

October - December 2014  
Volume 26, Number 4

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## PWCF's Annual State Conference

November 8, 2014 | Santa Clara, CA



PWCF held its Annual State Conference at the elegant Marriott in Santa Clara. Attendees were treated to a fantastic presentation by **Cynthia Ulrich Tobias, M. Ed.** that, in a most entertaining manner, helped us better understand our own learning style so that we can understand better our child/adult's learning style. Interesting differences were illustrated about how people concentrate, process, and remember information. There were a great many "Aha!" moments as couples could be heard whispering to each other, "Oh, you're a *visual* learner, so *that's* why you can't remember anything unless it's written down!" There was a great deal of focus on helping parents and care providers turn conflict into cooperation. Though Cynthia's expertise is not in PWS, her communication strategies were spot on, such as her insight into persons with PWS who "don't have trouble with authority – we have trouble with how you *communicate* your authority." How we communicate and ask questions of others, especially with our child/adult with PWS who has executive skills deficits, can either destroy or improve the quality of that relationship. Question styles that can help improve the relationship include, "Do you know why I want you to do that?"; "Is that what you meant to do?"; and even "Are you annoying me on purpose?" Questions that can destroy the relationship include, "When are you going to learn?"; "Why can't you just do what you're told?"; and "What's the matter with you?" It was an excellent presentation that offered a great deal of food for thought (if you'll pardon the pun).



**Ann Scheimann, M.D.** shared a great deal of critical information about the stomach and bowel problems that many persons with PWS experience. A complex, highly medical topic on which to present, Dr. Scheimann did a first-rate job breaking down the "technical" into "laymen" terms. GI, or stomach problems, are a common symptom of PWS ranging from feeding problems in infancy, to swallowing problems, reflux, liver issues, slow emptying stomach, slow emptying bowel, and constipation. She provided detailed and helpful suggestions for parents about how to treat and manage many of the GI symptoms. Of note, she noted recent concerns using Simply Thick thickening agent in typically developing infants, though no issues in infants with PWS are yet known. She also cautioned that Bariatric surgery to combat morbid obesity is not yet a safe option for persons with PWS because the surgery does not reduce the hyperphagic drive to eat. "Poop" received a great deal of attention as it becomes clearer how prevalent a slow emptying bowel is and the types of problems it can cause, including in some cases picking at one's bottom in attempt to "empty" it out. Gastroparesis, or slow-emptying stomach, is a symptom of PWS that is probably more common than previously thought, and one which parents and care providers don't yet have enough information about. Diet strategies include small frequent meals; limit fiber intake; prioritize protein in the diet; increase fluid in foods; ensure foods are chewed well; remain upright and move to help move food along. Those in attendance received an amazing amount of critical information about the GI issues affecting persons with PWS and, more importantly, how to better manage them.



**Janalee Heinemann, MSW** provided an extensive overview of PWS research which is understood by researchers around the globe to be a "window of opportunity." To highlight a few of the exciting advances she described, there is potential for weekly growth hormone shots (versus the current daily injections). Much has been learned about the nutritional phases of hyperphagia (drive to eat symptom). One promising drug, Beloranib, targets the hyperphagia symptom and is being studied in two clinical trial sites here in California. Other promising hyperphagia/behavior medications include Qsymia, Oxytocin, and Belviq. Vagal Nerve Stimulation is a potential non-drug hyperphagia intervention. We continue to learn more about stomach and bowel management strategies. New research reveals

*GEM Column continued on page 8*

**JOIN TEAM PWCF!**

WALK OR RUN WITH US IN THE

**LA BIG 5K**

OR THE

**ASICS LA MARATHON**

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CALIFORNIA FOUNDATION**  
*A Full Life Without Limits*

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**Our Mission:**

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

**PWS SUPPORT GROUPS AND CONTACTS**

**Northern California**

San Francisco Bay Area	Patti McRae	408-920-8003	<a href="mailto:pattimcrae@sbcglobal.net">pattimcrae@sbcglobal.net</a>
Sacramento	Diane Kavrell	530-753-5928	<a href="mailto:brandon.kavrell@cexpc.com">brandon.kavrell@cexpc.com</a>

**Central California**

Paula Watney (Teens & Adults with PWS)	559-299-8171	<a href="mailto:mikewat1@sbcglobal.net">mikewat1@sbcglobal.net</a>
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**Southern California**

Los Angeles County	Lisa Graziano	310-372-5053	<a href="mailto:LisaG@pwcf.org">LisaG@pwcf.org</a>
	Julie Casey	818-843-7321	<a href="mailto:julie.casey@att.net">julie.casey@att.net</a>
Orange County	Jenn Paige Casteel	949-735-0472	<a href="mailto:marchroses@hotmail.com">marchroses@hotmail.com</a>

**Inland Region Area**

San Bernardino County	Ester Del Real	909-213-5992	<a href="mailto:esterdelreal@ymail.com">esterdelreal@ymail.com</a>
	Maria & Ken Knox	909-421-9821	<a href="mailto:teachknox@aol.com">teachknox@aol.com</a>

**Spanish Speaking**

Mercedes Hernandez (Adults with PWS)	619-822-5742	<a href="mailto:mercedes.hernandez711@yahoo.com">mercedes.hernandez711@yahoo.com</a>
Maria Knox (Adolescents with PWS)	909-421-9821	<a href="mailto:teachknox@aol.com">teachknox@aol.com</a>
Kilma Carillo (Infants/Children with PWS)	760-427-1100	<a href="mailto:kilmab@excite.com">kilmab@excite.com</a>
Veronica Baez (Infants and Children with PWS)	760-357-8189	<a href="mailto:vbaz92@yahoo.com">vbaz92@yahoo.com</a>

**Online Support**

**PWCF Online Information Sharing Group for Members.** This online information sharing group is for PWCF members. To join the group, go to [www.yahogroups.com](http://www.yahogroups.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.yahogroups.com](http://www.yahogroups.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](http://www.pwsausa.org) Click Enter. Click "Support" for Families of Children Ages Birth-5 Years for Spanish-Speaking Families for Families of Children Ages 6-12 Years for Military Families for Families of Teens for PWS + Autistic Symptoms for Families of Adults for Persons with PWS for Siblings for Grandparents

**International PWS Organization**

**IPWSO** offers information about PWS in other languages. Go to [www.ipwso.org](http://www.ipwso.org)

**PWS SHARE & SUPPORT GROUPS MEETING CALENDAR 2015**

**Southern California**

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

**Sunday, January 11, 2015**  
**Sunday, April 12, 2015**  
**Sunday, July 26, 2015**  
**Sunday, October 25, 2015**

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

**Northern California**

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

**Dates TBA**

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

# PARENT TO PARENT

*“How do you support your other children/teens with their feelings about having a sibling with PWS?”*

Validation is huge. I often acknowledge to them that I know it’s very hard on them to have a disabled brother.

We encourage them to share their feelings. And what we have said is: any feeling you have had, we have had as parents, too. Disappointment, grief, anger, frustration, embarrassment, all of it. We have it, they have it.

I think just putting it out there and having our kids know it’s absolutely ok to be upset with/about their brother, keeps the communication open. They feel safe to share.

*Jessica Patay, mom of Ryan, age 11*

My Jane who is 13 says we involve her in the fun activities associated with PWS. She helps with our fundraisers and parties and that helps her feel connected. She knows several kids with the syndrome and loves them. She says we give her information

so she knows techniques that work with Kate and she likes how we let her help with Kate. We talk with her about Kate and what the doctors are saying so she has full information. She is an active participant in Kate’s life, rather than just a victim of Kate’s sometimes negative behaviors.

*Lisa Thornton, President, Utah PWSA and mom of Kate, age 13*

I would have to say that it is certainly not easy for siblings, especially when they are busy figuring themselves out. I think it is good to set aside time to be with just your non-PW kids and give them time to breathe. And of course, always be available to let them share their thoughts and feelings on what is going on in their heads. Lastly, when your child with PW has their breakdown, you have to let the non-PW kids know that this is normal for people with PW and everything is going to be OK with him/her.

*Regards, Andrew Greskovics, dad of GiGi, age 14*

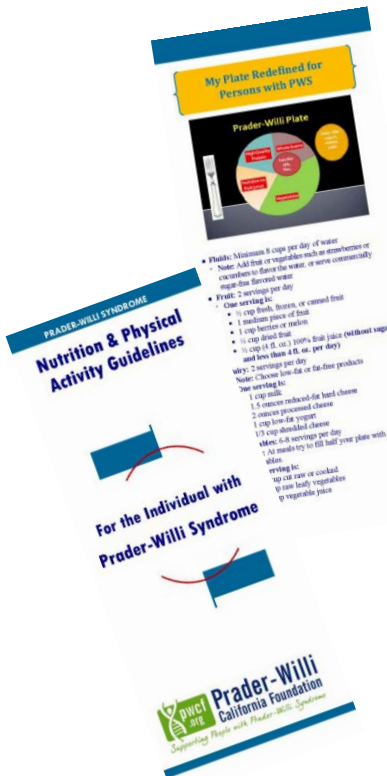
## Next Parent to Parent Question:

*“Some of my extended family don’t respect my decisions about food portions for my child with PWS. What can I do to help them understand that my child’s needs are different?”*

## MEMBER GIVE BACK Focus on Nutrition

This year’s **Member Give Back** includes a multitude of goodies! Look in the mail for your **cooking measurements cutting board**, an **adjustable measuring spoon**, a **Nutrition & Physical Activity Guidelines for the Person with PWS brochure**, and a **tool to help read and understand food labels**.

**PWCF works hard to give you, our valued member, the tools you need!**



## GADGET TIP: KITCHEN SAFE

*Submitted by Cherie Sakschewski of Paradise*



The Kitchen Safe is a time locking container that helps beat temptation and build good habits. USA Today and TIME Magazine call it “Brilliant!” Simply place an item in the Kitchen Safe, rotate the dial to set the time, and press the dial to activate the lock. Once locked, it cannot be opened until the timer reaches zero. No overrides! Now, you can enjoy the occasional snack, and keep it around the house.

The product is built from thick, sturdy, high quality, BPA free materials. Container walls are very rigid and 3X thicker than typical containers. A large, high contrast display shows the amount of time remaining. The locking mechanism is driven by a high quality motor.

The interface takes seconds to learn. Kitchen Safe can be locked for any amount of time between 1 minute to 10 days. Batteries last 6 to 12 months. And, it’s really fun to use. Who doesn’t like spinning and pressing a giant button? Comes in a clear or white base with your choice of lid colors blue, white, red, pink, white, and green. \$55 - \$59. Sold by Kitchen Safe and fulfilled by Amazon.

Learn more at [www.TheKitchenSafe.com](http://www.TheKitchenSafe.com)

## FOOD TIP: GOGO SQUEEZ

*Submitted by Cameron Graziano of Redondo Beach*

GoGo squeeZ pouches are healthy applesauce cups that are easy-to-eat even on the go! Each GoGo squeeZ pouch has about 60 calories; 0 fat; 0 sodium; 14g carbs; 1g fiber; 12g sugars; 0g protein. They come in 12 yummy flavors: Twelve yummy flavors: apple, grape, pear, cherry, strawberry, cinnamon, banana, peach, mango, berry, mixed fruit.

You can also pop them in the freezer and make a delicious slushy treat.

All GoGo squeeZ products are produced free of common allergens, including milk, egg, wheat, soy, tree nuts, peanuts, fish and shellfish.

For more information go to [www.gogosqueez.com](http://www.gogosqueez.com)



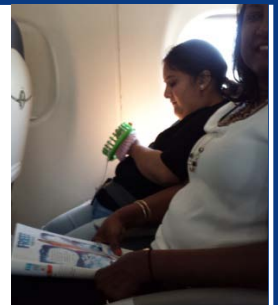
## WE GOT TALENT

*Submitted by Hasumukh Amarasekera of Winnetka*



**Lauren Amarasekera, age 22**, has a real knack for knitting! Lauren knits gorgeous baby hats which you can see here modeled by a beautiful baby girl.

Lauren takes her knitting everywhere... even while traveling on a plane!



# EXECUTIVE DIRECTOR'S COLUMN: A YEAR IN REVIEW

by Lisa Graziano, M. A.

This year marks PWCF's 35th year providing supports and services to people with PWS, their families, and the professionals who serve them. A lot has changed over the past three decades, but three things have remained unwaveringly constant: 1) we are moving closer to successfully treating more and more of the symptoms of PWS; 2) the needs of persons affected by PWS persist; and 3) PWCF will *never* stop working hard to meet those needs.

Change. The mere mention of the word can make parents and care providers shiver in our boots, for we know that 'change' is all too often 'the enemy' for our loved ones who have difficulty shifting attention, going with the flow, being flexible. When we initiate change, the experience is most likely experienced as welcome. But when change is *imposed* on us, our experience is quite likely anything *but* welcome and we're likely to resist it, fear it, and focus on its potential negative outcomes. Being able to adapt and respond effectively to change is a skill, one that is all too often lacking or, at best, challenged in our loved one with PWS. Welcome or not, easy or hard, change is inevitable... and can even provide opportunity for growth.

PWCF is not immune to the inevitability of change, some welcome and some not so much. As the general public and professionals have become more aware and knowledgeable about PWS, and as families have become more sophisticated in managing their child's/adult's symptoms, the demands on PWCF have changed, increased over the years. PWCF's Board has endeavored to meet those demands with new ideas, new and expanded programs and services, and the necessary staff.

After two years of dedicated service, we bid farewell to our Family Support Coordinator, **Katherine Crawford**, who moved with her husband to Wyoming. From May of 2012 through July of this year, Katherine provided educational trainings, advocacy services, and support services to families and professionals. Though she will no longer work in the office, we are fortunate that Katherine plans to continue to support PWCF families utilizing her talents in publications and graphic design, and other projects to the extent possible across the miles.

While we look for a new in-office Family Support Coordinator, we are fortunate to have contracted with **Cynthia Martinez**, a Masters-level student who now serves as a Family Support Consultant, working in the office whenever possible and soon to provide in-home support to families. To help keep up with administrative demands, PWCF created the position of Office

Manager. We are fortunate to have hired the very competent and congenial **Gloria Burns**, who will keep our busy office running smoothly, allowing me more time to be out in the field providing trainings and increasing awareness of the syndrome with people who can support PWCF. We now contract with **Sheila Umeda**, a Social Worker who is available to provide more specialized support to families. Also new this year we welcomed **Jill Nowak**, a Registered Dietician who now provides nutritional guidance to families and professionals.

The latter part of this article provides an overview of the programs, services and activities that PWCF provided in 2014. As you will see, addressing the myriad needs of our family and professional members is often as complex and extensive as the syndrome itself. Those who have personified PWCF throughout the past thirty-five years have been steadfast in their overall focus to meet the needs of persons with PWS. As we look ahead to the next thirty-five years, I can assure you that PWCF is in a remarkable position to provide even greater supports and services to its members. I feel equally confident that the only change in PWCF's commitment to improving the quality of life of all who are touched by PWS is that it will only grow stronger.

On behalf of PWCF, I wish you the happiest and safest of holiday celebrations, and a New Year filled with love and hope.

## Overview of PWCF's 2014 Programs and Activities

In 2014 PWCF served over 800 active members who live or work within every county of California as well as live or work in other parts of the country. The work of PWCF can be placed into four general categories of focus: Education, Support & Advocacy, Awareness, and Research. Each of our programs and services supports our mission and vision that all persons with PWS will live a full life without limits.

**Educational Activities** — PWCF produced four quarterly newsletters that reached over 800 people throughout the country. Each newsletter contained important medical information, research-related information, educational articles, and stories of support and hope written by and for parents. We created new articles including one on theft that is being used internationally. Also being used internationally is our *Understanding the Student with PWS: Strategies for Success* DVD which was recently translated into Spanish. We produced Behavior Management Training sessions that benefited families, teachers, behavioral therapists,

*Executive Director's Column continued on page 6*

Change is inevitable. Growth is optional.

~John C. Maxwell

## EXECUTIVE DIRECTOR'S COLUMN, CONTINUED

Regional Center case managers, vocational and residential service providers. We provided IEP advocacy training sessions to educate and empower parents. We created new educational brochures, including two that are included in this year's Member Give Back package: *Focus on Nutrition*. We kept our website up-to-date to bring even more educational, awareness, and support services to families, professionals, and the general public;

**Annual Conference**—PWCF produced another amazing annual statewide educational conference that provided valuable information and support to parents and professional, and a simultaneous Youth & Adult conference attended by children and adults with PWS and their siblings. The conference also serves to increase public awareness of PWS by recruiting university students in such fields as nursing, special education, physical and occupational therapy, pre-med students, psychology and social work students to help with the Youth & Adult Program;

**Summer Camp** — PWCF hosted our fourth annual summer camp with Easter Seals, the only camp in California that exclusively serves persons with PWS. This year we provided 55 PWCF members with a scholarship to reduce their costs. We provided campers with six fun-filled days, and respite for their families and care providers;

**School Trainings**—Knowing how PWS can impact the student with PWS can improve the quality of support that student receives. For schools located throughout the entire state we provided in-person or telephone inservice trainings for schools, as well as in-person or telephone support at IEPs meetings.

**Multidisciplinary Clinics**—PWCF continued our support of three PWS Clinics. Each Clinic provides state-of-the-art multidisciplinary treatment to children and adults with PWS;

**Residential Support**—We provided in-person, individualized training programs to group home staff, supported living staff, Regional Center case workers, and vocational work staff. This year our Residential Services Liaison Committee reviewed and updated its charter and will resume its task to visit at least annually every group home and supported living site that serves someone with PWS;

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

**Family Support**—New this year PWCF created the Family Fun Events Program to help families play together in a food-free environment. Coordinated by PWCF's President, **Julie Casey**, two of the events were held this year at the specialized *We Rock the Spectrum* gyms in locations in Northern and Southern California. These events were in addition to our existing Family Day events held this year at the L.A. Galaxy and the Oakland A's. As previously mentioned, our list of supportive consultants grew to include a Social Worker and a Registered Dietician. Initiated last year when we distributed free to all members the *PWS Medical Alert booklets*, this year's Member Give Back Program *Focused on Nutrition*. By year-end PWCF will send free to all of our members a newly-developed *Nutrition & Physical Activity Guidelines* brochure, a cooking measurements cutting mat, a set of measuring spoons, and a tool for understanding food labels. We continued to maintain our 24-hour PWS-related Medical Crisis Line and our statewide toll-free 800 line, hosted Support Group meetings, and maintained our online information sharing Yahoo group. We personally spoke with each and every newly diagnosed family, sent each a personalized Information Packet and Member Handbook & Records Keeper binder when they joined, and encouraged each to join the PWSA (USA) and their online support group. Each new family who desired one was connected with an experienced Parent Mentor for ongoing information and support.

**Public Awareness**—Community awareness was increased through PWCF's website, public service announcements, press releases, walk-a-thons/picnics, participation in the ASICS LA Marathon, Charity Relay, and LA Big 5K races thanks to the tremendous dedication of **Katherine Crawford** and **Kimberlee Morgan**. Team PWCF ran in the national Ragnar Race thanks to the colossal coordinating efforts of **Christopher Patay**. PWCF had awareness booths at children's concerts, at the Human Growth Foundation's walkathon, and at other local venues. Members held their own awareness and fund raising events including **Lisa and Neil Vitro** who held a car show, **Robin Lattimer** who held an art show, and **Ivette Ramos** who held garage sales. Thanks to **Julie Casey**, we have very active Facebook and Twitter pages with more social media to be added next year;

**PWS Research**—PWCF supported state and national research by working with PWSA (USA), local universities, teaching hospitals, researchers, and scientists all over the country to help recruit subjects and disseminate research materials. We are fortunate to have wonderfully collaborative relationships with researchers who are active in the study of PWS.

**The following excerpts from letters received this year from families and professionals demonstrate a sampling of PWCF's impact upon the lives of the families and professionals we serve:**

*Executive Director's Column, continued on page 7*

## SWALLOWING FUNCTION STUDY



Based on a recent study on the swallowing function in persons with Prader-Willi syndrome, PWSA (USA) has new information to share that may benefit all to hear, not just those with PWS. Dr. Roxann wanted to share a few safety tips based on the research to help families have healthy eating habits and to prevent choking.

“From what we are learning in our research and clinical PWS swallowing practice, liquids appear to clear the esophagus in many persons with PWS. We do not know if this is necessary for only foods that are chewable because smooth, puree food like pudding can also remain in the esophagus and build up as the meal continues.

“Most of our research subjects did not know that what they were eating had not “gone down,” yet because we used x-rays to see inside, we knew that the food remained. Drinking SIPS of liquids during a meal or snack (i.e. liquid washes) MIGHT clear the mouth and throat of any remaining, undetected residue. Taking additional saliva swallows may also be beneficial in clearing food residue.”

Roxann Diez Gross, PhD,CCC/SLP & Greg Cherpes, MD - The Children’s Institute, Pittsburgh PA.

*Executive Director’s Column continued from page 6*

Dear PWCF: I wanted to thank you again for our time together today. I’ve been sharing the information you shared with me all day and I having a feeling of HOPE! Sincerely, Rachel Velazquez, mother of Marisela, age 14

Dear PWCF: All of us - Sean, Michelle, Sean’s siblings, and I - so appreciate all that you’ve done to enrich Sean’s life. You know, I think, that he continues to do well in his apartment, in large part thanks to the training that you provided to his support staff. All the best for a great 2014. As ever, Mike Raleigh, father of Sean, age 33

Dear PWCF: Thank you so very much. There are no words for what you and the PWS [associations] have already given us and for what I’m sure will be a lifetime of support for our family. Natalie Inouye, mother of Sloane, age 1 month

Dear PWCF: Thank you for running the inservice for us on Thursday! The feedback was very positive, and the information as well as your suggestions will be helpful for the team at [our school]. Linda Spencer, Program Specialist

Dear PWCF: What an amazing experience [at the LA Big 5K]!

## PWCF HIRES OFFICE MANAGER



To keep pace with the ever-growing needs of members, PWCF’s Board of Directors authorized creating a new position of Office Manager. After an extensive search, PWCF hired our first Office Manager on October 7. We are pleased to introduce you to **Gloria Burns.**

Gloria has over twelve years experience in sales, administration, and customer service. She worked for American Airlines for seven years before leaving to pursue a career in sales with ADT security, and Worldwide Express where she was number one in national sales. Gloria is currently completing her BA degree in Business Management at California State University Dominguez Hills.

Gloria is passionate about helping others and giving back to her community. In 2011 she helped organize a non-profit scholarship organization called Circle of Friends where she continues to serve as its Secretary. In 2010 she ran a full marathon and raised money and awareness for leukemia and lymphoma support. We look forward to one day having Gloria run on Team PWCF, but for now we are most excited to have her working in the office providing much-needed organizational and administrative support.

Welcome, Gloria!

Already two of my friends have voiced an interest in joining next year! Hasmukh Amarasekera, mother of Lauren, age 26

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 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: 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

*Executive Director’s Column continued on page 13*

# Do You WIGGLE?

by Jennifer Paige Casteel



When Nicholas (PWS) was 9 years old I watched his rigidity and growing anxiety start to interfere with his enjoyment of everyday life. Seeing him struggle motivated me to seek help. I found a local therapist who had absolutely no experience with PWS. I didn't know where else to go so I took the chance. What she lacked in PWS knowledge, she made up for with a willingness to listen to me, and more importantly, to Nick.

One day she had a piece of dry spaghetti. She held it up and showed us what happens when we are inflexible... we SNAP. For Nicholas, the SNAP looked like a loud meltdown. For mommy, the SNAP looked like closing the bedroom door and crying as quietly as possible. The visual was very clear, we did not want to go through life as dry spaghetti. Luckily, there was another option. The cooked spaghetti noodle had learned to wiggle, to flex with the demands around it. Nick and I agreed we wanted to be "wiggly."

Getting your wiggle on takes a plan. We started with a "feel better bag" to prompt coping strategies when we needed to move from the SNAP (inflexible behavior) to the WIGGLE (flexible behavior). Nicholas's job was to try out the coping strategies in the bag and see what helped him calm down in a moment of increasing rigidity and stress. Bubbles were included to practice slowly inhaling and exhaling. An angry breath would pop the bubble. An eraser, to

literally erase the stress from right out in front of us and start over. Silly Putty to squeeze the frustration right out. A picture of a happy memory to look at while taking a quiet break. A baggie of cotton balls with lavender essential oil to smell our way through the stress. A worry stone to rub through the stress. Japa Mala beads for meditation or prayer. A small journal to write out the angry words until they get tired of being written and go away. I don't remember everything the therapist added and everything we added, but what grew was a bag of coping strategies to use before getting to the SNAP. We also gained a silly way to talk about flexibility and inflexibility when things were calm, so we could troubleshoot and plan together. Who wants to be dry spaghetti? Not us!!

For a few months we rotated through the tools. Eventually, you pick your favorite and keep it on hand at home, the car, your purse and school. While raising Nick I've learned how safe he feels when it's clear - Mom has the food security plan handled. The same holds true for behaviors. You can relax when you know there is a plan for those ugly moments when rigidity or anxiety is about to make you SNAP. I'm not sure if it works because of the redirection of the physical tools or the hilarity that ensues when your mother starts dancing around the room pantomiming "erase...and wiggle, erase...and wiggle...stop laughing and have your meltdown!"

Age 14 is flying by and things are getting harder, but Nick and I are also getting better as a team. We've learned that having plan A (for the expected) and plan B (for the unexpected), helps us both to relax. Don't forget the feel better bag for mom! I suggest marbles - for when you've lost yours - and a piece of rope. When you are at the end of your rope, just tie a knot and hang on.

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## GEM Column, continued from page 1

problems with swallowing; drinking water or some other liquid between bites may be an easy solution. PWSA (USA) is "paving the way for our new generation" and changing the future of our children.

The conference highlight for many was the **Breakout Share Sessions** held during the lunch hour. Divided into age groups, parents and care providers were able to network and share information, tips, guidance, and most critically, understanding. The Share Sessions are indeed an invaluable element of PWCF's conferences.

While their moms and dads were busy learning in the General Session, a great deal of fun was being had by their kids in the simultaneous **Youth & Adult Program**. Ladies and gentlemen of all ages quickly gathered around for the circus that came to town at this year's Youth and Adult Program (YAP)! The day's

events went off with huge success thanks to our amazing directors, **Cynthia Martinez, Ben Romero, Kevin Amarasekera, Kristen Amarasekera, and Brian Parenti**. PWCF's Traveling Circus featured various games such as ring toss, knock-the-cans-down, and hoop throws! In addition, Dotty the Clown make a visit and had the kids and adults laughing out of their seats! Audience members even participated in her puppet show. Other activities featured arts and crafts, Circus Bingo, and watching the movie *Madagascar: The Circus*. Attendees had a terrific time and, we're told, cannot wait for next year's Youth & Adult Program!

Mark your calendar now for **November 14, 2015** and we'll look forward to seeing you then at next year's **State Education Conference in Southern California!**



# CALL FOR PATIENTS: RESEARCHING PWS HYPERPHAGIA TREATMENTS

## *Beloranib and Diazoxide*



### **Beloranib**

Adolescents and adults (12-65 years) with PWS may be eligible to participate in a phase 3 clinical trial sponsored by Zafgen. This important clinical trial, *bestPWS*, will help determine the effectiveness of a novel treatment for PWS called

beloranib. In a phase 2 clinical trial completed earlier this year, beloranib showed a reduction of body fat and hyperphagia-related behaviors (the drive to eat) in a small group of PWS patients.

Eligibility for the study will include obese patients with a BMI of greater than or equal to 30, and, less than or equal to 60 kg/m<sup>2</sup> (or greater than or equal to 95th percentile for ages 12-17). The study will enroll people with PWS living in a family home environment or group home less than half time with a consistent primary caregiver.

Study participants will be randomly assigned to receive beloranib or placebo. Study participation will involve twice weekly injections administered by visiting nurses at the participant's home and approximately 8 visits to the study site over 7 months. Patients who complete the study will be eligible to enroll in an optional study extension where all patients will receive beloranib for another 6 months. Travel expenses for visits to the study site will be covered.

To learn more go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and type in "Zafgen Prader Willi" on the search bar. To participate in the study contact the site closest to you:

#### **Northern CA: UC Davis in Sacramento**

Contact: Majid Mirmiran, MD, PhD 916-734-4790  
[majid.mirmiran@ucdmc.ucdavis.edu](mailto:majid.mirmiran@ucdmc.ucdavis.edu)

#### **Southern CA: UC San Diego, Rady Children's Hospital**

Principal Investigator: Lynne Bird, MD  
Contact: Rachel Winograd 858-966-8453  
[rwinograd@rchsd.org](mailto:rwinograd@rchsd.org)

### **Diazoxide**

Essentialis, in collaboration with the UC Irvine, has initiated a clinical trial of diazoxide choline controlled-release tablets (DCCR) in patients with PWS. DCCR is a new once-per-day tablet formulation of diazoxide. Diazoxide has been approved in the US for nearly 40 years for the treatment of rare hypoglycemic conditions in neonates, children, and adults. The most common adverse effects of DCCR and diazoxide include the potential for fluid retention and peripheral edema (swelling of ankles, feet, or hands) and the potential for increases in blood sugar.

DCCR may benefit PWS patients in a number of ways. DCCR works on a part of the brain called the hypothalamus, which regulates appetite and energy expenditure, restoring a more normal balance of food intake and energy expenditure. DCCR also works on adipose (fat tissue) causing a shift from storing fat to burning fat for energy, reducing fat mass. In the liver, DCCR works to reduce the production and secretion of triglyceride (fat) and cholesterol. In clinical studies in obese patients, both DCCR and diazoxide have been shown to reduce appetite, induce weight loss and improve triglyceride levels.

This clinical study is designed to evaluate the safety and efficacy of multiple dose levels of DCCR in PWS patients. To be enrolled in the study, patients must be between 10 and 20 years old, obese and have a genetic confirmation of PWS, male or female of any race or ethnicity, receiving or not receiving growth hormone. They should be generally healthy. They cannot be diabetic. After screening, patients will return for 7 more visits over 14 weeks. During the first 10 weeks of the study, patients will receive DCCR and will have their dose increased up to 4 times. At the end of 10 weeks, patients who responded to DCCR with reductions in hyperphagia, or an increase in energy expenditure will be eligible to participate in a 4 week extension to the study. During the extension, half of the patients will be randomized to continue on DCCR and half will be randomized to placebo. Patients will be compensated for their participation in the study.

For more information go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and search for **NCT02034071**. To enroll in the study, contact Virginia Kimonis, M.D., principal investigator, at 714-456-5791 or 949-824-0571 or email [vkimonis@uci.edu](mailto:vkimonis@uci.edu). You can also contact Marie Wencel, research coordinator at 949-824-0521 or email [mwencel@uci.edu](mailto:mwencel@uci.edu).

**Support Cutting-Edge PWS Research: Join a Research Study!**

# PRACTICE MAKES PERFECT FOR EXECUTIVE FUNCTIONING

by Bob Cunningham, M.A., Ed.M., in-house advisor on learning and attention issues at [Understood.org](http://Understood.org)

Edited for PWCF News by Lisa Graziano

Executive functions consist of several mental skills that help the brain organize and act on information. These skills enable people to plan, organize, remember things, prioritize, pay attention and get started on tasks. They also help people use information and experiences from the past to solve current problems. Unfortunately, most people with PWS have Executive functioning issues which directly interfere with their ability to:

1. **Analyze** a task. Figure out what needs to be done
2. **Plan** how to handle the task
3. **Get organized.** Break down the plan into a series of steps
4. Figure out how much time is needed to carry out the plan, and **set aside the time.**
5. **Make adjustments** as needed
6. **Finish the task in the time allotted**

Executive functioning issues are tough. Without them there is difficulty with impulse control, emotional control, flexibility, working or short-term memory, self-monitoring, planning and prioritizing, task initiation, organization.

I've watched the most dedicated and caring parents and the best teachers break down as they try to make sense of what's going on with [people who have executive functioning issues] who struggle with organization, planning and time management. It's so easy to mistakenly see [someone] with executive functioning issues as careless, confused, lazy or rude. And it's so hard to be empathetic if that's what you think.

The conversations I've had with kids tell me that they're confused, too. They care about getting things done. They might even know how to get things done. But they never seem to actually get it done. And they feel the effects in and out of school.

## Practice, Practice, Practice

Having worked with many kids, I've found that the best way to address executive functioning issues is repeated practice of simple strategies that can meet changing needs over time.

For example, if a young child learns to use a picture schedule, he can learn to use a calendar to plan long-term assignments as he gets older. And a child who learns to use a binder with different folders can learn to use folders for email later on. The same basic ideas behind these strategies can grow with the child as his life gets more complex.

Practice is the key. In his book *Outliers: The Story of Success*, journalist Malcolm Gladwell writes that it takes 10,000 hours of practice to truly master a skill. He gives examples of high-level musicians and computer programmers.

Of course I'm not saying that [someone with executive functioning issues] has to spend 10,000 hours practicing a single strategy.

But I do think we often seriously underestimate the amount of practice it takes for someone to get really good at using a strategy. Sometimes, we change approaches too soon.

Organization, planning and time management don't always come naturally. [People with PWS] need to practice a lot for strategies to become second nature. It's up to us as parents and care providers to give our kids and adults the time and encouragement needed to get there.

There are a number of additional strategies, interventions, and accommodations that can be made in the home, school, and work environments to help compensate for deficits in executive skills. Some of these include:

**Make checklists.** Listing the steps involved in a task will make it easier for your child or adult with PWS to see how to get started. It also may lessen their anxiety around planning. Checklists provide a visual reminder of where your child or adult left off if they got distracted. You can make checklists for everything from the tasks they have to do before school or work to how to make a bed.

**Set time limits.** Your child or adult likely struggles to budget time for an activity and also for each step of that activity. On your checklists, consider giving a time estimate for each step. If your child or adult doesn't read, you can put some inexpensive kitchen timers around the house. Set them for the amount of time they should spend on everything from completing a math sheet to brushing their teeth.

**Use planners and calendars.** Not all planners have to be on paper, which is a good thing if your child or adult has trouble keeping track of items. You can put up a big family calendar somewhere and give your child or adult their own colored marker. For older kids and adults there are free or inexpensive apps and time-management software that can help ([www.understood.org/en/tools/tech-finder/find-tech](http://www.understood.org/en/tools/tech-finder/find-tech)).

**Explain yourself.** Like others with executive functioning issues who are inflexible thinkers and have difficulty with emotional control, people with PWS usually don't take feedback well or see the point of learning new ways to do things. Try to spell out why it's important to learn a new skill, or how it may save time and energy in the long run. And if the answer is simply, "Because that's the way it has to be done," don't be afraid to say that.

**Let your child or adult explain, too.** Just because kids have trouble with executive functioning skills doesn't mean their way of doing something isn't valid. If your child or adult's method doesn't make sense to you, consider taking the time to ask why before saying it has to be done differently. It may actually be an inventive approach that works for your child or adult. **The more successful strategies they come up with themselves, the better!**

# PWCF CONGRATULATES PRESIDENTIAL AWARD RECIPIENTS

PWCF proudly recognizes this year's President Award recipients, presented to them by Julie Casey at PWCF's Annual Education Conference on November 8 in Santa Clara.



**Suzanne Cassidy, M.D.** in recognition and appreciation of her long-time and extraordinary work directing the PWS Clinic in Fresno, California. Her dedication to patients with PWS is and always will be appreciated by every life she has touched

**Jacob Caldwell** in recognition and appreciation of his Fool Disclosure play that raised over \$1,000 to support PWCF's vital programs and services

**Katherine Crawford** in recognition and appreciation of her dedicated and enthusiastic work to support Team PWCF at the ASICS LA Marathon, Charity Relay, and LA Big 5K awareness and fundraising events

**Kimberlee Morgan** in recognition and appreciation of her work to support Team PWCF at the ASICS LA Marathon, Charity Relay, and Big 5K awareness and fundraising events

**Neil and Lisa Vitro** in recognition and appreciation of their Car Show that raised \$2,100 to support PWCF's vital programs and services

**Christopher Patay** in recognition and appreciation of his extraordinary work to organize PWCF's participation in the 2014 Ragnar RACE for PWS which raised over \$17,500 to support PWCF's vital programs and services.

## PWCF EVENTS CALENDAR 2015

Date	Day	Event	Location
January 11	Sunday	LA County Support Group Meeting	PWCF Office
January 23-25	Fri - Sun	Board Meeting	TBD
March 10	Tuesday	Board Meeting	Evening - Phone Meeting
March 14	Saturday	LA Big 5K	Dodger Stadium
March 15	Sunday	ASICS LA Marathon	Los Angeles
April 11	Saturday	Northern CA Walk	San Francisco
April 12	Sunday	LA County Support Group Meeting	PWCF Office
April 2	Sunday	Southern CA Walk	Griffith Park
May 16	Saturday	Board Meeting	PWCF Office
June 18-23	Thu - Tues	PWS Camp	Camp Harmon
July 14	Tuesday	Board Meeting	Evening - Phone Meeting
July 26	Sunday	LA County Support Group Meeting	PWCF Office
September 12	Saturday	Board Meeting	PWCF Office
October 25	Sunday	LA County Support Group Meeting	PWCF Office
November 1 - 7		Obesity Week	Los Angeles
November 3 - 7		PWSA (USA) Meetings/Conference	Orlando
November 13	Friday	Board Meeting	So. CA Hotel
November 14	Saturday	PWCF Annual State Conference	So. CA Hotel

# ENERGY EXPENDITURE (CALORIES SPENT) IN PWS: A BRIEF REVIEW

by Daniela Rubin, Ph.D.

Understanding the caloric expenditure of infants, children, adolescents and adults with PWS is vital for weight management. Several studies have been published since 2000. This review will comment on the most salient studies that provided data to make recommendations.

An early study by van Mil (2000) in children and adolescents with PWS ages 7 to 16 years, showed that the average daily metabolic rate (calories spent for sustaining normal function of our bodies which excludes physical activity) based on weight was about ~40% lower in PWS than in those without PWS. They also showed a much lower amount of (~50% lower) of calories spent doing physical activity, likely because of doing less activity and less lean mass (muscle).

In 2003, Bekx and collaborators evaluated total energy spent per day in 16 infants and toddlers with PWS aged 4-23 months who were not on GH replacement therapy. These authors concluded that infant and toddlers spent about 30% less calories than World Health Organization (WHO) norms. That translated to 71 kcals/day per kilogram of body mass compared to 104 kcals/day per kilogram of body mass recommended by WHO.

A later study by Dr. Butler (2007) demonstrated adults with PWS spent about 20% less of total calories per day compared to adults with obesity. This lower percentage of calories spent was related to adults with PWS having a lower amount of lean mass and doing about 35% less spontaneous amount of physical work (movement,

physical activity, exercise).

A question that comes to mind, then, of parents or caregivers is 'how many calories is my child actually expending when doing physical activity such as walking, playing games, sports, etc.?' The answer is we do not know yet. We know that they spend less about ~16%-21% less calories at rest (van Mil 2000, Butler 2007) and about 20 % for adults and 30% less in infants and toddlers and 40% less overall total calories per day (Bekx 2003, Butler 2007). Though, studies which have directly compared the calories spent doing specific activities like walking have yet to be done.

For now, something to keep in mind is that people with PWS will likely spend less calories while doing the same physical activities than people without PWS. This is important information for trying to match caloric needs when adding physical activity into the daily routines.

1. Bekx MT, Carrel AL, Shriver TC, Li Z, Allen DB. Decreased energy expenditure is caused by abnormal body composition in infants with Prader-Willi Syndrome. *J Pediatr.* 2003 Sep;143(3):372-6.
2. Butler MG, Theodoro MF, Bittel DC, Donnelly JE. Energy expenditure and physical activity in Prader-Willi syndrome: comparison with obese subjects. *Am J Med Genet A.* 2007 Mar 1;143A(5):449-59
3. van Mil EG1, Westerterp KR, Kester AD, Curfs LM, Gerver WJ, Schrandt-Stumpel CT, Saris WH. Activity related energy expenditure in children and adolescents with Prader-Willi syndrome. *Int J Obes Relat Metab Disord.* 2000 Apr;24(4):429-34.

## PWCF BOARD MEMBER HELPS INTENSIFY AMA'S FOCUS ON OBESITY



As a member of the American Medical Association (AMA), PWCF Board Member **June-Anne Gold, M.D.** helped influence the AMA's focus on obesity, a hallmark – yet preventable! – symptom of Prader-Willi syndrome.

At their last meeting, the Reference Committee recommended Resolution 811 which was approved. Below is the exact verbiage of Resolution 811.

### RESOLUTION 811 - HEALTH PLAN COVERAGE FOR OUTPATIENT OBESITY PRIMARY CARE VISITS

1. Our AMA will: (A) assume a leadership role in collaborating with other interested organizations, including national medical specialty societies, the American Public Health Association, the Center for Science in the Public Interest, and the AMA Alliance, to discuss ways to finance a comprehensive national program for the study, prevention, and treatment of obesity, as well as public health and medical programs that

serve vulnerable populations; (B) encourage state medical societies to collaborate with interested state and local organizations to discuss ways to finance a comprehensive program for the study, prevention, and treatment of obesity, as well as public health and medical programs that serve vulnerable populations; and (C) continue to monitor and support state and national policies and regulations that encourage healthy lifestyles and promote obesity prevention. 2. Our AMA, consistent with H-440.842, Recognition of Obesity as a Disease, will work with national specialty and state medical societies to advocate for patient access to and physician payment for the full continuum of evidence-based obesity treatment modalities (such as behavioral, pharmaceutical, psychosocial, nutritional, and surgical interventions). (BOT Rep. 11, 1-06; Reaffirmation A-13; Appended: Sub. Res. 111, A-14)

RESOLVED, that our AMA modify Policy D-440.954, Addressing Obesity, by addition to read as follows:

Resolution 811 asks that our AMA advocate and support state and federal efforts that would mandate universal health plan payment, including both private insurance and Medicaid, for pediatric primary care visits for childhood obesity/overweight.

# ASHG HONORS SUZANNE CASSIDY, M.D. WITH AWARD FOR EXCELLENCE IN HUMAN GENETICS EDUCATION



The American Society of Human Genetics named **Suzanne B. Cassidy, M.D.** the 2014 recipient of the annual Award for Excellence in Human Genetics Education. “This well-deserved award is a very prestigious honor few people ever achieve,” writes Sara Dwyer, Editor of PWSA (USA)’s *The Gathered View*.

Dr. Cassidy is a Clinical Professor of Pediatrics in the Division of Medical Genetics at the University of California, San Francisco. She is a long-time Professional Member of PWCF. She served hundreds of children and adults with PWS at the PWS Clinic in Fresno which she directed from 2005 until 2013, as well as at UC San Francisco. Dr. Cassidy served on PWSA (USA)’s Scientific Advisory Board since its inception and served as a past chair. She continues to support persons with PWS as the current President of the International Prader-Willi Syndrome Organisation.

The ASHG award recognizes an individual for contributions of exceptional quality and importance to human genetics education internationally. Awardees have had long-standing involvement in genetics education, producing diverse contributions of substantive influence on individuals and/or organizations. Dr. Cassidy received her award, which includes a plaque and monetary prize, on October 20 during ASHG’s 64th Annual Meeting in San Diego. She delivered her award address immediately thereafter.

Dr. Cassidy is well-known for her clinical and research leadership in Prader-Willi syndrome, a genetic disorder that causes low muscle tone, life-threatening obesity, and developmental delays. She has also played key roles in the medical genetics education of medical students, residents, and genetics trainees as well as

of patients and their families. She has developed a variety of education materials, including three editions of the textbook *Management of Genetic Syndromes* and clinical genetics training programs across the country.

“Dr. Cassidy has worked tirelessly to improve genetics education and support patients in a variety of roles – as a teacher, mentor, physician, author, and advocate. This award celebrates her contributions to science, medicine, and the patient experience,” said Joseph McInerney, MA, MS, Executive Vice President of ASHG.

Throughout her career, Dr. Cassidy has received numerous honors for her research and teaching, including election to several advisory boards, founding editorship for clinical genetics in the journal *Genetics in Medicine*, and visiting professorships at institutions in the United States and abroad. In addition, she was a member of the founding Residency Review Committee for Medical Genetics when it was first recognized as a medical specialty, and belonged to the American Board of Medical Genetics and Genomics, which accredits genetics training programs and certifies medical geneticists. ASHG also recognized Dr. Cassidy’s substantial contributions to the Society. A longtime member, she belonged to ASHG’s Education and Information Committee from 1987-1990, participated in its Rapid Action Task Force on Genetic Testing in 1995, and was a member of its Nominating Committee in 2007. Dr. Cassidy also served on the ASHG Board of Directors from 1993-1995.

PWCF’s President, Julie Casey, presented Dr. Cassidy a 2014 President’s Award for her sustained and dedicated support of persons with PWS. PWCF is grateful for and proud of Dr. Suzanne Cassidy!

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*Executive Director’s Column, continued from page 7*

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

Dear PWCF: Janalee [Heinemann of PWSA (USA)] sent me a copy of your article on theft... It’s a great article and very simple to follow. This kind of thing draws huge attention from our international group of parents. Kind regards, Linda Thornton, Communications Coordinator, International PWS Organisation [www.ipwso.org](http://www.ipwso.org)

Dear PWCF: [You] helped us many times when [our daughter’s] preschool didn’t understand how to approach her PWS issues like her tantrums and food control. We are so thankful for PWCF for helping us through the daily parenting battles. Sincerely, Rhonda

and Andy Faust

Dear PWCF: We can’t thank you enough for coming to STEP [supported living services agency] and sharing yourself and PWCF with us! Looking forward to a future of collaboration to better serve folks with PWS. Take care, Lynn Vaughan, Director of Medical Services.





The deadline to join Team PWCF in the LA Big 5k or the ASICS LA Marathon is mid-January!  
Contact PWCF at 310-372-5053 or info@pwc.org

For details, visit [www.pwcf.org](http://www.pwcf.org)

Join Team PWCF to help us improve the lives of those with PWS, one step at a time.



Did you know: 90 cents out of every dollar PWCF receives goes directly into its mission?

## THANKS TO ALL OUR RAGNAR RACE DONORS!

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# COURAGE

*Written by Chris Widener and shared by Clint Hurdle*

*The scars you acquire while exercising courage will never make you feel inferior. ~ D.A. Battista*

*Courage is a special kind of knowledge: the knowledge of how to fear what ought to be feared and how not to fear what ought not to be feared. ~ David Ben-Gurion*

*Courage is fear that has said its prayers. ~ Dorothy Bernard*

**Courage.** It is a word that conjures up images of great and dramatic actions. And yet I realize that we all have the opportunity to be courageous every day, in small and large ways. And it is when we choose to be courageous that we change our lives and the lives of those around us.

Can you name anything of any significance that did not emanate from some sort of courageous decision? I can't. Think of the changes that we have experienced in the last few decades and trace them back to their initial decision. Chances are, someone exhibited courage.

So what is courage? It is simply acting on what we want to do, regardless of any fear we may have. It is the choice to disregard worry. It is the choice to do right, to pursue our dreams, to be successful people, to lead the way for others.

Courage changes lives. Yes, it changes lives.

First, the day you begin to stare down your fears and worries, and instead act courageously, your life will change. You will be set free to fly like you never have before. You will accomplish things you once only dreamed of. You will experience things you thought were only for others—the courageous ones. You will realize that your fears were baseless and just paper tigers, a mirage. You will begin to live your dreams. You will become a person of character!

You will also change the lives of others. Simply put, courageous people pull others along with them. Everybody benefits from courageous people. I have a friend who I admire greatly. A little over a year ago he decided to leave a lucrative career and pursue a dream. All obstacles were thrown his way. The day he left his company, he found out that his wife had cancer. He went into a great deal of debt to finance his dream. He raised millions of dollars, putting his name and reputation on the line. He acted courageously.

A year later, he has more than 50 employees and growing monthly. Those employees are reaping the benefit of his courage! And his wife, who beat cancer, is acting courageously with him!

Here are some quick tips for acting courageously:

## **Know what you want.**

Courage is about choice. If you are to act courageously, you need to know what the right choice is. Be clear about your dream and vision.

## **Do not worry.**

I heard recently that worry is the wrong use of the imagination. That is perhaps the best definition I have ever heard. Worry is just thinking about all of the bad possibilities, isn't it? Well, courage is just thinking about all the great possibilities and then acting upon them!

## **Do your homework.**

It helps to get the facts. It helps because then you can make an informed decision that will put your heart and mind to rest. There will probably be a downside, but we understand that, choose alternatives and act decisively.

## **Act.**

There is no substitute for the first step. Do you know what you want? Have you thought of the possibilities? Have you done your homework? Then what are you waiting for? The next step is to take the first step, and ACT!

*Chris Widener is an author, businessman, public speaker, television host, and a State Senator of Ohio.*

*Clint Hurdle is a former Major League Baseball outfielder and current manager of the Pittsburgh Pirates. He is the father of three beautiful children, one of whom has PWS and another who maintains active membership in PWCF. He is the national spokesman for the Prader-Willi Syndrome Association (USA), and quite frankly, is one of the nicest men you'd ever hope to meet. Clint regularly distributes emails that contain various pearls of wisdom and motivation he's collected from various parts of the world. At the bottom of every email is his signature tag line, "Make a difference today. Love Clint" Whenever one opens an email from Clint one knows they will be challenged to make a difference today. We hope you are inspired to make a difference today too.*

## BOARD CORNER

Summary of Board Meeting on November 7, 2014

Submitted by Diane Kavrell

The Board met Friday, November 7 at the Santa Clara Marriott prior to the General Education Meeting meeting on Saturday, November 8. Those attending were Whitney Bras, Julie Casey, Roger Goatcher, Tom McRae, Nisha Mehta, Jacki Lindstrom, Daniella Rubin, Ph.D., Renee Tarica, Lisa Graziano (Executive Director), Gloria Burns (Office Manager) and Cynthia Martinez (Family Support Consultant).

The following reports were distributed prior to the meeting: Executive Committee Report, Executive Director's Report (incorporating the Program Committee and Support & Advocacy reports), Finance Committee Report, Social Committee Report, Residential Liaison Report, and Public Awareness Committee Report.

### Highlights of the meeting were:

- Gloria Burns (the new Office Manager) and Cynthia Martinez (the new Family Support Consultant) were welcomed and introduced to the Board.

- PWCF shall continue to send PWCF representative to PWSA (USA) Chapter Leaders' Meetings. It's important for collaboration and meaningful discussion.

- Lisa Graziano received high marks from her Annual Evaluation and was awarded a 7% salary increase effective 1/1/2015. Her last raise was in 2012.

- Member Give Back is on track for being shipped out by end of year.

- Board agreed to form a committee to continue outreach phone calls to members.

- Board Approved dates for 2015 calendar including PWS Camp (June 18-23), Northern California Walk (April 11); Southern California Walk (April 26), tentative General Education Meeting conference (November 13 and 14) in Southern California.

- 2015 Board Officers elected. Current officers agreed to continue serving and Board voted on their continued service: Julie Casey (President), Kimberlee Morgan (Vice President), Nisha Mehta (Secretary), and Renee Tarica (Treasurer). Renee will be a non-voting member.

- 2015 Board Candidates: Kimberlee Morgan, Whitney Bras and Roger Goatcher are running for another term while Renee Tarica has termed out from the Board but will continue to serve as Treasurer and a non-voting member. Jenny Wolkenstorfer is running for the vacancy left when Renee steps off as a voting member.

- Board reviewed and edited the existing Investment Policy and approved minor revisions including to change the growth rate target wording to "grow the fund at least at the rate of inflation".

### Discussion Items

Discussion about creating an Honorary Title to recognize Board Members and other Significant Contributors that have had an

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**VOLUNTEERS**  
are **Priceless**

PWCF thanks **Monze Patiño** and **Daniela Rubin, Ph.D.** for their work to create our newest brochure, *Nutrition & Physical Activity Guidelines for the Individual with Prader-Willi Syndrome* which will be mailed to all Individual, Family, Extended Family, and Professional Members in Good Standing as part of our 2014 Member Give Back Program.

PWCF thanks **Angela Lucero**, **Christine Bias**, and **Harmony McAfee** for their work to help prepare for PWCF's Annual Education Conference.

PWCF is grateful to **Tammie Penta** of the PWS Arizona Association and the national PWSA (USA) for providing legal advocacy support to one of our family members.

PWCF thanks **Julie Casey**, **Kimberlee Morgan**, **Jennifer Wolkenstorfer**, and **Hilda Martinez** for working at PWCF's Information Booth on December 6 at the Walk for Kids Growth hosted by the Human Growth Foundation and the Children's Hospital Los Angeles Center for Endocrinology, Diabetes & Metabolism.

## NEW MEMBERS ELECTED TO PWCF BOARD OF DIRECTORS *For 2015-2017 Term*

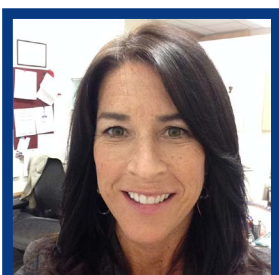
PWCF congratulates and welcomes our newly-elected Board of Directors who will serve for the 2015-2017 term.



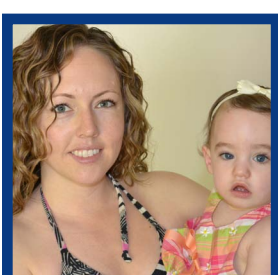
**WHITNEY BRAS**



**ROGER GOATCHER**



**KIMBERLEE  
MORGAN**



**JENNIFER  
WOLKENSDORFER**

Effective January 1, 2015, these four members will join the existing Board of Directors: **Julie Casey (President)**, **June-Anne Gold, M.D.**, **Diane Kavrell**, **Jacki Lindstrom**, **Tom McRae**, **Nisha Mehta (Secretary)**, and **Daniela Rubin, Ph.D.** PWCF's Treasurer, **Renee Tarica**, was elected by the Board to serve as its Treasurer.



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impact on the organization. Bylaws will need to be updated and nominating procedures need to be established.

In reviewing the Strategic Plan consideration was given to create an internal database of respite providers. Sibling Video Series is in the works with draft outline to be completed Jan. 2015, and the possible need for more information regarding Special Needs Trust planning.

A series of First Responders Training for Police Department personnel is being worked on with possible rollout by end of 2015 and a video for Parents, Officers, Schools and Resource Specialist to be available mid-2016.

Next Board Meeting will be a tentative retreat January 23-25, 2015 with a location to be determined.

## SCHOOL TRANSIT TRAINING *Excerpted from Wrightslaw.com*

*Are school bus drivers and bus aides who transport special needs children required to have training? Are they required to know the disability and be able to accommodate that disability?*

The need for training and support applies to all school personnel, including bus drivers and school bus aides.

School bus drivers are expected to handle children with different needs related to:

- Cognitive concerns
- Behavioral issues
- Physical impairment
- Medical conditions



A school bus driver may need training in behavior management techniques for children with [PWS] and emotional disturbances. The bus driver or aide may also need training from physical and occupational therapists about how to position a medically fragile child. The school nurse could train transportation personnel about how to transport a child with health impairments.

The National Highway Traffic Safety Administration (NHTSA) has a training module for Transportation of Children with Special Needs. The module advises bus drivers and attendants to “know your students and what they need.”

### Guidelines

- Have transportation personnel who work with a student at the IEP meeting to learn more about a child's transportation needs.
- The school bus driver/attendant should know the characteristics of the disability and the equipment the student needs and uses.
- Check each student's ITP (Individual Transportation Plan) for special instructions or precautions.
- The IEP should provide the necessary specificity so the driver, school, parent and student know what services to expect.
- NHTSA also has a training module on Emergency Situations when transporting children with special needs.

### Parents should:

- Check California's state regulations and any school policies about transporting children with special needs
- Discuss your child's transportation safety needs with the IEP Team
- Document in writing any transportation issues and concerns
- If your child has transportation needs, ask the school bus driver to join the IEP team. Any support and training for teachers and other school personnel (i.e., bus drivers and aides) must be written in your child's IEP.

## WE GET MAIL

Dear PWCF: Wow...newsletter looks great, love the look and content! *Best, Kim Morgan*

Dear PWCF: Thank you for Prader Willi California Foundation's generous grant of \$8,651.00 to benefit the Prader-Willi Syndrome Clinic at Rady Children's Hospital- San Diego. As you know, children with Prader-Willi syndrome typically have learning disabilities and behavioral problems. The Prader-Willi Clinic at Rady Children's Hospital-San Diego is a multidisciplinary clinic that manages medical, developmental and behavioral needs of children with Prader-Willi syndrome. Children who come to the clinic are seen by a clinical geneticist, pediatric endocrinologist, nutritionist and social worker. Your generosity will help fund critical resources available to children and families affected by this condition. On behalf of all those who will benefit from your generosity, thank you. You are truly making a difference. *Sincerely, Stephen Jennings, Senior Vice President and Executive Director*



Dear PWCF: It was such a pleasure meeting all the families living with PWS [at PWCF's Annual Education Conference in Santa Clara]. I felt very welcomed and thank you for making it possible for me to be there. I'm already looking forward to next year. *Susan Abrams, PWCF Member*

Dear PWCF: I thought the conference was top-notch and ran very smoothly. The presenters were amazing and very approachable after their time. Thank you for all your hard work. *Jacki Lindstrom, PWCF Board of Directors*

Dear PWCF: I was so surprised and honored to receive the wonderful 2014 President's Award from PWCF in the mail today!! I had no idea it had occurred. I am so very sorry that I wasn't at the PWCF Educational Conference, but almost a year ago I had agreed to give a presentation (on PWS) at the 20th anniversary of the Center for Human Genetics at Case Western Reserve University in Cleveland that I had developed and directed when it started. Once I learned about the PWCF conference, it was too late to change my plans.

I have always found my work with people with PWS and their families very rewarding and enjoyable. It seems amazing to also be recognized for doing it. Please accept my deep gratitude, and please also extend it to Julie Carey. I will treasure this special award. *My very best, Suzanne Cassidy, M.D.*

## BE A SHINING STAR! YOUR SUPPORT MAKES A WORLD OF DIFFERENCE



Looking for a worthy organization to receive your end-of-year tax donation? **Please give to PWCF.**

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

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

In 2014 PWCF provided caring support to newly diagnosed parents; provided critical advocacy services to families; brought invaluable education and training to families and professionals including residential providers, teachers, and Regional Center staff; funded PWS Multidisciplinary Clinics; raised the public's awareness of PWS; and helped researchers progress PWS research.

Your tax-deductible donation will help us do even more. **Please be a Shining Star and support PWCF's mission.**

# MEMBER ACTIVITY

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

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

*Renew your membership today!*

## New Professional Members

Ashley Phelps-Leak

## Renewed Extended Family Members

Nell & Jim Bremner

Tammie Nance

Joyce & Norman Smith

Carol Williams

Ron & Pat Vargin

## Renewed Family Friend Members

Steven Grogan

## Renewed Professional Members

Linda Hamilton, Lee Street Homes

Valerie Nix, North Star Services

People's Care, Orangecrest Villa

## New Family Members

Lisa & Eric Clinton

Stephanie Lawson

Aleigh & Carlos Luis

## New Extended Family Members

Rima & Robert Buch

Carolyn & William Rubin

# 5TH ANNUAL PWS CAMP AT EASTER SEALS CAMP HARMON

June 18th - 23rd, 2015



The fifth annual PWS Camp session will be held from June 18-23, 2015 at Easter Seals Camp Harmon located in the beautiful Santa Cruz Mountains of Boulder Creek, CA. Online registration opens January at [www.PWCF.org](http://www.PWCF.org). **Space is limited!**

PWCF Camp is open to PWCF members. Members in Good Standing are eligible for a Camp Scholarship to reduce their cost.

For more information about programming, menu, or if you need help registering contact PWCF at 310.372.5053.



## WE GOOFED!



Last issue we reported that **Beverly Ginyard** volunteered to help on August 20 at PWCF's Info Booth at the Levitt Pavilion children's concert.

In fact it was her husband, **Dominic Ginyard**, who volunteered, along with their sons **Spencer** and **Tyler**.

Thanks, guys, and our apologies for the mistake!

**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@pwcfc.org

## DONATIONS

### October - December 2014

#### Shining Star Donations

##### Sirius (\$1,000 or more)

Anonymous donation in honor of the Ryan Family  
Peter & Rocky Chiang in honor of Rocky Chiang  
Judith Flanders  
Peter & Monique Thorrington in honor of Ryan Patay

##### Canopus (\$500 - \$999)

Gillian Gray in honor of Brooke Marich  
Nancy & John Jenkins in honor of Cameron Graziano  
Suzanne Privette in honor of Samantha Morgan  
(monthly donation)  
Stuhlmuller Family Gift Fund in honor of the  
Steinhart family

##### Alpha Centauri (\$250 - \$499)

Holger & Mary Bracht in honor of Kean Bracht  
Melinda & Chuck Morrow in honor of Cameron  
Graziano  
Bob Graziano & Wendy Wachtell in honor of  
Cameron Graziano  
Richard & Sharon Willis in honor of Ryan Casey

##### Arcturus (\$100 - \$249)

Andrew Cantos in honor of Brooke Marich  
Julie Casey in honor of Ryan Casey  
Bill & Judy Castle in honor of Scarlett Meade  
Chet & Sally Collom in honor of Jennifer Collom  
Mary & John Fischer in honor of Dustin Watney  
Joel & Janet Goldberg in honor of the Ryan Patay  
Graziano Family Trust in honor of Cameron Graziano  
Lisa & TJ Graziano in honor of Cameron Graziano  
Marie Claire Leon in honor of Ryan Casey  
Raymond Marchant III in honor of Oliver Young  
Jennifer Meade in honor of Scarlett Meade  
Robin Rabens  
Patricia L. Reitz in honor of Dustin Watney  
Mark Ryan  
Sukoshah Shah

##### Vega (\$1 - \$99)

Marty & Gary Girdaukas in honor of Michael  
Girdaukas  
Aleigh & Carlos Luis in honor of Delfino Luis  
Margaret & Bill Spinelli in honor of Cameron  
Graziano

#### General Donations

Lauren Adeniran  
A. P. Ancheta  
Susan Augustine  
Marlene & Thomas Burke in honor of Kean  
Bracht  
Nell & Jim Bremner  
Car West Charity Donation  
Joe Castelino in honor of Neil and Lisa Vitro  
Sandra Castleberry Daigh  
Rhonda & Andy Faust  
Madaline Fluhr & Edward Resendes  
Patricia Grey  
Jeffrey & Jacquelynn Lindstrom  
Georgene & Ralph Lowe  
Marina Lubinsky  
Isabel & Paulo Matos  
Patti & Tom McRae (monthly donation)  
Kathleen Morgan  
William Morgan  
John O'Sullivan  
Martina O'Sullivan  
New York Life via The Benevity Community  
Impact Fund  
Michelle & Mike Raleigh  
Ivette & Luis Ramos in honor of Victor Ramos  
Gordon Schneiders  
Joyce & Norman Smith  
Erik Walberg  
Carol Williams  
Robert Beresford Williams

#### Donations in Memory of Keith Johnson and in Honor of

##### the Bonk Family

Antoinette Guttilla  
Janice Guttilla  
Antoinette Scopellito  
Anita & Joseph Weisenfeld  
Rosemarie Wilson

#### Donations to Support PWS Camp

Suzanne Privette in honor of Samantha Morgan  
(monthly donation)

#### Donations in Honor of Samantha Morgan at the Request of Ita & Nick Moran in Celebration of their 60th Wedding Anniversary

Catherine Bailay  
Jeanette & B.G. Banks  
Hermina & Leonard Dryness  
Karen Frederiksen  
Mr. & Mrs. Paul Gannon & Family  
Terry & Nick Gannon  
Kathleen Hitt  
Carmel & Daniel Kelly  
Mr. & Mrs. Brendan Laughnane  
Michael John Lawless  
Patricia Lawless  
Maritza & Robin Madrigal  
Linda O'Neil  
Margaret Peacock  
Mary Ruane  
Michael Sasaki  
Diane & Tom Ruane  
Mr. & Mrs. Brendan Sheridan  
Emma Triplett  
Pat Wheatley

#### Donations to Support the PWCF Annual State Conference

Lisa Graziano  
Tom & Carole LaBossiere  
Jacki & Jeffrey Lindstrom  
Manerah Mohamed  
Paula Watney  
Renee & Henry Tarica

**THANKS TO ALL OUR  
RAGNAR RACE DONORS!**

See page 14  
for our *Ragnar Race* donor list

**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)