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)

April - June 2015
Volume 27, Number 2

In this issue:

LARGEST TURNOUT EVER

for Statewide *Walking for PWS* Events!

"It was the most beautiful experience ever! So emotional. I loved it. My six year old told me, 'This is the happiest day of my life! I'm going to wear my t-shirt to school' and he did. Both he and his big brother, Carlos, who has PWS, wore their PWS t-shirts to school on Monday." ~Maria Berber, parent, about the Northern California Walk

Mari Ota and daughter, Audrey Wang

"The pictures (on Facebook) are wonderful, thank you! I also wanted to send you a note thanking you for sharing the story of your son. In my humble opinion, simple awareness is not as meaningful as having understanding and empathy. I was very fortunate to have learned this through your insights and from the other parents who took the time to speak to us students. Thank you for such a wonderful experience that has truly changed my life and my future nursing practice for the better." ~Candi, nursing student, about the Southern California Walk

PWCF's annual *Walking for Prader-Willi Syndrome* events are more than "just a walkathon." Each of the three statewide events, hosted in Southern, Central, and Northern California, are unique unto themselves. In all, over 700 people gathered at a Walk site this year, the largest attendance in the Walk's fifteen year history. For many it was an opportunity to reconnect with families they've come to know and value. For others, it was the very first time meeting someone else who has PWS. For all, this year's Walk events were meaningful and memorable.

Northern California's Walk

Glorious sunshine welcomed the over the 250 attendees at the first Walk on April 11 in Crissy Field under San Francisco's Golden Gate Bridge. As at all of our Walk events, PWS information signs were posted along the well-populated Walk path to inform the public about this rare disorder. There was plenty of fun for the kids at the arts and crafts table, the face painting booth, raffle, relay races, even a water balloon toss. Entertaining all with some awesome tunes was our signature live band, The PWS Noisemakers, led by our very own **Austin de Lone** (keyboards and uber stompin') with **Lisa Kindred**

Walk continued on page 14

PWCF ANNUAL STATE CONFERENCE

November 14, 2015

Crowne Plaza, Los Angeles

See page 18!

PRADER-WILLI CALIFORNIA FOUNDATION
A Full Life Without Limits

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Fran Moss, Editor, PWCF News
Katherine Crawford, Graphic Designer

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

PWS SUPPORT GROUPS AND CONTACTS

Northern California

SF Bay Area (young child)	Patti McRae	408-920-8003	pmcrae@sbcglobal.net
SF Bay Area (teen to adult)	Michelle Donaldson	415-759-8740	michelle.sf@comcast.net
Sacramento	Diane Kavrell	530-753-5928	diane.kavrell@gmail.com

Central California

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

Southern California

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

Inland Region Area

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

Spanish Speaking

Mercedes Hernandez (Adults with PWS)	619-822-5742	mercedes.hernandez711 @yahoo.com
Kilma Bournigal (Infants/Children with PWS)	760-427-1100	kilmab@hotmail.com
Veronica Garcia (Infants and Children with PWS)	760-357-8189	vbaez92@yahoo.com

Online Support

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

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

PWSA (USA) Online eSupport Groups www.pwsausa.org Click Enter. Click Support.

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

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

PWS SHARE & SUPPORT GROUPS MEETING CALENDAR 2015

Southern California

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

Sunday, July 26
Sunday, October 25

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

Northern California

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

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

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

PARENT TO PARENT

"How do you carve out time and what do you do, either for yourself or for you and your spouse, to feel rejuvenated, refreshed, re-energized and ready to react calmly to the next day's stressors?"

Meditation. I was taught Transcendental Meditation when I was a kid and have recently taken the time to reintroduce it into my life. I find that the 20 minutes in the morning and then again in the evening (before meals) are calming and rejuvenating. I am not as consistent as I want to be but I'm working on it! I also am a proponent of date night once a week. We try a new restaurant and generally a night cap at a second place and the rule is that we can't talk about our children! It's fantastic! Hot baths after my son has gone to bed. LOVE them. I hope this helps.
Danielle Peretz, mom of Kai, age 11

As my daughter becomes older and I work full time, I have decided to use a company (Maxim) out here in Indio. UCP is another agency where you can have home health providers come to your home and help with your child. Regional Centers will pay for the cost unless you need additional hours. You can use a combination of UCP (as it is paid for separately) and another agency. Home Health providers seem to be a good answer for adult PWS clients. I am trying to find a better day program for my daughter but in the mean time need these helpers for her! I try not to take my daughter out in late afternoons or evenings, as her behaviors (or medications) have worn down. Mornings are best for both of us.
Renee Lovern, mom of Kimberly, age 24

Next Parent to Parent Question:
"If you could go back in time and give yourself any advice about the PWS diagnosis, what would you say?"

"HARRY POTTER" STAR GIVES DYSPRAXIA ADVICE

by Geri Coleman Tucker

Excerpted from Understood.org

Harry Potter is a hero to a generation of kids and their parents who are fans of the books. But actor Daniel Radcliffe, who plays the clever wizard in the *Harry Potter* movies, has also become a hero, of sorts. He's speaking out for kids with dyspraxia, a condition that makes it hard to plan and coordinate physical movement.

Radcliffe, who has a mild form of dyspraxia, knows the challenges it can bring. As a child, he had trouble with handwriting and tying his shoelaces. His early school years were very difficult because he was awful at "everything, with no discernible talent." Radcliffe still has trouble tying his shoes saying, "I sometimes think, why, oh why, has Velcro not taken off?"

In a recent Facebook chat with *The Wall Street Journal's* Speakeasy blog, Radcliffe offered encouragement to a 10-year-old girl with dyspraxia. "Do not let it stop you," he said. "It has never held me back, and some of the smartest people I know are people who have learning disabilities. The fact that some things are more of a struggle will only make you more determined, harder working and more imaginative in the solutions you find to problems."

Dyspraxia is not as well known as other learning and attention issues, such as dyslexia and ADHD. But it's quite common and often co-occurs with those issues. Between 6 and 10 percent of all children show signs of dyspraxia. "Typically developing" boys more likely to have it than girls.

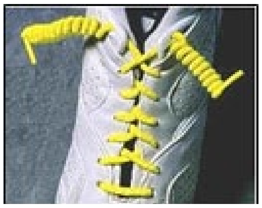
Many persons diagnosed with Prader-Willi syndrome have dyspraxia which results in coordination and motor planning problems and can be treated in occupational and physical therapy. Coordination of speech is another frequent challenge for persons with PWS. Diagnosed as Childhood Apraxia of Speech (CAS), speech dyspraxia is best treated by a Speech and Language Pathologist who is knowledgeable and trained in CAS.

For more information about PWS and Childhood Apraxia of Speech and Physical Therapy, contact the PWCF Office.

See page 8 for another article about dyspraxia, and page 16 for an extended article on treatments for Childhood Apraxia of Speech.

GADGET TIP: NO TIE SHOELACES

Submitted by Angela Garcia



Does your child or adult have a difficult time tying their shoes, or tying them tight enough to give their ankles better support? Maybe no tie shoelaces will help.

From Providence Spillproof, these no-tie Curly Laces are $3 per pair (plus $2 shipping). They're available in white, black, brown, tan, burgundy, pink, and teal. Call toll free 888-843-5287 or order online at http://www.kcup.com/orderl.htm

No tie show laces are also available on Amazon. These laces, from Zizzle Shoe Laces Curly Twisted Elastic, are 2 pair $6 and can be ordered at:
www.amazon.com/No-Tie-Twister-Shoelaces-Elastic/dp/B00IRM8FPA/ref=cm_cr_pr_product_top?ie=UTF8

Want to make your own no-tie shoelaces? Here's a YouTube video demonstrating how:
www.youtube.com/watch?v=1ZipEzWjfkQ

FOOD TIP: LEAF & LOVE

Submitted by Shannon Hunt of Moraga, CA

My son, Jaylon, who has PWS, is only one year old but I'm starting now to serve my family nutritious, low calorie meals and snacks so that when Jaylon is ready for table foods, everyone is already in the groove of eating healthy.

Looking for healthy items for my 4 year old son's school lunches and snacks, I discovered these organic lemonade juice boxes. Each box is only 5 calories and contains 0 grams of sugar, is sweetened only with organic stevia, and is gluten-free, vegan, non-GMO, and has a low glycemic index. They're perfectly portable for lunchboxes, my purse, birthday parties, playdates, and after-sports refreshment. My four-year-old son and two-year-old son love the lemonade!"

Leaf & Love co-founder **Sara Williams-Curran** reached out to PWCF just before the Southern California *Walking for PWS* event and donated over 400 lemonade boxes! In our eyes Leaf & Love has absolutely met their mission "to provide families with a delicious alternative to the current array of empty-calorie children's beverages."

Leaf & Love Organic Lemonade is in 160 Bay Area stores including Good Earth Natural Foods, Mill Valley Market, and Raley's Markets. Use this link to find more stores www.leafandlove.com/where-to-buy/ .They're also available on Amazon (search Leaf & Love organic lemonade).

Enter the Amazon Coupon Code **LOVEPWCF** and get $3 off a case of the 32 juice boxes! Coupon expires 8/15/15.

OUR KIDS GOT TALENT

Submitted by Rhonda Faust

Angela Faust, age 6, did her first cheer event with her Special Olympics girl group for a boy's Basketball Special Olympics event. She was that top girl of the V pyramid!

We are so proud of her journey.

EXECUTIVE DIRECTOR'S COLUMN:

by Lisa Graziano, M. A.

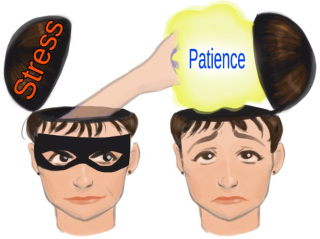
I recently had a Terms of Endearment moment (www.youtube.com/watch?v=jxpMCBSl-a4). Not one of the touching, heartwarming scenes. My moment was like when Debra Winger's character screams at her son in the parking lot to "Wait over by the car, honey. Wait over by the car. Now. NOW. **NOW!**" Mine was a more private breakdown, though I'm sure *someone* saw or heard my crazy bellowing at my poor teenage son to "Stop talking, honey. Stop Talking. STOP TALKING **NOW!**"

I was lost while driving him to meet a friend for a special event. Given my track record at getting lost, you'd think I'd have developed better strategies by now to calm myself when in the thick of anxiety. I was already at the tipping point when my son told me one more time to "turn right" at the exact same place we'd turned right three unsuccessful times before. And that's when I lost it. All I wanted from that moment on was to shock and awe him into silence. I knew I shouldn't yell at him, that my yelling would not keep him from hammering at me about what I should do. Yet I simply could not stop myself. I lost control and screamed at him as loud as I could. And it worked... For a full seven seconds after I screamed he was silent. But then, he was not only anxious about our being lost, he was also freaked out that his mother just out-of-control-screamed at him.

I believe my experience is similar to what our loved ones with PWS feel when their anxiety level tips the scale, when they'll do *whatever* it takes reduce their anxiety, including acting out in socially inappropriate ways. I understand this because even with all my "adult" thinking skills and fairly adequate problem-solving skills, I felt powerless in that moment to wrangle in my anger and express myself calmly and appropriately.

After we finally found our destination, and after we worked through his declaration that because I had ruined his mood he no longer wished to attend the event, and after we were both calm enough to communicate kindly with each other again, I felt ashamed. Deeply ashamed. The kind of shame that incessantly gnaws in the pit of one's stomach. I had been demanding that he manage his anxiety while giving in to my own which was grossly unfair to him and I knew it.

In retrospect, I'm sure my outburst was facilitated by a neglected need for self care. In my mind I picture "Stress Woman" menacingly stealing from "Patient Woman." For me, the greater my stress, the lower my patience.



And so I excitedly looked forward to combing through the many insightful responses I was sure we'd receive in response to this issue's Parent to Parent question, *"How do you carve out time and what do you do, either for yourself or for you and your spouse, to feel rejuvenated, refreshed, re-energized and ready to react calmly to the next day's stressors?"* We received two very helpful responses. But only two. *Two!*

Why did we receive so few replies to what I believe is a critically important question?

Is it that other parents have indeed found some awesome way to re-energize themselves but are reluctant to share it with the rest of us because if they do, they'll have less of it? Like the babysitter phenomenon when you find that sitter who is so *awesome* you never share her name with anyone for fear she'll be stolen away? As cynical as I can be about the Typical World's self-centered inclinations, I tend to believe that people who populate the Special Needs World are often more altruistic and more likely to share any Fountain-of-Youth-like-soul-rejuvenating-formula they discover.

Could it be that not very many of us know *how* to carve out time for ourselves to feel rejuvenated, refreshed, and reenergized?

Certainly there has to be at least *one* hour in a day that we can devote to some self-care. Maybe first thing in the morning, before everyone else is up can be a good time for some self-care? Yeah right, who am I kidding? Like getting up any earlier in the day could feel good. Surely, then, we can carve out one measly hour for ourselves at the *end* of the day – after tending to the needs and wants of our immediate family members and any extended family who need us, after taking care of our beloved pets, after working at the office, after taking care of our daily home responsibilities like laundry, bill paying, toilet cleaning, scheduling doctor and therapist appointments, grocery shopping, meal preparation and cleanup, after everyone is bathed or showered, tucked into bed and asleep – that's *got* to be *our* time. Right? Sure it is, as long as everyone stays asleep. And as long as there's another adult in the house. And, if you're like me, as long as we can actually stay *awake* long enough to *enjoy* that whole hour of "self-care."

Maybe it's that we've forgotten what we *could* do to rejuvenate: Sleep in. Take a day off. See a movie. Play golf. Read a book. Go to the beach. Take a vacation. Get a massage. Go for a bike ride. Walk at the beach. Ok, this train of thought is ridiculous. Who among us has ever bonked ourselves on the head suddenly remembering how wonderful it could feel to sleep in or take a vacation?

Could it be that we *know* how to take care of ourselves, but we simply can't/don't/won't?

"Can't" I can understand. I can think of literally a hundred

Executive Director's Column continued on page 9

ORDINARY MOTHERS WHO DO MORE: SALUTING THE MOTHER OF A CHILD WITH A DISABILITY

by Lori Borgman, The Province

Expectant mothers waiting for a newborn's arrival say they don't care what sex the baby is. They just want it to have 10 fingers and 10 toes. Mothers lie.

Every mother wants so much more. She wants a perfectly healthy baby with a round head, rosebud lips, button nose, beautiful eyes and satin skin. She wants a baby so gorgeous that people will pity the Gerber baby for being flat-out ugly.

She wants a baby that will roll over, sit up and take those first steps right on schedule. Every mother wants a baby that can see, hear, run, jump and fire neurons by the billions. She wants a kid who can smack the ball out of the park and do toe points that are the envy of the entire ballet class. Call it greed if you want, but a mother wants what a mother wants.

Some mothers get babies with something more.

Maybe you're one who got a baby with a condition you couldn't pronounce, a spine that didn't fuse, a missing chromosome or a palate that didn't close. The doctor's words took your breath away. It was just like the time at recess in the fourth grade when you didn't see the kick ball coming and it knocked the wind right out of you.

Some of you left the hospital with a healthy bundle, then, months, even years later, took him in for a routine visit, or scheduled her for a well-check and crashed head first into a brick wall as you bore the brunt of devastating news. It didn't seem possible. That didn't run in your family. Could this really be happening in your lifetime?

I watch the Olympics for the sheer thrill of seeing finely sculpted bodies. It's not a lust thing, it's a wondrous thing. They appear as specimens without flaw -- muscles, strength and co-ordination all working in perfect harmony. Then an athlete walks over to a tote bag, rustles through the contents and pulls out an inhaler.

There's no such thing as a perfect body. Everybody will bear something at some time or another. Maybe the affliction will be apparent to curious eyes or maybe it will be unseen, quietly treated with trips to the doctor, therapy or surgery. Mothers of children with disabilities live the limitations with them.

Frankly, I don't know how you do it. Sometimes you mothers scare me. How you lift that kid in and out of the wheelchair 20 times a day. How you monitor tests, track medications and serve as the gatekeeper to a hundred specialists yammering in your ear.

I wonder how you endure the clichés and the platitudes, the well-intentioned souls explaining how God is at work when you've occasionally questioned if God is on strike. I even wonder how you endure shmaltzy columns like this one -- saluting you, painting you as hero and saint, when you know you're ordinary. You snap, you bark, you bite. You didn't volunteer for this, you didn't jump up and down in the motherhood line yelling, "Choose me, God. Choose me! I've got what it takes."

You're a woman who doesn't have time to step back and put things in perspective, so let me do it for you. From where I sit, you're way ahead of the pack. You've developed the strength of a draft horse while holding onto the delicacy of a daffodil. You have a heart that melts like chocolate in a glove box in July, counter-balanced against the stubbornness of an Ozark mule.

You are the mother, advocate and protector of a child with a disability. You're a neighbor, a friend, a woman I pass at church, a sister. You're a wonder.

Happy Mother's Day.

> Being deeply loved by someone gives you
> strength,
> while loving someone deeply gives you
> courage.
>
> *~Lao Tzu*

LOVING FATHERS

Excerpted from AllProDad.com

Being a father isn't easy, but it is one of the most important and fulfilling jobs on the planet.

"He saved me," said thirteen-year-old Gracie Johnson, after her parents, sister, and two cousins were tragically killed in a rock slide. She was speaking about her dad, Dwayne Johnson. The family had gone for a hike along the Agnes Vaille Falls trail in Buena Vista, Colorado. Recent rainfall had made areas of the mountains unstable. As they were walking, one witness described what sounded like loud thunder cracking and boulders the size of cars coming down the mountain as the Johnson family stood helplessly in their devastating path. In an act of heroism, Dwayne dove on top of Gracie as a shield, saving her life and surrendering his own.

In situations like that you have no time to think, instinct takes over. Dwayne Johnson's natural instinct was that of a loving father. Loving fathers are self-sacrificing and protect their children.

Here are 10 more things loving fathers do for their children:

1. Loving fathers… love their children's mother

Love your wife without reservation - you can't do much more for your kids than that. If you are divorced, treat your children's mother with respect, even if it is not reciprocated. Never return disgrace with disgrace.

2. Love them unconditionally

Make sure that your children know you love them no matter what. Don't confuse this with permissiveness. Unconditional love does nothing to encourage the wrong kind of behavior. In fact, kids who are secure in their father's love tend to act out less, not more.

3. Grow up

We're talking about the us here, not the kids. Children don't want another buddy; they want a dad. They want someone who thinks things through, makes tough decisions, and engages life with responsibility. Someone they can count on.

4. Be there

"Quality time" is all well and good, but it has nothing on Quantity Time. Make the time. Everyone has the same 24 hours available. Make yours count.

5. Provide

As best you can. Material provision can be tough when jobs are lost and tough times hit. However, you can always provide a stable home with love and affection.

6. Discipline

Children appreciate an even hand, balance, accountability, and love-drenched discipline. It's called consistency and, without clearly defined boundaries, it is very difficult to grow up.

7. Value education

Don't just read to them; read with them. Don't just fuss about grades; get involved with their homework. Don't just talk about learning; be a hands-on advocate.

8. Raise them to leave

[In the case of raising a child with PWS, it is a challenging line we walk to raise our child to be as independent as possible within his or her individual ability. As research brings us ever-closer to treatments that will manage PWS' life-limiting hyperphagic drive to eat, we will need to teach daily living skills that will allow for more independence than adults with PWS have heretofore known. ~PWCF edit]

9. Teach them to take responsibility

Kids who learn how to duck responsibility and avoid cost will – sooner or later – fall flat on their faces. Loving fathers make sure their children know how to own up, clean up, and move forward.

10. Teach them to love this life

The best predictor of happiness in children is happiness in their parents. If we learn how to love this life and then give that blessing to our kids, they will be well prepared for satisfaction.

As you celebrate Father's Day, you may want to ask yourself, "What is the most loving thing my father ever did for me?" And then, huddle up with your kids and ask them, "What have I done this week to show you that I love you?"

PWCF celebrates *you*, Dad, and
wishes you a very
Happy Father's Day!

Slow-Motion Mothering for Dyspraxia

by Lisa Peters

I am a fast moving kind of a gal.

I like to go, go, go and get things done, done, done.

I like making lists and checking things off.

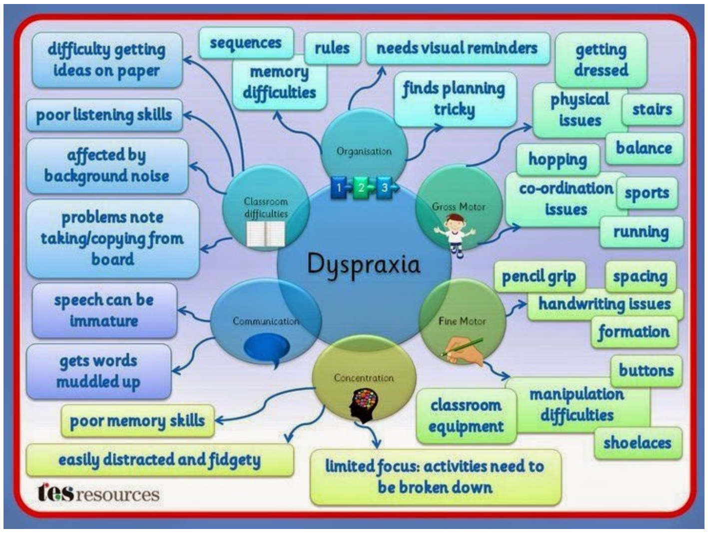
I guess it would be safe to say that I am most happy when I am moving.

But this fast moving, freewheeling, on-the-go lifestyle is not very conducive to raising children diagnosed with things like sensory processing disorder and poor motor planning issues. In fact, I have discovered, somewhat reluctantly, that raising my children is all about learning how to slow things down, way down. It is a painful life lesson often delivered to me with blunt force trauma to the brain.

But applying the brakes has never come easy for me. For a long time, I resisted this notion of slow motion mothering. I continued to run faster than a speeding bullet, slowing my pace only slightly as I dragged my overwhelmed children from one chaotic event to another.

I was surprised, even angry, when my children began to scream and cry. I thought at first, that the trouble was them.

What I have learned most recently... is that the trouble is me. As many of you know, Nicholas has been diagnosed with Prader Willi syndrome. Many individuals diagnosed with this disorder are also diagnosed with dyspraxia. Dyspraxia is a developmental coordination disorder that causes weakness in comprehension, information processing and listening. It is a disruption in the way messages from the brain are transmitted to the body.



Often children diagnosed with dyspraxia also have issues related to the processing of sensory information. Too much sight, sound, smell, touch or taste information delivered too fast to the body overwhelms the brain resulting in emotional overload.

What I have learned is this behavior is not telling me "*I want to be defiant,*" it is telling me "*I'm overwhelmed.*"

Slowing things down and minimizing the amount of sensory input is crucial to enabling my son to be successful in this world. It enables him to enjoy loud events, boisterous activities and large crowds.

As a mother of a child diagnosed with this condition it is my responsibility to slowly build Nick's sensory endurance. Introducing events and new experiences slowly, building each time in intensity so that he can finally begin to function and relate better to our fast-moving world. This is a necessity if he is ever going to be able to live on his own, go to school or secure a job.

And so it is with much difficulty that I am learning how to slow down the eager speed demon.

Now if I can just get the rest of the world to understand this important lesson.

Lisa Peters writes more about family life at www.onalifelessperfect.blogspot.com.

Dyspraxia

is a relatively common developmental coordination disorder which interferes with a person's ability to coordinate their muscle movements. It can affect fine and/or gross motor skills, as well as speech.

Sensory Processing Disorder

can coincide with Dyspraxia. In SPD, too much sight/sound/taste/touch information can overwhelm and overload the brain.

CINDY BELES RETIRES FROM PWSA (USA)

After ten years of exemplary and dedicated service, Cindy Beles announced her retirement from PWSA (USA) effective May 20.

Cindy was an integral part of PWSA (USA). Often the first person families spoke with after receiving their child's diagnosis, Cindy's gentle and calming manner was appreciated by all who interacted with her. Her recent work as PWSA's New Parent Mentor Coordinator was a perfect fit.

Cindy leaves PWSA (USA) to care for a family member. She will be missed by all who had the pleasure to know and work with her. PWCF bids her farewell and best wishes as she goes on to the next chapter of her life, and thanks her for her years of dedicated service.

Executive Director's Column, continued from page 5

examples why I can't take better care of myself, all of which fit very neatly into three buckets: 1) I don't have enough time; 2) I don't have enough childcare; and 3) I don't have enough money.

"Don't" I also understand. I don't take better care of myself because I can't. See above.

"Won't," on the other hand, is an intriguing concept probably having something to do with prioritizing and placing more appropriate value on myself, which requires more intense focus and more time than I actually have right now.

While it is true that I don't prioritize my own self care, I do breathe to feel better. It's no secret to those who know me or have heard me speak on stress-reducing strategies that I am a *huge* proponent of breathing when feeling stress. Does deep breathing always work? Nope, but only because during times of stress we don't always remember to do it. But breathing is so very crucial to managing stress and anger. Check out this video *Just Breathe* (www.youtube.com/watch?v=RVA2N6tX2cg), shared with you by PWCF's Office Manager, **Gloria Burns**. I hope this will help you remember to breathe the next time you feel angry or stressed.

Laughing is another awesome self-care tool too. As I've written before, I try to always end my night watching some half hour comedy show in hopes for a big belly laugh. Like breathing, laughter releases some great stress-reducing endorphins. But Gloria hasn't found a video of laughing yet so you're on your own to remember to do that.

Please know that while you're doing whatever self-care you do (that you're not sharing with the rest of us), PWCF has been busy during this second quarter of the year working to create opportunities for you to feel rejuvenated, refreshed, and re-energized so that you can take even better care of your family.

We sponsored three Walking for PWS events and connected and refreshed over 700 families. These very successful events also raised public awareness which improves our lives because the more the public understands PWS, the less we need feel alone and isolated. We held a PWS Family Day at the Oakland As for some summertime connection and fun. We held our fifth annual PWS Camp at Easter Seals Camp Harmon (to be featured in the next issue) to re-energize each of the sixty campers and rejuvenate their families.

Also this quarter we hired **Emily Dame** as our new full-time Education and Training Coordinator to bring residential and vocational and Regional Center training sessions to professionals and families. We are moving full-steam ahead to provide a PWS Staff Training at least annually to every residential setting that serves someone with PWS in California because we believe that training re-energizes and improves the quality of life of all.

Research activity is *exploding*, especially in the areas of hyperphagia and anxiety reduction. For those of us who may have lost a little hope along the way, I hope your hope is renewed as you read about the current advances in research and the exciting opportunities for even greater advances in critical symptom areas.

PWCF is proud to be a part of your life. Please keep your membership current. Please make a donation you can afford to give, and then give just a *liiitle* bit more – remember, it's tax deductible. And as always, let us know when we may be of support or service to you and your family, and how we can help you feel more refreshed, rejuvenated, and re-energized!

Cameron and Lisa Graziano

Call for research participants

PATIENTS NEEDED FOR RESEARCH STUDIES TARGETING HYPERPHAGIA

Beloranib Study

zafgen

This important phase 3 clinical trial sponsored by Zafgen, ***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.

Participants: Adolescents and adults (12-65 years) with PWS, obese with a BMI of greater than or equal to 30, and, less than or equal to 60 kg/m2 (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.

To learn more go to 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

Southern CA: UC San Diego, Rady Children's Hospital
Principal Investigator: Lynne Bird, MD
Contact: Rachel Winograd 858-966-8453
rwinograd@rchsd.org

Oxytocin Study

UCIRVINE

The purpose of this study is to investigate if intranasal oxytocin will improve hyperphagia, social skills, and behaviors in subjects with PWS. Individuals with PWS have been found to have a deficit of oxytocin-producing neurons and decreased oxytocin receptor gene function, so this study will determine if oxytocin administration will improve some of the aspects of PWS that are particularly troublesome for children and their families (the insatiable appetite and social behaviors).

Participants: Children (ages 5-11 years) with a confirmed diagnosis of PWS, in nutritional phase 2b or 3, as determined by Dr. Kimonis, currently on growth hormone treatment and have been receiving growth hormone treatment for at least one year prior to screening date.

Virginia Kimonis, M.D., Lead Researcher, Division of Genetics and Metabolism, Professor of Pediatrics, UCI.
949-824-0571
vkimonis@uci.edu

or **Claudia Shambaugh**, Study Coordinator
949-824-0521
cshambau@uci.edu

MEDICATION TRIALS VERY HOPEFUL FOR PWS HYPERPHAGIA AND FOOD-RELATED BEHAVIORS

Researchers are making exciting progress in a number of medication trials for hyperphagia and food-related behaviors in PWS. Clinical trials have started for several medications which may provide therapeutic options for those with PWS. Ideally, these treatments will help alleviate the complex metabolic issues that are part of this syndrome.

According to PWS endocrine specialist Jennifer Miller, M.D., "This is a tremendous time of hope for potential treatment of the appetite issues in PWS. Given the fact that the great majority of patients are now diagnosed in infancy, the combination of early intervention and early growth hormone therapy, along with a medication to decrease the appetite issues could result in a much improved quality of life, and increased independence, for individuals with Prader-Willi syndrome."

To read the most recent journal summary of medication trials for PWS hyperphagia and food-related behaviors, visit www.pwcf.org or contact the PWCF office and we'll be happy to email it to you.

PATIENTS NEEDED FOR RESEARCH STUDIES ON MOVEMENT AND ENERGY USE IN PWS

Energy Expenditure in Children with PWS While Walking on a Treadmill

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

Complete 1 site visit at CSU Fullerton lasting 2.5 hours. Children will receive a $20 gift card for their participation

For more information or to participate call or email **Frank** at frank.chavoya@csu.fullerton.edu
or **Dr. Daniela Rubin** at drubin@fullerton.edu or the Research Office at 657-278-3671

Languages: English/Spanish

CALIFORNIA STATE UNIVERSITY FULLERTON

Attention Fathers: We Need You!

Are you a father of a child with Prader-Willi syndrome? The University of Newcastle is interested in your experiences of well-being, coping styles, and access to support, as well as your level of growth since your child's diagnosis. If you want more information, or would like to complete the questionnaire, please follow this link: www.findlab.net.au/are-you-a-father-of-a-child-with-a-genetic-syndrome/

Kristy Rudd
Kristy.Rudd@uon.edu.au
Dr. Linda Campbell
Linda.E.Campbell@newcastle.edu.au

THE UNIVERSITY OF NEWCASTLE AUSTRALIA

IMPORTANT ANNOUNCEMENT ON THE OXYTOCIN STUDY

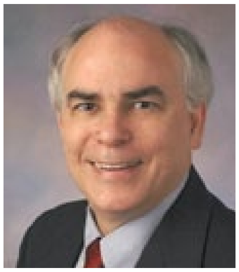
with PWSA (USA) from PWS Endocrine Specialists Dr. Jennifer Miller and Dr. Dan Driscoll

We are thrilled to announce that we have almost completed Phase 1 of our oxytocin trial in individuals with PWS. The preliminary results appear exciting and we are anxious to move forward with a Phase 2 study. At this time we have been unable to obtain support from a pharmaceutical company to sponsor these studies. However, we feel that it is crucial that we move forward as quickly as possible with a Phase 2 trial with a medication that has a high potential to benefit our children. Thus we are appealing to the PWS community to help raise the necessary funds.

We are very grateful to the PWSA (USA) for providing the funding to allow us to complete the Phase 1 study and are pleased to announce that PWSA (USA) and TREND are leading fundraising efforts for the next phase of the study. We are working to develop the Phase 2 trial as a multi-center study, include a dose-finding component, and to include a wider age range of participants.

We estimate that the cost of the Phase 2 study will exceed $1 million. If you want to ensure that your fundraising goes directly to support this oxytocin initiative, the funds need to be directed to PWSA (USA) and designated for the "**Oxytocin Initiative**," as this is the only mechanism by which your funds can be earmarked specifically towards this study. We are tremendously enthusiastic about the potential benefits of oxytocin for individuals with PWS. We hope that the community will come together to support this exciting research initiative for a medication that could directly benefit individuals with PWS and their families.

Please help us get this landmark next study started as soon as possible by setting up fundraising pages or donating directly to www.firstgiving.com/pwsausa/oxytocin-study. We thank you for your support.



Jennifer Miller, M.D., Pediatric Endocrinology
Daniel J Driscoll, M.D., Ph.D. Pediatric Genetics and Metabolism
University of Florida, College of Medicine

EXERCISE AND MAINTAINING A HEALTHY WEIGHT FOR ADULTS WITH PRADER-WILLI SYNDROME

by Dr. Daniela Rubin

I am asked "what is the best exercise plan for weight loss?" And trying not to sound condescending, I say "the one you can stick to." Exercise routines are much like diets: the diets that work are the ones people adopt and make a part of their lives. With exercise routines, it is the same: what is most important is that one is physically active and builds in exercise or activity as part of the day.

Though I have to say that, yes, we know from the controlled trials that a combination of diet and aerobic and resistance exercise is what works best not only to lose weight (Johns et al. 2014; Miller et al. 2013) but also to maintain the weight loss (Dombrowski et al 2014). **Aerobic exercise** is the one that you can sustain for several minutes such as walking, running, biking, swimming, dancing, or hiking. **Resistance exercise** is when you work against a load or resistance such as free weights, machines, stretch bands, or your own body weight.

Most effective trials for weight loss include diet and aerobic exercise 3-5 days a week to accumulate 90-225 minutes of moderate to vigorous intensity activity in a week, and in combination with resistance exercise about 2-3 days a week on alternate days **(**Miller et al 2013). The most recent recommendation from the American College of Sports Medicine recommends that adults should do 150-250 minutes per week of moderate intensity activity to prevent weight gain. If the intention is to promote weight loss or sustain the loss achieved, then adults should strive for more than 250 min per week of moderate intensity activity (Donelly et al. 2009). *Yes, it is a lot more difficult to maintain weight loss than prevent unhealthy weight gain. This is why it is so emphasized that people with and without PWS do not gain unhealthy weight.*

In a very general recommendation, **the best exercise intensity to promote weight loss is moderate to vigorous intensity.** Moderate intensity stimulates the body's utilization of stored fat to produce energy that our muscles, our brain and our heart use when we exercise. We want to strive for a minimum of 30 minutes of moderate intensity, but ideally we want to build up to 60 minutes on most days of the week.

How can you monitor the intensity of your workout or walk? Something simple is to track your ability to either talk or sing. If you are able to sing while walking then you are probably walking at a low speed or low intensity. If you can talk while you walk but can't sing, you probably are exercising at moderate intensity. When you have a more difficult time talking or maintaining a conversation, you are probably exercising at vigorous intensity. If you can't talk at all, then the intensity is probably too high and you will not able to maintain the exercise for as long as you need to and you should slow down.

In terms of resistance exercise or strength exercises using our own body weight, machines or free weights, you want to make sure the exercises involve large muscle groups, that your routine has a minimum of eight different exercises, and you do a minimum of 2-3 sets per exercise with 8-12 repetitions per set. What I mean is that if you do leg lunges, you should try doing 8 leg lunges continuously, then work on a different exercise and do a second set of 8 lunges again. Recommendations always give ranges, so you can tailor your effort to what it feels good for you.

What is the benefit of incorporating strengthening or resistance exercises? These exercises, done every other day, stimulate the making of protein in the muscle. When we cut calories to induce weight loss, because we have fewer calories than what our bodies need we begin a process of breakdown of our reserves (catabolism) which are not only fat but also muscle. Strengthening exercises trigger the opposite situation, inducing building of muscle (anabolism). Thus, despite whether the body has fewer calories than it needs, the amount of breakdown happening on the muscle will be much less than if we did not do strengthening exercises or exercise at all.

If your adult is not already physically active, you should absolutely incorporate physical activity into his or her life in a gradual manner. It will be a good idea to consult with your primary care provider to see if there are any health conditions you should consider before doing activity of vigorous intensity or lifting weights. You might also want to consult with an exercise specialist to put together an exercise plan for you. Ask if the exercise specialist who works in your local health clubs has certification from the American College of Sports Medicine, the National Strength and Conditioning Association, or has a Bachelors or Masters degree in Kinesiology or Exercise Science.

You might feel sore for a couple of days after you begin a new exercise routine and that is normal. As you continue to repeat the routine, your body should get used to it and you should not feel as sore as before. Always give yourself a day of no structured exercise during the week, but you still can be active if you chose to. **Remember, the best exercise routine is one you enjoy and makes you feel good about yourself.** The key is to enjoy and build activity into your life!

References:

Dombrowski SU, Knittle K, Avenell A et al. (2014) Long term maintenance of weight loss with non-surgical interventions in obese adults: systematic review and meta-analyses of randomised controlled trials BMJ;348:g2646

Donelly JE, Blair SN, Jakicic JM et al. (2009) Appropriate Physical Activity Intervention Strategies for Weight Loss and Prevention of Weight Regain for Adults Med Sci Exerc Sports 41:459-471

Johns D, Hartmann-Boyce J, Jebb SJ, Aveyard P (2014) Diet or Exercise Interventions vs. Combined

Behavioral Weight Management Programs: A Systematic Review and Meta-Analysis of Direct Comparisons J Acad Nutr Diet;114:1557-1568.

Miller CT, Fraser SF, Levinger I, Straznicky NE, Dixon JB, et al. (2013) The Effects of Exercise Training in Addition to Energy Restriction on Functional Capacities and Body Composition in Obese Adults during Weight Loss: A Systematic Review. PLoS ONE 8(11): e81692. doi:10.1371/journal.pone.0081692

PWCF Hires New Education & Training Coordinator

Introducing Emily Dame, M.Ed.

Because the name of the game when it comes to PWS is "Education, Education, Education" PWCF has hired another staff person to provide much-needed education and training throughout California to residential staff, work site and day program staff, Regional Center coordinators — *anyone* else who needs information about PWS and training!

Emily Dame is very excited to begin growing with PWCF! She has 3 years of experience working with individuals with many special needs including PWS, and providing counseling services to individuals and families.

Ms. Dame received a BA in Psychology in 2009 and she earned High Honors when completing her M.Ed. in Applied Behavioral Studies with Professional Counseling in 2012. She is passionate about advocating for prevention, psychoeducation, and equality for those with disabilities.

Emily hopes that through her work with PWCF she can assist caregivers in helping those with PWS learn the essential daily living, communication, and interpersonal skills they need to achieve their goals. She believes that "living with vulnerability gives us the ability to give and receive unconditional love."

Professionals, contact PWCF when you'd like to schedule a PWS Training Session at your facility. Parents, contact PWCF to explore how to have a PWS Training Session at your child/adult's group home, work site, day program, school site, or if you'd like us to speak with your Regional Center case coordinator. Families, call us if you'd like to explore how one of our professionals can meet with you in your home.

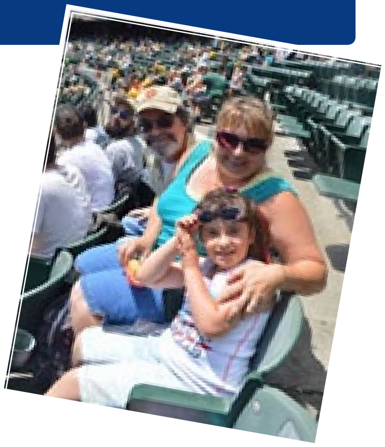
PWCF's mission is to provide individuals with PWS, their families, and professionals with a state network of information, advocacy and support services. PWCF is proud to add Emily Dame to our staff of professionals who are here to serve you.

PWCF Family Day at the Oakland A's

by Michael Moore

PWCF held a Family Day event at the Oakland A's on June 26. The A's lost a heartbreaker late in the game to the defending American League World Series champion Kansas City Royals, on a beautiful sunny (and hot!), day at the Oakland Coliseum. This year's small group of about 20 people were entertained by a 5th inning visit in our seats by the A's mascot, Stomper the Elephant.

PWCF thanks **Michael Moore** for coordinating this fun event!



PWCF Family Fun Day Events

Order your tickets today online at www.PWCF.org or call the PWCF Office at 310-372-5053

Family Fun at the Anaheim Angels!

Angels v. Texas Rangers
Sat., July 25 at 6:00 p.m. at Angels Stadium, Anaheim
Club Loge Behind Third Base $28/ticket
Post Game Fireworks!

Family Fun at the LA Galaxy!

Galaxy v. Portland
Sun., Oct. 18 at 4:00 p.m. at the StubHub Center, Carson
Upper Preferred Seating $29/ticket
Exciting Last Game of the Season!

WALK continued from page 1

(vocals), **Caroline de Lone** (vocals), **Dick McDonough** (drums), **Willie Riser** (bass), and **Adam Gabriel** (guitar, PA and generator). Flory Dekovic, District Commissioner of the Golden Gate District Boy Scouts of American, and Eric Denker volunteered their help and benefited from their experience so much they promised to bring out the Troops for the 2016 Walk!

Special Thanks and Recognition Go To:
Patti and Tom McRae – Event organizers, fundraisers
Maddy Fluhr and Eddie Resendes – Entertainment and decorations, fundraisers
Diana Vega, Ashley Hurdle, Sara Formslag – Registration, fundraiser
Diane Kavrell, Gloria Burns, Roger Goatcher – Education booth, fundraisers
Lesley de Lone, Diane Kavrell, sibling Jackson Kavrell – New Member Welcome Committee
Sibling Edward George – Games
Monte McAbee and Pfizer Endocrine Care – Water donation, Growth Hormone education

Gratitude is Extended to the Top Five Northern California Fundraisers:
Sally & Mark George honoring Luke George
Laren & Vilami Latu honoring Ahlyjah Latu
Lisa & Neil Vitro honoring Justin Vitro
Malea & Rich Bonk honoring Nolan Bonk
Maddy Fluhr & Eddie Resendes honoring Emma Fluhr Resendes

Central California's Walk

This event was held the following weekend on April 18 at Dry Creek Park in Clovis. Tremendous appreciation is extended to **Paula Watney** who fundraised, organized, and worked the entire event. Paula and her husband Mike created a special place for families to picnic and bond as only PWS families can. **Special Thanks and Recognition** also goes to **Monte McAbee** and **Pfizer Endocrine Care** for donating waters and being available to educate families about growth hormone medication.

Central California Walk

Southern California's Walk

The final Walk event was held on April 26 in Los Angeles at Griffith Park. After 400 people checked in, we lost count of attendees! There is always a variety of fun at the Southern California event, with arts and crafts tables, table-top games, a bounce house, face painter, DJ Extraordinaire **Jimmy Rudon**, relay games, raffle event, and hosted Subway lunch. Almost 70 nursing students volunteered at this year's Walk to learn first-hand about PWS. The opportunity is considered so valuable, West Coast University has made it a requirement of their nursing program to volunteer at our Walk events!

Hilda, Sophia, Martin, and Deanna Martinez

Special Thanks and Recognition Go To:
Renee and Henry Tarica – Event organizers, fundraisers, registration
Julie Casey – Event organizer, fundraiser
TJ and Cameron Graziano – Volunteers
Carolyn Meyer – Education booth
Fran Moss – Registration
Lianne & David Noddle – Volunteers
Jeanine & Mark Millner – Volunteers
Melanie Cross, R.N. – Director of West Coast University Nursing School Volunteers
Katherine Crawford - Graphic design, creation of this year's T-shirt
Gloria Burns and niece Brittany – Games, raffle, education booth
Hilda Hernandez and Petra Ali-Martinez – New Member Welcome Committee
Angela and Robert Lucero – Fruit donation coordination
Albertson's Grocery Stores – Fruit donation
Kimberlee Morgan and her daughter Tayler and friend Alex
Kathleen O'Connell and Pfizer Endocrine Care – Water donation, Growth Hormone education
Kimberly Storr – Photographer
Leaf & Love – Lemonade boxes donation
Subway Tarzana – Sandwiches discount

Gratitude is Extended to the Top Five Southern California Fundraisers:
Nisha & Minesh Mehta honoring Siena Mehta
Linda & Mark Ryan honoring Trevor Ryan
Angela & Robert Lucero honoring RJ Lucero
Jennifer & Jay Wolkensdorfer honoring Averie Wolkensdorfer
Julie & Dan Casey honoring Ryan Casey

WALK continued on page 15

WALK continued from page 14

Fifteen years ago a small group of parents led by **Toni Campoy** (current PWCF member), **Renee Tarica** (current PWCF Treasurer), and **Fran Moss** (current Newsletter Editor and co-chair Residential Services Committee) envisioned PWCF's first walkathon and raised $20,600. So far, PWCF's Walks have raised over $70,000 to fund PWS Clinics, education in schools, training in residential settings, PWS Camp, research efforts, public awareness-raising efforts, and so much more. If you haven't yet made a donation to the Walk to support someone you care about, do it today at www.pwcf.org or call us at 310-372-5053.

On behalf of all of our families PWCF thanks you for your support!

TREATMENT APPROACHES FOR CHILDHOOD APRAXIA OF SPEECH (CAS)

by Sue Caspari, M.A., CCC/SLP

Excerpted from www.apraxia-kids.org

Many children with PWS have Childhood Apraxia of Speech (CAS), a neurological motor speech disorder in which the child has difficulty rapidly, accurately, and consistently producing and timing the movement sequences needed to produce speech. CAS is not due to having weak muscles for speech. A treatment plan for a child with CAS should be based on the nature of the disorder and on the individual needs and strengths of the child. Below are approaches often successfully used in treating the speech impairments of children with CAS. Note: Often these children also need additional approaches that target other communication difficulties such as expressive and receptive language skills.

Principles of Motor Learning

Because speech is a highly skilled motor task and CAS expresses itself as a speech movement disorder, the principles of motor learning are often incorporated into a clinician's treatment plan when treating children with CAS. These principles of motor learning tell us that the ability to perform a skilled action gets better with practice, and that certain types of practice will be most effective, as outlined below:

Practice makes perfect: The most important aspect to motor learning is practice. If a child practices the correct movement sequence over and over again, motor learning will occur. Children with CAS need frequent, intensive practice opportunities.

Preparation is beneficial: Practice is best if a child is "ready" before beginning the practice. This involves establishing trust, motivation and focused attention to the speech movement practice tasks.

Explanations are helpful: Optimal motor learning occurs when the child knows what is being asked of him and why.

How we distribute practice matters: Practicing only one skill at a time may produce faster learning of that skill, but slower carry over and use of the skill outside of the treatment session. Practicing several skills at the same time may take longer but is believed to yield better carry over to situations outside of treatment.

Rate influences learning: Slowing the speed of a motor task can facilitate motor learning, but rates that are too slow may interfere with learning the skill.

Feedback is important: The type, timing and amount of feedback given to a child will greatly impact how quickly and how well he ultimately learns the skill. These factors can help guide decisions on activities and reinforcers, frequency of sessions, instructional methods, number of speech production targets to include in therapy, optimal number of repetitions to elicit within a session, distribution of practice within and across sessions, rate of production of target utterances, and type of feedback provided for the child's speech attempts.

Treatment Techniques

When individualizing a treatment plan based on a child's needs and strengths, any of a number of treatment techniques that incorporate the principles of motor learning can be used in order to try to elicit "correct" speech movement gestures. Some traditional approaches are modified for children with CAS to incorporate speech motor learning principles. In everyday use, many of these techniques are combined in speech therapy for children with CAS.

Multi-sensory cueing techniques use a variety of sensory cues to help the child hear, see, feel, and/or understand the target speech movement gestures being requested of them as they practice words or phrases Fact Sheet Treatment Approaches for Children with Childhood Apraxia of Speech (CAS) The Childhood Apraxia of Speech Association of North America (CASANA) is the only national nonprofit 501(c)3 public charity exclusively dedicated to improving the lives of children and families affected by apraxia.

Integral stimulation approaches use a well-defined and structured hierarchy of speech targets and require the child to imitate utterances (syllables, words, or phrases) modeled by the clinician in a "look, listen, do what I do" approach. In this approach, the child's auditory attention is focused on listening to the words, and his visual attention is focused on looking at the clinician's face. Over time as the child's skills improve, the clinician varies the timing of the child's repetition and then ultimately works toward the child's self-initiated correct production of speech targets.

Progressive approximation and shaping techniques use speech productions that children are currently capable of producing and then, through various forms of feedback and practice, attempt to shape the child's movement gestures into closer and closer approximations of the target word.

Phonetic placement techniques provide verbal information and instruction to the child regarding what to physically do with their mouth, tongue, lips, or jaw during speech attempts in order to achieve more accurate articulatory positions for certain sounds that may be difficult for them to produce. However, the main focus of speech therapy is on speech movement sequences.

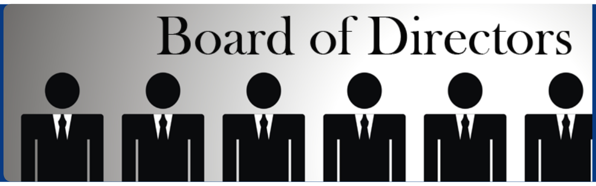
Tactile facilitation approaches use touch or manipulation of the head, face, lips and jaw during speech production so that the child can better "feel" and over time remember how to move their articulators correctly in order to produce the speech movements. Assistance is often provided at first and then faded as the child obtains independence at making the movements gestures for speech.

Prosodic facilitation, uses rhythm and melody to provide timing or rhythmic structure within which speech movements can be achieved.

Gestural cueing involves hand cueing to represent targeted shapes and movements of the articulators.

Again, variations of these approaches are combined together in treating children with CAS. Additionally, because many children with CAS have co-occurring language-related issues, therapy approaches that best address those needs are certain to be included in the overall speech/language treatment plan, though they are not addressed in detail here. For more information about PWS and Childhood Apraxia of Speech contact the PWCF Office.

CALL FOR BOARD CANDIDATES



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 commit to serve a 3-year term

What will you gain by participating on the Board?

- 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 is expected of you from 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 at **info@pwcf.org** or write to PWCF, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277.

The deadline to submit nominations for the 2016-2018 Board of Directors is **August 5, 2015**.

PWCF EVENTS CALENDAR 2015

Date	Day	Event	Location
July 14	Tuesday	Board Meeting	Evening - Phone Meeting
July 25	Saturday	Family Day at the Anaheim Angels	Anaheim
July 26	Sunday	LA County Support Group Meeting	Redondo Beach, PWCF Office
August 22	Saturday	IEP Advocacy Training	Redondo Beach, PWCF Office
September 12	Saturday	Board Meeting	Redondo Beach, PWCF Office
September 19	Saturday	Northern CA Support Group Meeting	San Francisco
October 3	Saturday	Behavior Management Training	Redondo Beach, PWCF Office
October 4	Sunday	Brass Golf Tournament	Black Gold Golf Club, Yorba Linda
October 18	Sunday	Family Day at the LA Galaxy	StubHub Center
October 25	Sunday	LA County Support Group Meeting	Redondo Beach, PWCF Office
November 1-7	Sun-Sat	Obesity Week	Los Angeles
November 3-7	Tues-Sat	PWSA Meetings/Conference	Orlando, FL
November 13	Friday	Board Meeting	Crowne Plaza, LA Int'l Airport
November 14	Saturday	PWCF Annual State Conference	Crowne Plaza, LA Int'l Airport

WE GET MAIL

✉ Dear PWCF: For many months we have been trying to get more support hours from In-Home Support Services. We hired an attorney who specializes in cases against IHSS and PWCF wrote us a beautiful letter in support of our efforts and struggle… and it was a struggle. We successfully won significantly more support hours! We are so pleased with our results. Thank you, PWCF, for being there! *Cindy Hampton, mom of Oscar, age 21*

✉ Dear PWCF: Just to say how much I love the way you transmit your passion on what you do for PWS!!! I loved [the executive director's] recent article in the Newsletter. *Kilma Bournigal*

✉ Dear PWCF: Your website is just what I have been searching for for several years. My 39-year-old son has 16p11.2 micro deletion and weighs almost 500#. He does not have PWS, but overeats. His chromosome anomaly is associated with morbid obesity. He lives by himself and has worked out of town the past ten years, gaining about 200#. We have tried everything we can think of to control his eating, even taking control of his finances and ordering groceries for him to pick up. This turned out to be a major stress on all involved, including his older brother. Thank you for addressing this problem in adults and offering resources. His weight is so serious that he's on administrative leave and about to lose his State groundskeeper job. I look forward to reading more on your website because I still have hope. *Sincerely, Donna*

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

PWCF ANNUAL STATE CONFERENCE

Saturday, November 14, 2015 • Los Angeles, CA

DON'T MISS OUT!

Meet with top PWS specialists at **PWCF's Annual State Conference**. Families and professionals alike need to stay up-to-date with information about PWS and the PWCF Annual State Conference is one of the best ways to do it. This year's program brings you specialists on critical topics including educational services, residential services, and various therapeutic interventions for persons of all ages, and Sharing Sessions that provide families and professionals the unique opportunity to share information, experience and insights.

PWCF's simultaneous **Youth & Adult Conference** features age-appropriate childcare for persons with PWS of all ages and siblings. Your kids or adult with PWS get to network and play while you network and learn!

Get together with other families and professionals at the **Meet & Greet** held the Friday night before the conference. A favorite amongst regular conference-goers, the connections that families and professionals make at these get-togethers last a lifetime and are priceless in terms of information sharing – not to mention the invaluable experience of mutual support and understanding.

PWCF Annual State Conference

Saturday, November 14, 2015
8:00 am - 5:00 pm
Crowne Plaza Los Angeles Int'l Airport
5985 W Century Boulevard
Los Angeles, CA 90045

Meet & Greet Mixer

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

Youth & Adult Program

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

To Register

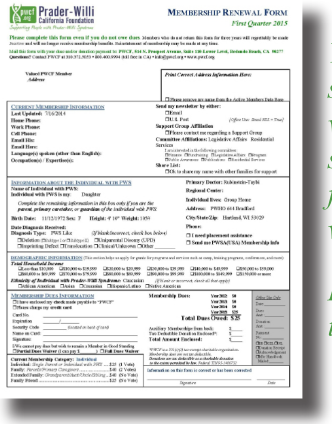
Go online at www.pwcf.org
or call the PWCF Office 310-372-5053
PWCF Member: $60 / $90 per couple
Non-PWCF Member: $75

Register by Sept. 1 for the Discount Rate!

Reserve your hotel room at 888-315-3700
by October 13 for the $120 PWCF discount rate

MEMBER ACTIVITY

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


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

MEMBERSHIP RENEWAL FORM
First Quarter 2015

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

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

Valued PWCF Member
Address

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

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

Send my newsletter by either:
☐ Email
☐ U.S. Post
Support Group Affiliation
☐ Please contact me regarding a Support Group
Committee Affiliations: Legislative Affairs Residential Services
Share List:
☐ Ok to share my name with other families for support

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

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

DEMOGRAPHIC INFORMATION
Total Household Income
Ethnicity of Individual with Prader-Willi Syndrome: Caucasian
☐ African American ☐ Asian ☐ Caucasian ☐ Hispanic/Latino ☐ Native American

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

Membership Dues:
Total Dues Owed: $25
Auxiliary Membership from back: $
Tax-Deductible Donation Enclosed*: $
Total Amount Enclosed: $

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

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

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 Individual Members

Carol Gomez
Linda Kelly
Rachel Linonis
Maria Madrigal
Moana Misailegalu
Michelle Petitt

New Family Members

Michelle & Mark Bossee
Diana Estrada & Vincent Flores
Tamara Zvereff & Jorge Lana

Renewed Auxiliary Members

Jeremy Frend, M.D.
Linda Smith

Renewed Extended Family Members

Mark Savit
Frances & Dave Sim
Cassie & Tod Holdorf
Stephen Patay

Renewed Family Friend Members

Patrick Maxon
Janice Nakagawa & Steve Grogan
Nancy & John Jenkins
Ronnie Raffaniello
Tyna & Ray Triggs

Renewed Professional Members

Lynne M. Bird, M.D.
Rady Children's Hospital

Lynn DeFreece
North Valley Services

Joetta Griffin
Griffin Family Care Homes

Virginia Kimonis
UCI Medical Center

Phillip D.K. Lee, M.D.
University of Texas Medical Branch

Bobbi McGann, LCSW
Children's Hospital Orange County

Rosary Oliva
Lucky Homes

Rosary Oliva
New Life Homes II

Melissa Sweet
PRIDE Industries

Joe Tontodonato
Arc San Diego

Lynn Vaughn
STEP

VOLUNTEERS are Priceless

PWCF thanks the countless volunteers who poured their time, energy, and love into our *Walking for PWS* events.

We couldn't do it without you!

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

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

DONATIONS

April - June 2015

PWCF Expresses Our Deepest Appreciation to the Following Major Donors for the *Walking for PWS* Events:

In honor of Emma Fluhr-Resendes
Suzanne Fluhr

In honor of Ahlyjah Latu
Laren Latu

In honor of Duncan McRae
Donald McRae

In honor of Siena Mehta
Sukumar & Jayshree Shah
Manilal & Savita Mehta
Dr. Ashish & Asha Mehta
Nisha & Minesh Mehta
Sata Milan
Saran Atul
Megha & Nihar Shah
Jenny Astrachan
Milan Sata

In memory of Yvette Tarica
Comet Electronics
Allison Moldo

In honor of Justin Vitro
Lisa & Neil Vitro

In honor of Dustin Watney
Heidi Watney

In honor of Amanda Wissmann
Shari Kairey

In honor of Unknown Individual or Family
Evan Thomas

Shining Star Donations

Canopus ($500 - $999)
Suzanne Privette in honor of Samantha Morgan
(monthly donation)

Arcturus ($100 - $249)
Luso-American Fraternal Federation

Magnanimous General Donations

Storr Family Foundation

General Donations

Adobe matching donations
received for Patti & Tom McRae
Lynne M. Bird, M.D.
Julie & Dan Casey
Community Health Charities of the West
(on behalf of Anna Montoya)
Thelma Cruz
Elisabeth & Rob Fuller
Mercedes Hernandez
Eileen Higgins
Cassie & Tod Holdorf
Janice & Neil Hubberth
Karla & Clint Hurdle
Lisa Jean in honor of Dan Casey's 50th birthday
Paige Johnson in honor of Dan Casey's 50th birthday
Virgina Kimonis, M.D.
Kroger Stores
Jacki & Jeffrey Lindstrom
Stephanie Lutjens
Dr. & Mrs. Allan McCown
in memory of Fontaine Kramer
Patti & Tom McRae (monthly donation)
Rosary Oliva, Lucky Homes & New Life Homes II
Cynthia Pate in memory of Fontaine T. Kremer
Jessica & Chris Patay
Katherine Randall in memory of Karen DeNatale
Rose Sakurai in memory of Richard Sakurai
Elizabeth Saltos
Silicon Valley Community Foundation
Emmeline St. Vaughn
Lori Wade
Paula & Mike Watney

Donations to Support PWS Camp

Suzanne Privette in honor of Samantha Morgan
(monthly donation)

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

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

IEPs and Prader-Willi Syndrome

From the Basics to the Advanced: IEP strategies and supports to empower parents at their IEP meetings

- **How does a school determine what services are necessary?**
- **How does a school determine whether a 1:1 aide is appropriate?**
- **How do I know if my child is benefiting from the services in the IEP?**
- **What are the needs of my child? How can I make sure s/he participates with other kids in class?**

We will help you answer the most common questions parents face in their IEP meetings. By the end of this training, you'll have your own personal IEP binder filled with information to use at your next IEP meeting.

Please bring your child's current IEP for this interactive workshop

Presented by **Roger Goatcher, PWCF Board of Directors, Senior Director of Student Services/Special Education**
Provided by PWCF as an extension of PWSA (USA)'s Wyatt Special Education Advocacy Training

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

Date: **Saturday, August 22, 2015**

Time: **10:00 a.m. — 2:00 p.m.**

Place: **Beach Cities Health District Complex**
Beach Cities Room (Lower Level)
514 N. Prospect Avenue
Redondo Beach, CA 90277

Childcare: **Child care (ages 12 and under only) is provided free of charge, courtesy of PWCF. Space is limited**; call the PWCF office as soon as possible with your childcare needs. Childcare is held in The Clubhouse located on the second floor. Take your child/ren to The Clubhouse at 9:50 a.m. to be on time for the meeting.

Registration Fee Includes IEP Binder and Light Lunch!

Questions: Call the PWCF Office 800-400-9994

IEPs and PWS Registration Form

PWCF Members $35 // Non-Members $50

Name(s)____
Number Attending ____________ **Phone** ________________
Address ____
City ____________________________**Zip**__________
Email ____
Amount Enclosed/To Be Charged: $______ ☐ Check made payable to PWCF ☐ Credit Card
Name on Card ________________ Signature ________________
Card No.____
Expiration Date __________________ Security Code ________ *(on back of card)*
Billing Address ___________________________________ *(if different from address above)*

Register by Phone, Online, Fax, or Mail

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

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

NEW DVD!

Prader-Willi Syndrome Behavior Management Strategies that Work DVD

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

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

Topics addressed include:

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

Be the First to Pre-Order Your DVD!
Expected Production Date: Mid August

About the Featured Presenter

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

PWS Behavior Management Strategies DVD Pre-Order Form

PWCF Members $25 ǁ Non-Members $35

Ship To:

Name(s) ____________________

Facility/Company Name (if applicable) ____________________

Address ____________________ **Phone** ____________________

City ____________________ **Zip** ____________________

Total DVD's Ordered: __________

Amount Enclosed/To Be Charged: $ __________

☐ Check made payable to PWCF
☐ Credit Card

Name on Card ____________________ Signature ____________________

Card No. ____________________

Expiration Date ____________________ Security Code ____________________ *(on back of card)*

Email ____________________

Billing Address ____________________ *(if different from address above)*

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

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

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