ryan
Lisa & TJ Graziano in honor of Cameron Graziano
Ashok Gujral in memory of Christopher Clarke-Gujral
Brenda & Robert Harrison in honor of Samantha Morgan
Matthew Helganz in honor of Austin Williams
Helpful Honda Dealers of Southern CA
Jacqueline & Rigo Jimenez in honor of Giovanni Jimenez
Robert Klein in memory of Yvette Tarica
Maria & Ken Knox in honor of Jamilet Knox
Marie Claire Leon in honor of Ryan Casey
Miriam Liberman in memory of Yvette Tarica
Helen Lopez in honor of Austin Williams
Angela & Robert Lucero in honor of RJ Lucero
Candelaria & Ignacio Martinez in honor of Ignacio Martinez
Nisha & Minesh Mehta in honor of Siena Mehta
Savita Mehta in honor of Siena Mehta
Ita & Nick Moran in honor of Samantha Morgan
Judith & Roberg Morgan in honor of Samantha Morgan
Fran Moss in honor of Melissa Moss
Maria Camacho & David Naranjo in honor of Brian Naranjo
Kathleen O'Connoll of Pfizer Endocrine Care
Claudia Rosenthal in honor of Trevor Ryan
Roti Indian Bistro in memory of Christopher Clarke-Gujral
Jimmy "The DJ" Rudon
Linda & Mark Ryan in honor of Trevor Ryan
Salon Vivase in honor of Ryan Ramirez
Milan Sata in honor of Siena Mehta
Courtney Schneider in honor of Ryan Ramirez
Nihar Shah in honor of Siena Mehta
Sukumar Shah in honor of Siena Mehta
John Storr in honor of Naomi Storr
Carol & Hans Storr in honor of Naomi Storr
Rick Swartwout of Pfizer Endocrine Care
Renee & Henry Tarica in memory of Yvette Tarica
Aiden Williams in honor of Austin Williams
Richard Willis in honor of Ryan Casey
Amy & Paul Wissmann in honor of Amanda Wissmann

Northern California

Tim Applegate in honor of Nolan Bonk
Malea & Rich Bonk in honor of Nolan Bonk
Maria Camacho & David Naranjo in honor of Brian Naranjo
Nikki Chung in honor of Nolan Bonk
Lesley & Austin de Lone in honor of Richie de Lone
Joseph DiFilippo in honor of Grace DiFilippo
Maddy Fluhr & Eddie Resendes in honor of Emma Fluhr-Resendes
Bob Priest & Terri Grass in honor of Duncan McRae
Mary & Bob Hill in honor of Oscar Hill
Carolyn & Gordon Jones in honor of Duncan McRae
Diane & Brandon Kavrell in honor of Haley Kavrell
Laren, Viliami & Kainoa Latu in honor of Ahlyjah Latu
Jacki & Jeff Lindstrom in honor of Julia Lindstrom
Ed Mann in honor of Maddox Rutledge
Jonathan Mann in honor of Maddox Rutledge
Mary & Edward McDonald in honor of Duncan McRae
Patti & Tom McRae in honor of Duncan McRae
Poppy & Bella McRae in honor of Duncan McRae
Gabriela Medina in honor of Carina Flores
Lisa & Nate Miller in honor of Levi Miller
Kirsta & Michael Moore in honor of Lillian Moore
Elena & Darrell Mulligan in honor of Megan Mulligan
Pat Noland in honor of Brent Noland
Roberta Parsons in honor of Maddox Ruttledge
Pfizer Endocrine Care
Elevina Popp in honor of Ahlyjah Latu
Ivette & Luis Ramos in honor of Victor Ramos
Cecilia & Noel Ramos in honor of Victor Ramos
Julia & Jeremy Rutledge in honor of Maddox Rutledge
Michael Rutledge in honor of Maddox Rutledge
Ann Sharpan in honor of Teresa Sharpan
Francis & David Sim in honor of Ahlyjah Latu
Diana Vega & Jose Huizar in honor of Pablo Huizar
Lisa & Neil Vitro in honor of Justin Vitro
Kristin & John Widdifield in honor of Lucas Widdifield
Delene Waltrip & Duane Shewaga in honor of Duncan McRae

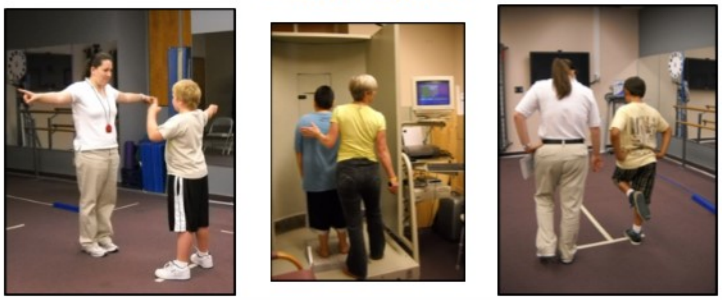
PWS Noisemakers Band in Northern CA

Austin de Lone (Band Coordinator)
Buffalo Bruce Barlow (Bass)
Caroline de Lone (Vocals & Guitar)
Dennis Geyer (Guitar)
Lisa Kindred (Vocals)

We Walked for PWS!

Research

CALIFORNIA STATE UNIVERSITY
FULLERTON



UNDERSTANDING MOVEMENT DIFFICULTIES IN CHILDREN WITH PRADER-WILLI SYNDROME

Physical activity and exercise are key aspects in daily lives of people with Prader-Willi Syndrome. The Prader-Willi Syndrome, Childhood Obesity, and Physical Activity Studies research team at California State University Fullerton (CSUF) is evaluating different aspects of movement abilities and difficulties in young children with Prader-Willi Syndrome.

Children with PWS ages 4 to 7 years are invited to participate. The study takes place at the CSUF campus and requires three visits. The first visit will last 1-2 hours, the second and third visit will last 3-4 hours. During these visits, participants will complete an intelligence test and movement assessments to measure balance, coordination, agility and strength.

Children will receive a package of toys worth $20 following each completed visit. Parents/guardians will be reimbursed for mileage for the visits to CSUF and will be provided with free parking.

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

Research office: 657-278-3671 / pwstudy@fullerton.edu
Dr. Daniela Rubin: 657-278-4704 / drubin@fullerton.edu
Website: http://pws.fullerton.edu

Clinical Study of a New Investigational Drug

Essentialis, in collaboration with UC Irvine, has initiated a clinical trial of **diazoxide choline controlled-release tablets (DCCR)** in patients with PWS. DCCR may benefit PWS patients in a number of ways. In clinical studies in obese patients, both DCCR and diazoxide have been shown to reduce appetite, induce weight loss and improve triglyceride levels. **Patients must be between 10-20 years old, have a genetic confirmation of PWS, and be obese.** They can be male or female, of any race or ethnic background, not diabetic, and generally healthy. To learn more go to www.clinicaltrials.gov; search for NCT02034071. To enroll contact Virginia Kimonis, M.D. 714-456-5791 or 949-824-0571 or vkimonis@uci.edu or contact Marie Wencel at 949-824-0521 or email mwencel@uci.edu.

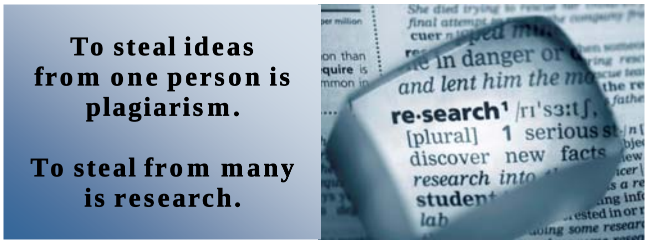
SAINT LOUIS UNIVERSITY
Higher purpose. Greater good.

Effect of Growth Hormone Replacement Therapy on Physical and Behavioral Sexual Development in Persons with PWS 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 PWS. This study is supported by FPWR. The subject population will include 20 adults (10 males and 10 females ages 18+ years) and 20 youngsters (10 males and 10 females between the ages of 10-14 years) with PWS. 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.

Parental Coping Are you a parent or caregiver to a child with PWS? Following on from an earlier study, the University of Newcastle would like to further understand how your child has impacted your life and how you have coped. You can do this study even if you participated in the Disclosure study in 2012/2013. For more info contact Jane Goodwin, PhD Candidate, School of Psychology, Univ of Newcastle Jane.Goodwin@uon.edu.au To complete the survey go to www.wix.com/c3094005/geneticdisorders

MICHIGAN STATE UNIVERSITY

Social Behavior Marisa Fisher, Assistant Professor of Special Education, is conducting a study about the social behaviors of adolescents and adults with and without intellectual/developmental disabilities. For this study, parents/guardians of a child who is 12+ years are invited to complete a short online survey about their child's social behaviors. Questions will ask about the child's background, ways the child interacts with others, and whether the child displays behaviors that might make him/her more vulnerable to social victimization. The survey should take 20-45 minutes. Dr. Fisher is collecting this information to better understand whether certain social behaviors are related to increased social vulnerability, and will be used to develop interventions to teach individuals to protect themselves from victimization. She will forward the results of the study to interested participants. For more info contact Dr. Fisher 517-432-3926 or fishermh@msu.edu. To participate go to https://msucoe.qualtrics.com/SE/?SID=SV_9XED9l2U9uwXZ2d



Theft, continued from page 7

PWS sees food, he wants it, and he can't get the thought of it out of his mind.

When working through food-related theft (whether one-, two-, or three-step) it is best to respond by matter-of-factly acknowledging the taking of the food and quietly reducing calories from the remainder of the day or week to compensate. Take responsibility for your lack of providing adequate food security and secure the food source so that it is no longer accessible. Never punish or shame the individual for stealing food; this is simply a symptom of PWS.

Some may suggest punishment (such as taking away a preferred activity) in response to a food-related theft. Such a person might say, "Megan knows that she can't go out to recess because she stole chips from another student's lunch. How could we reward her with recess after she stole food from another student?" They may even be proud of the individual with PWS for verbalizing their understanding that they have lost recess because they stole food. But the question is not "*does the person understand why they are being punished*" but rather "*will the experience of punishment or threat of punishment prevent the individual with PWS from stealing food in the future?*" In almost all cases the answer is "No, neither punishment nor threat of punishment prevents food stealing behavior." The critical piece to understand is that even if the individual with PWS understands and accepts such punishment *it will not shape future behavior,* which is the intended goal of punishment.

The most effective way to manage food-related theft is to eliminate all opportunities for the individual with PWS to do it!

Non-Food Related Theft

There is a different kind of theft that occurs in some people with PWS, that of stealing non-food items. This behavior can range from the "innocent" taking of items to compulsive stealing. Underlying all non-food stealing are likely higher degrees of egocentricity ("It's all about me") and impulsivity ("I want what I want and I want it right now").

Not understanding social boundaries ("what's yours is yours and what's mine is mine") may make stealing non-food items more likely. In the case of Isabelle, this would be the case if she took the star eraser from her teacher's desk without understanding that she should ask before taking something that is in or on someone else's property.

Having low impulse control may increase the potential for non-food stealing behavior. An example of this might be the individual who walks through a store, sees an item they really like, and impulsively pockets it. In our case of Isabelle, the fact that she knows the eraser does not belong to her, or that to take it constitutes theft, or even that she's already been in trouble for stealing something in the past does not enter into her impulsively-made decision-making process.

There are also people with PWS who appear to have extremely "sticky fingers" and indiscriminately steal objects. These individuals may experience more of a compulsive "need" to steal or "collect."

Managing Non-Food Related Theft

The management of non-food theft is similar to that of food-related theft. First, teach and reinforce the understanding of boundaries. Make sure that stolen objects are returned to their owners with a written letter of apology whenever possible. Writing the owner's name on all objects to the extent possible is helpful. Mutually and cooperatively creating rules regarding non-theft behavior is helpful. Writing down or using pictures to symbolize the rules helps make it easier to enforce them. Here's an example scenario of how to create those rules together.

Aide:	"Isabelle, I heard that you *love* erasers! Which eraser is your favorite?"
Isabelle:	*"I don't have a favorite. I like all of them."*
Aide:	"Me too! Hey, I was thinking of our class rules the other day. Do you think it would be a good rule to say that other student's shouldn't take your erasers, even if they like them?"
Isabelle:	*"Yeah!"*
Aide:	"What should a student do if they take an eraser?"
Isabelle:	*"Give it back and say sorry."*
Aide:	"Brilliant idea! I'll write that down on the bottom of our Class Rules List! Students should not take erasers from other students. If they break that rule, they should give the eraser back and say sorry."

You'll notice that throughout this dialogue the aide is phrasing things in the positive and turning the discussion towards how Isabelle would feel if someone took *her* erasers. This is done to get Isabelle's buy-in to increase her compliance, not necessarily to reduce her degree of egocentricity or to teach empathy, although these are excellent skills to teach.

It should be remembered that Isabelle's egocentric desire to have that eraser may still overpower her affection or empathy for her teacher. There is, however, an appropriate recourse built into the rule-making process: Isabelle told the aide what a student should do if they take an eraser and it's written down in black and white. Isabelle may initially deny and/or perseverate,

Continued on page 15

We Remember

David A. Wyatt

April 7, 1932 - April 9, 2014

The PWS world suffered a tremendous loss when we lost **David Wyatt** on April 9.

David was a tremendous and tender presence at PWSA (USA) where he served as their Crisis Counselor, providing his gentle brand of support and advocacy assistance to hundreds of families.

David was in and out of hospitals for the past many years, but rarely was he out of commission. More often than not David's hospital bed was also occupied by his advocacy files, the welfare of others first and foremost on his mind. Says **Janalee Heinemann**, PWSA's Director of Medical Affairs and Research, "Although he has had many of his own medical crises, David worked harder than most full time paid employees. I remember many times David would be in the hospital bed with his clip board in his hand, making crisis calls, and coming to work with IV lines in his arm or chest."

Born in Amarillo, Texas David earned a Masters degree and was ordained as a Methodist minister. He spent most of his career as a chaplain, with 37 years of experience as a hospital chaplain and chaplain instructor. He moved to Sarasota, Florida after retirement in 2000 to serve as PWSA's volunteer crisis counselor and assumed the intense responsibility of responding to non-medical crisis calls. Throughout his life, David was a strong human rights advocate. He died peacefully on April 9 at the age of 82.

David was the beloved father of Deborah Wyatt, M.D. of San Francisco, and her spouse Andree Hest, Todd Wyatt, daughter-in-law Carrie, and grandfather of Garrett and Everett Wyatt of Pleasanton, CA. He was preceded in death by his four-year-old daughter, Dana. David was also the beloved adopted family member of Janalee and Al Heinemann, with whom he lived, and their children: Sarah and Chris Tenaglia, Tad and Gina Tomaseski, Tracy and Jeff White, Tina and John Kiel, and Matt Heinemann.

A memorial service was held at MCC/Church of the Trinity in Sarasota, Florida. View his moving service at https://www.youtube.com/watch?v=gTBx0xTn3_Q. Says Janalee, long-time friend of David, "Everyone said that it was the most beautiful memorial service they have ever attended. You can hear Al [Heinemann] sing, me and Tad [Janalee's son] give testimonials, a short video of David talking about his life https://www.youtube.com/watch?v=M2uipCL-mr8, a beautiful video of pictures and music https://www.youtube.com/watch?v=oUfxHMO917I (both of those thanks to my grandson Tyler), his daughter Debbie speaking, his 11-year-old grandson trying to speak, and [PWSA's] crisis counselor Evan [Farrar] giving a beautiful tribute. Lots of tears were shed, but they were good tears for a very deserving man."

Anyone wishing to do so may make a donation to the church or to PWSA (USA), 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238.

David was loved by many and will be remembered for his joyful life, kind spirit, gentle heart, and smiling face.

Remembering David Wyatt

"David was a wonderful human being. He will be missed by all of us." *Mark Ryan*

"…I am privileged to have known David. He truly was a gentle soul who suffered greatly with his medical problems. Now he is at peace. He will be missed, but he left a lasting legacy."
Janice Forster, M.D.

"He was a long time buddy of mine as well."
Barb Whitman, Ph.D.

"Oh my... terrible news! And I had no idea he was in his 80's."
Phillip Lee, M.D.

"…this is so sad. What a loss for the community."
Lynne Bird, M.D.

"I am so sorry to hear about David. I had the opportunity to speak with him when Haley was first diagnosed. He made me feel so good. He truly had a gift. What a loss for the PWS community." *Diane Kavrell*

"Please extend our deepest condolences to his family and friends." *Diana Vega*

"David was an extraordinary human being who positively influenced the lives he touched. I will remember him with great affection and admiration for as long as I live." *Lisa Graziano*

Skin Picking

by Linda Gourash, M.D. and Janice Forster, M.D. of *The Pittsburgh Partnership*

The following article has been condensed. For a copy of the article in its entirety contact the PWCF Office

The "skin picking" behavior of PWS has a wide range of severities from patient to patient and sometimes in the same person over time. As Wigren reported in 1999, stability over time is more typical. Some patients have occasional minor skin picking while others maintain large open wounds.

In the PWS Personality presented in 2006, we separated *skin picking as a habit behavior* (common) from *self mutilation* associated with extreme emotional distress (less common). Here we will only address the former and leave the latter and rectal picking for another day.

Why do they pick? Some speculation Much of PWS behavior makes more sense when we view it as a failure to inhibit an idea or an impulse. The eating behavior in PWS is due to defective "brakes" called satiety. The drive to skin pick in PWS may start out as a normal drive (who has not picked a scab or other bodily irregularity?), but the limiting signals are weakened. We speculate that these signals are pain and disgust; both are neurologically based and apparently reduced in PWS.

Skin Picking as a Habit Behavior Here, skin picking is defined as a repetitive, driven activity that has no apparent function. It goes on when the person is calm, and it does not appear to be causing any emotional distress. It has been related to boredom and anxiety, but objective evidence for has been difficult to establish. It is characterized by opportunistic typography; that is, the location of skin picking is convenient to reach.

No specific intervention has been uniformly effective. The behavior often extinguishes if healing of the wound is achieved. There has been limited success using protective dressings and an intense program of providing alternative activities until wound healing occurs. Behavioral interventions have been effective in some cases.

Points on Management

- ♦ Because skin picking behavior occurs intermittently and clandestinely in many cases, behavioral interventions targeted at the activity itself are difficult to implement. A basic principle is that no attention (positive or negative) should be paid to the behavior itself other than to require that the person observe social conventions and good hygiene.
- ♦ The behavior appears to be "compulsive", however this is not an obsessive compulsive behavior and medications[1] targeting OCD (obsessive compulsive disorder) or anxiety have not been helpful. If the behavior is clearly related to other signs of anxiety, then the anxiety should be addressed with environmental changes including a re-evaluation of the individual's food security.
- ♦ Topiramate (Topamax) in low doses has been effective for some people and should be considered in those with severe picking. In 2002 Shapira[2] and others gradually increased to 150-200mg daily and reported that some patients responded and some did not. Side effects include irritability, cognitive blunting, and RTA (renal tubular acidosis) all dose dependent and reversible. These issues should not deter a trial of the medication, but provide a guide for what the physician should monitor. If lesions heal, a trial off the medication makes sense, since healed lesions are often left alone. Allow 2-3 months on the medication to evaluate efficacy.
- ♦ Anecdotally, sensory stimulation has been quite effective for some severe picking behaviors. Sensory modalities have included vibration or massage administered on a schedule multiple times per day. The sensory stimulation should not be linked verbally or temporally with the picking behavior as this could result in inadvertently rewarding the behavior. More information on using sensory integration techniques has been assembled by Janice Agarwal, PT and is available on the PWSA (USA) website at www.pwsausa.org

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[1] Anti-anxiety medications, while helpful for anxiety, carry the risk of increasing irritability or triggering mood activation (hypomania, irritability, increased impulsivity, restlessness, increased goal-directed behavior including food seeking). Mood activation can begin weeks or months after the medication has been started even if it is effective for reducing anxiety.

[2] International Journal of Neuropsychopharmacology (2002), 5, 141±145

Would you like to read more?

Visit **www.PittsburghPartnership.com**
for access to more information on this and other
PWS-related topics.

Health Bridge Children's Hospital – Houston, TX
Opens Prader-Willi Syndrome Program

HealthBridge Children's Hospital Houston now provides an **inpatient pediatric Prader-Willi syndrome Program**.

Approach to Treatment HealthBridge Children's Hospital PWS Program is an Inpatient interdisciplinary treatment program that addresses the complex medical, physical, emotional and social needs of children and adolescents with PWS. Their program incorporates physician led plans, which include Registered Dietician developed meal plans, set daily schedules, individualized physical training programs, and mental health support for both patient and family.

Health Bridge utilize a multidisciplinary team approach to provide individualized specialty assessment and treatment planning, including Board certified pediatric physicians, a nursing staff that is specially-trained in the management of children and adolescents with PWS, Registered Dietician, respiratory therapists, who are specially-trained in the care of neonatal, pediatric, and adolescent patients, psychologist, psychiatrist, physical, occupational and speech therapist, case manager, child life specialist and a Pediatric Physical Medicine and Rehabilitation Physician. Additional team member includes a Social Worker who will assist the case manager in facilitating a smooth transition home.

Health Bridge recognizes that every child that visits them is special and unique and thus sets each treatment to fit every individual's needs. Their expert staff is committed to seeing every single child achieve their health goal during and after discharge, and to provide families with the support necessary to achieve success.

Caregiver Training Caregiver training is critical to ensure continued progress on weight loss and behavioral goals, following discharge. As part of the admission, families and/or caregivers are expected to participate in trainings. During training, families meet with the doctor, case manager, psychologist, nurse, dietitian, physical therapist, occupational therapist, speech therapist and teacher, as appropriate. Family training will be scheduled by the case manager.

Referrals The admissions team at HealthBridge Children's Hospital works closely with referring hospitals to ensure that the admission process is efficient. Nurse liaisons and admission coordinators assist in our referral and admission process. To refer a patient to HealthBridge Children's Hospital, physicians and families may call the Admissions Department at (713) 351-6623 and speak with Ms. Kim Dick, Admissions Coordinator.

Theft, continued from page 12

but if the aide is patient and calmly brings Isabelle's attention to their written agreement, this will help Isabelle return the eraser. As soon as Isabelle returns the eraser the aide will praise praise *praise* her.

What if our hypothetical Isabelle brings home an object from school that does not belong to her, and when questioned she says a friend gave it to her? The circumstances of this scenario should be investigated for accuracy. Or what if another parent calls Isabelle's parents because they believe Isabelle took their child's CD? While Isabelle is adamant that the CD is hers, a search of her collection reveals an identical CD. It could be that Isabelle didn't *intend* to steal anything but actually believed her friend's CD was indeed her own. This example underscores the importance of labeling all of the individual's items to allow parents and care providers the ability to quickly resolve such situations.

What we're looking for isn't exactly a "cure" for impulsive theft but rather management of the environment to eliminate the expression of the symptom. It is possible that the individual with PWS may struggle with impulsive theft throughout their lifetime, so the knowledge and understanding of this symptom by those around them will make a big difference.

Continuous supervision is highly advisable when someone is known to have a history of stealing, and especially in situations where theft could have serious repercussions. It is also advisable to introduce your individual with PWS to your local police department, and provide officers with written information about the syndrome, available from the PWCF office and our website.

Theft can be tricky to manage in persons with PWS. The fundamental keys to reducing both food and non-food theft are environmental management, supervision, and continuous caring support of the individual with PWS.

Board Corner

Summary of Board of Directors Meeting

May 17, 2014
PWCF Offices, Redondo Beach
Submitted by Julie Casey

The Board of Directors met on Saturday, May 17th at the PWCF office in Redondo Beach. The meeting was attended by Board members Julie Casey, Roger Goatcher, June-Anne Gold, Diane Kavrell, Nisha Mehta, Tom McRae, Daniela Rubin, and Renee Tarica, as well as Executive Director Lisa Graziano, and Family Support Coordinator Katherine Crawford.

The following reports were prepared and distributed prior to the meeting and approved on the consent agenda: Executive Committee Report, Executive Director's Report, Finance Committee Report, Social Media Report, Program Committee Report and Residential Services Committee Report. Highlights of the submitted reports include:

- Linda Ryan was appointed as the new Chair of the Residential Services Committee
- PWCF is now a charity on the Amazon Smile Program. Anyone can now designate PWCF to receive a percentage of their eligible Amazon purchases when using this link http://smile.amazon.com/ch/95-3480752
- PWCF now has a LinkedIn Profile page
- A $10,000 grant was awarded by the Joseph Drown Foundation
- PWCF staff have provided various trainings (family support, school support, residential support, Regional Center training) since the last Board meeting
- Lease for office expansion is being negotiated
- 2014 ASICS LA Marathon netted proceeds of almost $13,000
- Two IEP S.O.S. Training Seminars were conducted, one in Northern CA and one in Southern CA
- Daily PWS Facts posted on Facebook commemorating National Prader-Willi Syndrome Awareness Month were once again extremely popular

<u>Discussion Items</u>

Residential Services Committee Chairperson Linda Ryan requested authorization that the committee's travel expenses as they conduct visits to group homes, supported living sites, day programs, and vocational work sites would be reimbursed. The Board confirmed that reasonable travel expenses will be reimbursed and auto mileage will be reimbursed at the current IRS non-profit rate.

The Board discussed the 2014 ASICS LA Marathon event and voted to apply for the 2015 marathon.

Dr. June-Anne Gold and Daneila Rubin, Ph.D. provided updates on several new research studies. See page 11 for more information on research you can participate in.

The Board reviewed final plans for the Family Fun Events scheduled with the Anaheim Angels on July 26th and with the Oakland A's on August 24th. Julie also proposed that PWCF conduct two smaller events to give families an opportunity to get together. The Board voted to host two additional events in 2014, one in Northern CA and one in Southern CA, with a budget not to exceed $1,000. Stay tuned as we plan these events and if you have any suggestions email Julie at president@pwcf.org. Even if it doesn't happen in 2014, we will keep a list of ideas for the future.

The Board spent significant time discussing PWSA (USA)'s request to become an official chapter. PWCF has always maintained a good working relationship with PWSA but has remained independent. The Board voted not to sign a chapter agreement but emphasized the importance of maintaining a good working relationship with PWSA. The Board also recognizes the categorical value of PWSA's work and their need for financial support, therefore the Board agreed to commit to granting at least $5,000 a year to PWSA (USA) for the next three years.

Julie has been talking to two investment managers to gather information for the possibility of moving PWCF's investment accounts. Julie presented her impressions and provided proposals from both companies. It was determined that a sub-committee would continue the vetting process.

The rest of the afternoon was spent on strategic planning. The following priorities were discussed:

- The need for additional office support staff
- Identify and hire a replacement Executive Director by the end of 2016 when Lisa anticipates stepping down
- Conduct First-Responder Trainings to educate law enforcement about the unique needs of PWS
- Determine how PWCF can help families with their Conservatorship/Guardianship/Trustee needs
- Hire a Public Relations/Marketing firm to help raise PWS awareness
- Develop a "full-service" nutritional program
- Increase the number of Family Fun events throughout CA

To start action on these priorities and because requests for various trainings continues to increase the Board recognized the need for additional administrative help so that Lisa and Katherine can devote more time to training and advocacy duties and as such voted to hire a part-time Office Manager.

The Board will continue to draft a detailed strategic plan and work on the ideas that came out of the May meeting.

It is a pleasure to work with such a dedicate group of people who are committed to fulfilling the vision of PWCF – A Full Life Without Limits. If you are interested in serving as a Board member or committee member please let the office know.

Do You Have What it Takes to Serve on PWCF's Board of Directors?

☑ Ability to listen, analyze, think clearly and creatively, work well with people individually and in a group
☑ Willingness to prepare for and attend Board meetings (3 in-person, teleconferences as needed), committee meetings, and other special events.
☑ Ability to ask questions, take responsibility and follow through on any given assignment, contribute personal and financial resources as generously as your personal circumstances allow
☑ Possess honesty, sensitivity to and tolerance of different views; a friendly, responsive, and patient approach; community-building skills; personal integrity; a developed sense of values; concern for the Foundation's development; a sense of humor
☑ Willingness to develop certain skills if you do not already possess them, such as chairing a committee or project, the ability to read financial statements, ask for donations, recruit new Board members and other volunteers
☑ Willingness to commit to serve a 3-year term

If so, PWCF's Board of Directors Needs YOU!

What will you gain by participating at the Board level?

- A sense of pride knowing you are working for the benefit of all persons impacted by PWS
- Input into decision-making that directly affects persons with PWS and their families
- Increased knowledge about Prader-Willi syndrome and its treatment and management strategies
- Increased knowledge about supports and services available in California
- Increased exposure to professionals who work with individuals with PWS

What will you give up by sitting on the PWCF Board?

- Three to four Saturdays per year to attend Board meetings (most held at PWCF office located in Redondo Beach. All reasonable travel expenses are reimbursed.)
- Time and energy spent on a committee, project or event
- Time to attend the annual General Education Meeting and an annual *Walk* event.

Nominate yourself or someone you believe has the skill set that will benefit PWCF. Contact Kim Morgan, Chair, Nominating Committee via email info@pwcf.org or write to PWCF at 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277. **The deadline to submit nominations for the 2015-2017 Board of Directors is August 5, 2014.**

2014 Calendar of PWCF Events and Activities

LA County Support Group	July 26, 2:00pm - 4:30pm, Redondo Beach
Family Fun Night with The Anaheim Angels	July 26, 6:05pm, Angels Stadium
Family Fun Night with The Oakland A's	August 24, 12:30pm - 5:00pm, Oakland Coliseum
Bay Area Support Group Behavior Training Session	September 20, 10:30am - 1:30 pm, San Francisco
IEP S.O. S. Training	September 20, Redondo Beach
LA County Support Group	October 26, 2:00pm - 4:30pm, Redondo Beach
Annual Educational Conference	November 8, Northern California

We Get Mail

📪 Dear PWCF: What an amazing experience [at the LA Big 5K]! Already two of my friends have voiced an interest in joining next year! *Hasmukh Amarasekera, mother of Lauren, age 26*

📪 Dear PWCF: Really lovely and heartfelt essay by Cameron [Graziano, age 15]. *George Anderson, father of Juliette, age 12*

📪 Dear PWCF: Thank you so much for sharing your knowledge with us at Remi Vista! I learned so much from your training and experience with Prader-Wili syndrome. Thank you for helping me improve my skills and understanding to better work with these special individuals. [Lisa Graziano] has so much energy and passion for what you do and it is so awesome! Thank you for sharing with us! I hope to work with you again in the future. *Taylor Keenen and all of us at Remi Vista*

📪 Dear PWCF: Thank you for the presentation to the staff at Orange Unified School District. We appreciated all the great input. *Sincerely, Germaine Martel, Coordinator of Alternative Education*

📪 Dear PWCF: Please let Katherine know how much I'm enjoying her writing about her brother Michael. I finally picked up the October-December newsletter from my nightstand and read about Michael's transition to a group home. I'm impressed with how deftly and lovingly Katherine and her mother chipped away at Michael's wall of NO and showed him how living in a group home would help him achieve his goals. That's a great model for handling a [person with] PWS negativity in a loving and rational way. Thanks for sharing, Katherine. *John Storr, father of Naomi, age 11*

📪 Dear PWCF: Thank you very much – I loved the [New Member] binder, it gives me more professional order to my info. *Peri Anders, grandmother of Kali, age 13*

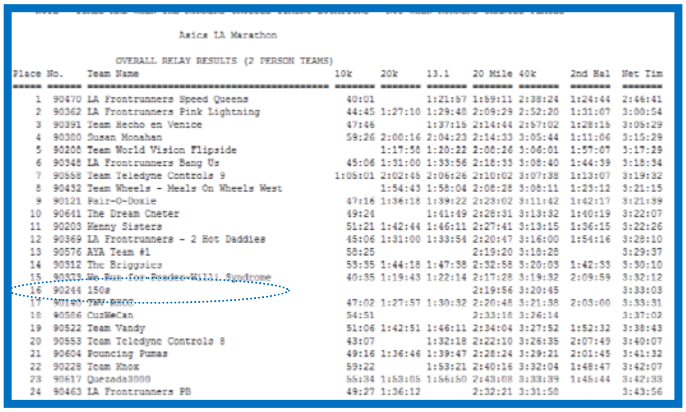
📪 Dear PWCF: Great Day Sunday [at Northern CA's Walking for PWS Event]!
Jacki Lindstrom, mother of Julia, age 29

📪 Dear PWCF: Thank you SO much for the wealth of information and articles. I have printed each one of them and will keep referring to them, probably daily! My husband has been great about educating me from the start and we do implement many of these techniques but no family is perfect and it's so great to have reminders on how to work with our sweet little guy. I have also joined a couple of online PWS support groups (on Facebook) in the past week. It's great to hear from other parents who have some of our shared concerns. Again, thank you for the information. Have a great day! *Megan Shea, stepmother of Landon, age 7*

📪 Dear PWCF: Katherine did a fabulous job [presenting to the care providers share session] this morning; she's SO knowledgeable. We had several psych interns attending in addition to our parents leaders and there were numerous questions asked that were fairly technical about brain development and such, yet Katherine had such expertise to share. *Kathleen McFarlin, Supervisor, Comfort Connection Family Resource Center, Regional Center of Orange County*

📪 Dear PWCF: Thank you so much for the information and for chatting with me [regarding behavioral supports in residential settings] on Tuesday. We are having some success in her home this week, and the staff are motivated to try some new things. Again I really appreciate your time and willingness to share! *Tayler Pecha, North Star Services*

It's Not Just Our Kids Who've Got Talent…



Asics LA Marathon

OVERALL RELAY RESULTS (2 PERSON TEAMS)

Place	No.	Team Name	10k	20k	13.1	20 Mile	40k	2nd Hal	Net Tim
1	90470	LA Frontrunners Speed Queens	40:01		1:21:57	1:59:11	2:38:24	1:24:44	2:46:41
2	90362	LA Frontrunners Pink Lightning	44:45	1:27:10	1:29:48	2:09:29	2:52:20	1:31:07	3:00:54
3	90391	Team Hecho en Venice	47:46		1:37:15	2:14:44	2:57:02	1:28:15	3:05:29
4	90380	Susan Monahan	59:26	2:00:16	2:04:23	2:14:33	3:05:44	1:11:06	3:15:29
5	90208	Team World Vision Flipside		1:17:58	1:20:22	2:08:26	3:06:01	1:57:07	3:17:29
6	90348	LA Frontrunners Bang Us	45:06	1:31:00	1:33:56	2:18:33	3:08:40	1:44:39	3:18:34
7	90558	Team Teledyne Controls 9	1:05:01	2:02:45	2:06:26	2:10:02	3:07:38	1:13:07	3:19:32
8	90432	Team Wheels - Meals On Wheels West		1:54:43	1:58:04	2:08:28	3:08:11	1:23:12	3:21:15
9	90121	Pair-O-Doxie	47:16	1:36:18	1:39:22	2:23:02	3:11:42	1:42:17	3:21:39
10	90641	The Dream Cneter	49:24		1:41:49	2:28:31	3:13:32	1:40:19	3:22:07
11	90203	Kenny Sisters	51:21	1:42:44	1:46:11	2:27:41	3:13:15	1:36:15	3:22:26
12	90369	LA Frontrunners - 2 Hot Daddies	45:06	1:31:00	1:33:54	2:20:47	3:16:00	1:54:16	3:28:10
13	90576	AYA Team #1	58:25			2:19:20	3:18:28		3:29:37
14	90312	The Briggsics	53:35	1:44:18	1:47:38	2:32:58	3:20:03	1:42:33	3:30:10
15	90373	We Run for Prader-Willi Syndrome	40:35	1:19:43	1:22:14	2:17:28	3:19:32	2:09:59	3:32:12
16	90244	150s				2:19:56	3:20:45		3:33:03
17	90140	TWV RHCC	47:02	1:27:57	1:30:32	2:20:48	3:21:38	2:03:00	3:33:31
18	90586	CuzWeCan	54:51			2:33:18	3:26:14		3:37:02
19	90522	Team Vandy	51:06	1:42:51	1:46:11	2:34:04	3:27:52	1:52:32	3:38:43
20	90553	Team Teledyne Controls 8	43:07		1:32:18	2:22:10	3:26:35	2:07:49	3:40:07
21	90604	Pouncing Pumas	49:16	1:36:46	1:39:47	2:28:24	3:29:21	2:01:45	3:41:32
22	90228	Team Knox	59:22		1:53:21	2:40:16	3:32:04	1:48:47	3:42:07
23	90617	Quezada3000	55:34	1:53:05	1:56:50	2:43:08	3:33:39	1:45:44	3:42:33
24	90463	LA Frontrunners PB	49:27	1:36:12		2:32:21	3:31:58		3:43:56

PWCF Board of Director **Daniela Rubin, Ph.D.** and her husband **Ricky Garcia** ran for Team PWCF in the ASICS LA Charity Relay last March.

Says Daniela, "I normally do not brag, but this is fun. Ricky and I came in 15th place in the relay race, coinciding with PWS' Chromosome 15! Thank you for organizing this event. It gave me goose bumps to see everybody at PWCF's Cheer Booth at Mile 15, in particular some of the kids at the booth." Thank you, Daniela and Ricky, for your dedication to PWCF and for sharing your running skills to raise awareness of PWS!

Let us know if you know someone who's got talent!

MEMBER ACTIVITY

April - June, 2014

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

Beverly & Dominique Ginyard
Susie & J.B. Jones
Sharon Koay & David Ishimaru
Ava Wang & Lalo Rodriguez

New Extended Family Members

Peri & James Anders

New Professional Members

Bet Tzedek
Kwaj Overton, BSN, RN, The Center for Prader-Willi Syndrome at The Children's Institute
Rosalinda Garcia, Pediatric Therapy Network
Stacy Schafer, M.A., So CA Integrated Health & Living Project, Resource Developer

Renewed Extended Family Members

Dolores Albaugh
Lisa Ann Bonk
Terri Canales
Sally & Chet Collom
Mary Culver
Laura & Ray Esau
Molly Fuller
Wendy & Bob Graziano
Sandra Hansen
Jo & Floyd Hatcher
Tod Holdorf & Cassie Wilcox
Kelly Jaeger
Carolyn & Gordon Jones
Cyndie & Tony Kelly
Sharri & George Marich
Linda McGee
Carolyn Meyer
Judy & Bob Morgan
Lynn & Chuck Morrow
Lianne & David Noddle
Kathy & Ralph Paige
Stephen Patay
Nancy & Christopher Rohan
Karen & Michael Rutledge
Judy Schlafer
Frances & David Sim
Judy Soden
Margaret & Bill Spinelli
Billy Vitro
Mary & Pat Williams

Renewed Family Friend Members

Irene & Kyle Kaiser
Nancy & Jim Kaiser
Michele Maher
Tyna & Ray Triggs

Renewed Professional Members

Phil Bonnet, Executive Director, Alta CA Regional Center
Mary Lane Carlson, EdD, MPH, RD, CDE
Vicky Cox, M.S.
Gayle Anne Cronic, Puckett Residential Services
Lynn DeFreece, North Valley Services
Laura Douglas, SLS Coordinator, Remi Vista Inc
Janet Foos, Nutritionist, Redwood Coast Regional Center
Mitchell E. Geffner, Executive Director, M.D., Children's Hospital of Los Angeles
Dexter Henderson, South Central LA Regional Center
Larry Landauer, Executive Director, Regional Center of Orange County
Phillip D.K. Lee, MD
Daniel Morris, Senior Service Coordinator, North Bay Regional Center
Dan Moore, Inland Regional Center
Rosary Oliva, New Life Homes, Lucky Homes
Michelle Ramirez, Director, On My Own Community Services
Mary Ring, Southwest SEALPA
Steven Roblee, Rainbow Acres
James L. Shorter, Executive Director, Golden Gate Regional Center
Melinda Sullivan, Executive Director, Frank D. Lanterman Regional Center
Richard Swartwout, Pfizer Endocrine Care
Lynn Vaughan, STEP
Wendy Wachtell, President, Joseph Drown Foundation
JoAnne Williams, Modern Support Services

Thank You for Renewing Your Membership and Keeping PWCF Strong!

***PWCF News* is the newsletter of the Prader-Willi California Foundation (PWCF) and is sent to all 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 or 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 or 800-400-9994 (toll-free in CA) or email us at info@pwcf.org.**

Deadlines for submission: February 5 - Jan-March edition; May 5 - Apr-June edition; August 5 - July-Sept edition; November 5 - Oct-Dec edition

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

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April - June, 2014

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Suzanne Privette in honor of Samantha Morgan

Magnanimous General Donations

Joseph Drown Foundation
Carol & Hans Storr of the Storr Family Foundation

Donations to Support the ASICS LA Marathon, Relay, and 5K Events

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Andres Nicolas Cruz
Felipe Patino

Donations to Support PWS Camp

Patti & Tom McRae
Suzanne Privette in honor of Samantha Morgan
Robert Scott

Donations to Support the Southern CA IEP S.O.S. Training

Beach Cities Health District

Special Thanks to the
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for their generous grant to support
PWCF's Operations

Special Thanks to the
Storr Family Foundation
for their generous support of
PWCF's programs and services

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Paula & Mike Watney
Carol & Maurice Williams in honor of Melissa Moss

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).