PWCF NEWS

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

The Newsletter of Prader-Willi California Foundation | AN AFFILIATE OF PWSA (USA)

July ~ September 2012
Volume 23, Number 3

In this issue:

Putt for Prader-Willi Raises Awareness and Over $8,000 for PWCF


Chloe Cropper

Sam and Kristin Cropper held their *Putt for Prader-Willi Charity Golf Tournament* in June that raised the public's awareness of the syndrome and over $8,000 to support PWCF's programs and services. The Croppers share, "Like many other parents who have a child with PWS, we have a long road ahead of us as our daughter Chloe develops into an amazing and independent individual. With your help, and the support of PWCF, we feel it may be a smoother journey.

"We have received a lot of positive feedback and thus feel confident that this is just the beginning… so we hope that you will all join us in the future for the 2nd Annual Fundraiser in 2013. We will always be looking for ways to improve our event, so any feedback or suggestions would be greatly appreciated.

"We look forward to your continued support as we strive to make a difference for those struggling with Prader-Willi Syndrome and the families it affects."


Sam & Kristin Cropper

PWCF thanks Kristin and Sam for their dedication and hard work!

Supporters of the *Putt for PW Charity Golf Tournament*

Jane & Mark Anderson
Nichole & Todd Au
Bay Alarm
Benovia Winery
Ashley Beseda
Scott Beseda
Diane Bourassa
Beth Bruno
Brett Bruno
Brush Hair Salon
Cassandra Houghton Massage Therapy
Melissa Cash
Charlie's Restaurant
Brett Chairez
Luke Chiurco
Michael Chiurco
Susan Chong
Clos du Bois Winery
Copperfields Books
Kristin & Sam Cropper
Judy & Nick Cropper
Dragonfly Farms
Penelope de la Montagne
Eagle Distributors
Enernoc
Kathleen Farrell
Coleman Finley
Francis Coppola Winery
Geyser Peak Winery
Lisa & TJ Graziano
Hartford Family Winery
Hawkes Family Winery
Healdsburg Fire Department
Heritage Systems, Inc.
Thomas Hill
Michelle Hogan
Harry Humes
J&J Burton Silversmithing
Michael Jeffries
Mariane & Thomas Kent
Dorothy Kime
Jamie Jean Jewelry
Karin Tredea Massage Therapy
Jeannie Koby
Kosta Browne Winery
Limmerick Lane Winery
Deirdre Lordan
M Clothing
Kelly & Jaeson Mackura
Madrona Manor
Mayacama Golf Club
Raafia Mazhar
K. McGee
Stephen Meeker
Meyer Cellars
Matthew Meyer & Karen Edwards
Gretchen & Chris Meyers
Georgiann & Stephan Micallef
Anne Millikin
Austin Milliken
Moustache Cupcakes
Aaron Niderost
Noelle & Michael (last name unknown)
Derrol Nail
Tamara & Angel Ochoa
Piccolo
Powell's
Ellen Rosenfels
Simi Winery
Beverly Singer
Daniel Stevens
Allyson & Jeff Stewart
Christina & Donald Turgeon
Tina & Gabriel Valenzuela
Marjorie Van Dusen
Villagio Dental
Emily & Scott Wallace
Paula & Mike Watney
Deborah & Brent Watney
Nick Watney
Ashley Whittington
Windsor Golf Club
Wurst Restaurant
Yasuko Clothing
Yoga On Center

514 North Prospect Avenue
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Redondo Beach, CA 90277
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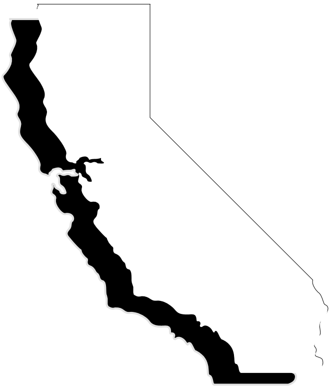
310-372-5053 (Phone)
310-372-4329 (Fax)

E-mail: PWCF1@aol.com
Web address: www.PWCF.org
Facebook: www.facebook.com/pwcf1



"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families."

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	PWCF Office	310-372-5053	pwcf1@aol.com
Sacramento	Diane Kavrell	530-753-5928	brandon.kavrell@cexp.com

Central California

Debbie Martinez (Teens & Adults with PWS)	559-227-0294	martinezds@gmail.com
Paula Watney (Teens & Adults with PWS)	559-299-8171	mikewat1@sbcglobal.net
Jennifer Rinkenberger (Infants & Children with PWS)	559-930-7834	jenrink@mac.com

Southern California

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

Inland Region Area

San Bernardino/ Riverside County	Maria & Ken Knox	909-421-9821	teachknox@aol.com

Spanish Speaking

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

On-Line Support

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

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

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

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

International PWS Organisation

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

Parent to Parent

What incentives do you give to your child or adult child to encourage them to exercise?

Shannon is in a day program where her daily activities are scheduled a week in advance. Exercise is part of every day, whether it's walking around the Farmers Market, bowling league, or twenty minutes on exercise bike or treadmill. She does one to two exercises a day and she helps choose which ones. She earns 25 cents for each exercise completed and she loses 25 cents for any exercise scheduled but not completed. This is all part of a financial weekly incentive we use for not only exercise and foraging, but for other behaviors such as skin picking, stealing, lying, arguing and so forth. It works really quite well.
Susan George, Mom of Shannon, 35

Next issue's Parent to Parent question is ***"In what at-home income-earning business does your adult with PWS successfully engage?"***

Two Easy Ways to Support PWCF Without Spending Any Extra Money!

Ralphs will support PWCF when you register your Ralph's Reward Card online in the Community Contribution Program. Once you register, every time you shop for groceries with our Ralph's Reward Card, a donation will automatically be made to PWCF at no additional cost to you!

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

Sign up for eScrip which encompasses three ways to support PWCF

1) Sign-up and register your reward cards, credit cards and debit cards then whenever you shop at participating merchants a portion of your purchase amount will be given to PWCF

- Visit www.escrip.com to sign up
- Click on "about the program" along the top then click on "sign-up"
- Search for Prader-Willi California Foundation or enter group ID# 500042750
- Once our name appears you can select it and then continue your enrollment
- Once your cards are registered a portion of purchases made at participating merchants will automatically be donated to PWCF

2) Shop at the eScrip online mall

- Once you set up your eScrip account you can shop lots of merchants including Amazon right from your personal eScrip page or install the AutoEarn program to make sure participating online merchants are redirected to your eScrip page to ensure a portion of your purchase is donated to PWCF
- Alternatively you can shop through this link: https://secure.escrip.com/jsp/group/onlinemall/groupmallredir.jsp?gid=500042750

3) Participate in the eScrip Dining by Rewards Network

- Once you enroll in the eScrip program and register your cards, a portion of purchases made at participating restartaunts will automatically be donated to PWCF

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

Weight Loss Drug Approved by FDA

by Janalee Heinemann, MSW
PWSA (USA) Director of Research & Medical Affairs

As many of you are probably aware, there is a new weight loss drug, **Qsymia**, just approved by the FDA. The weight loss was more with this drug than with two others recently reviewed by the FDA and one approved (Lorcaserin/Belviq) that was not nearly as remarkable regarding weight loss. Qsymia is a combination of two older drugs that have long been known to help with weight loss: phentermine (the safer half of the old fen-phen drug that was banned) and topirimate – a drug that was studied back in April 2000 under a PWSA (USA) grant, *"Open-Label Pilot Study of Topirimate in Adults with Prader-Willi Syndrome.*" Topirimate is an anticonvulsant drug that makes people feel more satiated after eating, which is why we sponsored the study by Nathan A. Shapira, M.D., Ph.D. The study showed that Topirimate did not significantly change the calories consumed, Body Mass Index, or decreased self-reported appetite in PWS. In addition, there were no significant changes in compulsions. Surprisingly though, Topirimate treatment resulted in a clinically significant improvement in the self-injury (i.e., skin-picking) that is characteristic of PWS.

The researchers of Qsymia state that it targets multiple brain signals that drive people to overeat. We cannot say at this time if it will be effective with PWS. Please know that we will keep you informed of any new outcomes on this and other obesity drugs that might be helpful with PWS. Currently, I have been working informally with two pharmaceutical companies who are working on potential products that might impact on PWS, but as with all pharmaceutical companies, there are always strict agreements of confidentiality. We are also working with FPWR on financially supporting the Best Idea Grants after the hyperphagia conference with 2012 One Small Step funds. We never forget that the #1 deadly enemy of PWS is the appetite.

Food Tip

It's Dryers… need we say more? Each bar is a delicious treat or dessert. The No Sugar Added flavors are Black Cherry, Strawberry-Kiwi, Mixed Berry, Strawberry, Tangerine, and Raspberry.

Sweetened with Splenda, each bar has only 25 calories, 6 carbs, and contains 20% Daily Value of Vitamin C.

Available at Vons, Ralphs, Albertsons, Lucky, Safeway, and Smart & Final stores.

Gadget Tip

Game Spinner. Natural Learning Concepts' item voted in the top five for "motivating tools to teach." This is one of their MOST POPULAR items and with good reason. It makes everything FUN!

Are you teaching reading? Attach words to the spinner. Read or make sentences with that word. Are you teaching conversation? Attach topics to the spinner and discuss whatever it lands on. Are you teaching functions? Attach items to the spinner and name the functions when the spinner stops. Or do you need a superb MOTIVATION TOOL? Attach pictures of all the items your child or student loves such as toys, stickers, movies, or video games. When your child or student completes the task, he spins the wheel for one of his favorite treats. The possibilities are endless!

Some skills you can teach with this item include Motivation; Choices & Decisions; Fine Motor; Play Skills; and Turn Taking.

Each Game Spinner is $25. For more information or to order, contact Natural Learning Concepts at 800-823-3430 or http://www.nlconcepts.com/products/index.php?main_page=product_info&cPath=113_117&products_id=311

Executive Director's Column

Lisa Graziano, M.A.

As California's State budget is decimated by legislators who appear both blind and deaf to the devastation they're wreaking in the lives of the most dependent of our citizens, we will hear more and more often that a needed service is no longer available, be it a Regional Center service, a school-related service, insurance authorization or reimbursement, or housing support.

Auto insurers often use the "Three Ds" strategy to save their company money**:** delay handling your claim, deny you were hurt, and defend their decision in drawn-out court battles (Anderson Cooper's blog, *Insurance companies fight paying billions in claims*, February 07, 2007). In the medical insurance industry a common cost-saving claims processing strategy is to "Deny, Delay, Confuse and Refuse."

Why do insurers and other providers of services automatically deny services or reimbursement? Because statistically, anywhere from 25% to a whopping 70% of people who file a claim and are denied, simply go away. And that saves them money.

More than likely, similar statistics hold true for our family members. Too often we feel discouraged, confused, or overwhelmed when we're denied something we've requested. And we just go away.

It's no secret that the various pots of money once designated for the care of persons with disabilities are dwindling precipitously, while the number of persons needing services continues to grow. At best, this means that providers of services must be prudent with how they expend their resources; at worst it means that services will be improperly denied.

Sometimes authorities may use a different kind of "go away" strategy. We may feel relieved upon hearing that our almost-three year old child doesn't qualify for Regional Center eligibility because he or she is "functioning so well," or reassured when our child's physician or insurer advises that our child is "growing just fine" and doesn't need growth hormone medication, or comforted when the IEP Team assures us that an absent skill will "naturally develop with age." If we believe deep in our gut that our child or adult child does indeed need that denied service despite the authority's stance, we *must* consider that that service often *is* available *if we persevere and pursue all appeal mechanisms*.

If we don't know whether or how to appeal an authority's decision, a good place to start is to contact the PWCF office, as well as reach out to other parents who've previously walked the same path.

The recently passed "Trailer Bill" AB 1472 hacks away at the very spirit of the Lanterman Act and commands all persons who live outside of California and are funded by a Regional Center to return to California. The Prader-Willi California Foundation's Board of Directors and staff are working to keep our adults with PWS who are successfully living out of state in their current out-of-state homes. *Families are advised to formally oppose and appeal any action that would place your child or adult child's quality of life in jeopardy.* The Prader-Willi California Foundation can and will provide family members with advocacy support. Contact us.

Always appeal a denial of an appropriate service, whether it's a Regional Center service, insurance reimbursement, medication authorization, a school-related service, or a request for residential placement. *Don't just walk away from a denial without appealing that denial.* If your appeal is not successful the first time, appeal again. And again. Don't just go away.

How about we create our own PWS strategy… maybe call it the **Three Ps**: We shall **patiently educate**, we shall **persistently advocate**, and we shall **pursue relentlessly** every support and resource we believe will benefit our child.

> *Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying, "I will try again tomorrow."*
>
> *~ Mary Anne Radmacher*

Research on Cognition and Everyday Behavior In Children with Prader-Willi Syndrome

A clinical psychology (neuropsychology emphasis) doctoral student at Wheaton college is conducting dissertation research to better understand how a very important thinking process called executive functioning relates to the everyday behaviors of youth with Prader-Willi syndrome. Findings from this study may provide valuable information about how to improve treatment strategies and daily functioning of affected children.

This project only requires a parent or legal guardian to fill out a few questionnaires taking approximately 30 minutes. If you are an interested parent of a child diagnosed with Prader-Willi syndrome aged 5 to 19 years old, please contact Patrick Hall at phall777@gmail. com or (630) 815-8553 and I will send you the questionnaires with a postage-paid return-addressed envelope. Participation will be completely confidential. This investigation has been approved by the Wheaton College Institutional Review Board.

Study Title: The Relationship of Executive and Adaptive Skills in Prader-WIlli and Down Syndromes.

Rationale: There is a scarcity of research examining the role of executive functioning in youth with Down Syndrome (DS) and Prader-Willi Syndrome (PWS) (Pennington et al., 2003; Rowe, Lavender, & Turk, 2006; Whitman & Thompson, 2006). However, the cognitive, behavioral, and neuropsychological characteristics of DS and PWS documented in the extant literature suggest these persons are vulnerable to executive dysfunction (Paquier & Mariën, 2005; Schaer & Eliez, 2007; Walley & Donaldson, 2005; Woodcock, Oliver, & Humphreys, 2009b). Although several studies have shown executive functioning deficits on performance-based neuropsychological measures in DS and PWS, whether these deficits are manifested in the everyday behaviors of affected youth has received little attention (Pennington et al., 2003).

Notably, ecological measures like the BRIEF have been able to identify executive functioning impairments when lab-based instruments have not (Anderson et al., 2002; Mahone et al., 2002). Identifying the executive factors associated with adaptive outcomes in these syndromes may contribute to the improvement of treatment strategies, adaptive competencies, caregiver burden, and functional independence in affected individuals. To date, the ecological correlation between executive functioning and adaptive functioning has not been systematically examined in these specific syndromes.

Approval: This project has been approved by my dissertation committee (Chair, Ben Pyykkonen, Ph.D; ph: 630.752.5759) and has recently attained human subjects IRB approval (Wheaton college).

Personal Information: I am a 4th-year clinical psychology (neuropsychology emphasis) doctoral student at Wheaton College and am currently an advanced neuropsychology extern at the University of Chicago Medical Center. I was also at the Child and Adolescent Behavioral Health Clinic at Mt. Sinai Hospital for a year and have participated on multi-day outreach clinics with the University of Kentucky Genetics Team (Under the supervision of Bryan Hall M.D.).

Measures: The Behavioral Rating Inventory of Executive Functioning (The BRIEF - parent form) and the Adaptive Behavior Assessment System (ABAS-II). The BRIEF has been used as a primary instrument in a number of reputable studies with children with other genetic disorders (e.g. CHARGE syndrome, Autism, Williams Syndrome, 22q11 Deletion Syndrome, etc.). In addition, the standardized clinical sample of the BRIEF included children with developmental and acquired neurological disorders. Please let me know if you would like more information on this measure. The ABAS-II is widely used questionnaire of used by parents with children with Intellectual Disability (ID), learning difficulties, and other impairments.

ACTIVE PLAY AT HOME STUDY

RECRUITING PARTICIPANTS

Interested in being more physically active as a family?

The Kinesiology and Health Science Departments at California State University Fullerton (CSUF) are evaluating a home-based physical activity (PA) program for youth with Prader-Willi Syndrome.

Youth with PWS ages 8-16 years and one parent/guardian are invited to participate. Families will participate in a 24-week home-based program using interactive console and playground games provided to them at no cost. Participation also requires five visits (~3.5 hours long) to the CSUF campus. During the visits, your child will complete a health screening, a very easy and accurate body fat measurement, and movement-related assessments. Youth and parent participants will complete questionnaires. Parents will be trained in how to deliver the PA program at home. The child may participate in an ancillary study evaluating markers related to diabetes and cardiovascular disease that requires a single blood draw during two of the site visits. In addition, the parent/guardian participant may choose to participate in a decision-making intervention using a personal digital assistant (PDA) device.

Incentives for youth include: 1) $30 gift cards for visits, 2) keeping the provided sports and media equipment, 3) $60 gift cards during the program. The child participating in the ancillary study will also receive a $15 gift card per blood draw. Incentives for parent participants (PDA) include $60 gift cards during the program. Parents/guardians will be reimbursed for mileage for the visits to CSUF and will be provided free parking.

For more information or to participate in this study,
please contact us or visit our website.
Research office: 657-278-8737 / 3671
pwstudy@fullerton.edu;
Dr. Daniela Rubin: 657-278-4704
drubin@fullerton.edu;
Website: http://pws.fullerton.edu.

Hablamos español.

California State University, Fullerton

More Research Opportunities

Study of Behavior in Prader-Willi Syndrome: This NICHD funded study is a continuation of the current Elisabeth Dykens PWS study to characterize and accurately describe the behavioral features of Prader-Willi Syndrome (PWS) and how these can be different based on age, gender, family history and genetic subtype of PWS. The study looks at key psychiatric features of PWS, like rigid and repetitive behaviors, insistence on sameness, tantrums, aggression and depression and how these change over a lifespan. We want to see if intervention timing is related to successful outcomes and effectiveness.

We hope to see 170 families with children aged 5 and up through adulthood with PWS for a one day visit at Vanderbilt Kennedy Center in Nashville TN over the next 5 years. We want to see how children with PWS change and we will follow them every other year to track changes. Parents will receive a written feedback report of all results and behavioral management tips during visit. There are travel funds to help with expenses. Parents who are interested should contact Elizabeth Roof at elizabeth.roof@vanderbilt.edu or 615-343-3330 to get more information about the study.

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

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

WHERE: UCI Medical Center and General Research Centers at UCI Med Ctr. and Children's Hospital, Orange County in Orange, CA.

CONTACT: Virginia Kimonis, M.D. at 949-824-0571 or email at vkimonis@uci.edu or Marie Wencel, research coordinator at 949-824-0521 or email at mwencel@uci.edu.

Study of Adolescent Siblings: Vanderbilt Kennedy Center is interested in how having a brother or sister impacts adolescents. Families with 2 children, both between the ages of 12 and 18, are invited to participate in an online survey. Families with and without children with disabilities are invited to participate. One adolescent and one parent will be asked to:

- Go to the Survey Link https://redcap.vanderbilt.edu/surveys/?s=RbeQdw
- Respond to questions about himself or herself and his/her family. Parent survey is 20 minutes; adolescent survey is 15 minutes.

For your participation, you will be entered in a drawing for one of 40 $50 Target gift cards. You will have approximately a 1 in 10 chance of winning a gift card.Contact: Carolyn Shivers, MS, Graduate Student 330-704-6291 / carolyn.m.shivers@vanderbilt.edu

CHLA Research Study

Can the medication, exenatide, help patients with Prader-Willi Syndrome lose weight?

Prader-Willi is one of the most common genetic causes of obesity and it is characterized by increased appetite, increased food consumption as well as destructive behaviors such as food seeking and food hoarding. Obesity can lead to major medical problems such as sleep apnea, poor cardiac function, diabetes and atherosclerosis.

Exenatide (Byetta; Amylin Pharmaceuticals, San Diego, CA) is a subcutaneous injection given twice a day which has been shown to lead to weight loss in adults. We are starting a study to see the effects of exenatide on obesity factors in overweight patients with Prader-Willi Syndrome between the ages of 13-20 over a 6 month period.

The study will involve 5 visits to Children's Hospital of Los Angeles (CHLA). There will be an initial screening visit which involves blood tests and if the patient qualifies, 4 more visits will be scheduled at CHLA. All visits will include physical exams, blood draws, as well as an appetite questionnaire. In addition, two of the visits will include a mixed meal tolerance test (MMTT) and a DEXA scan. The MMTT involves placing an IV and series of 4 blood test over 2 hours. The DEXA scan is an x-ray that will measure body fat.

The study is being conducted by Dr. Debra Jeandron and Dr. Parisa Salehi from the CHLA Endocrinology department. The following describes the requirements of the study. If you are interested, please contact us to discuss the study further.

To participate in this study, you:
Must have Prader-Willi Syndrome
Must be 13-20 years old
Must have a body mass index >85th percentile
Must NOT be using or have used exenatide or related medication
Must NOT have a current of past history of pancreas of kidney illness or problems
Must NOT have another diagnoses which may affect taking the medication of its results

Payment
$ 50 will be provided at each visit as compensation for your participation

Contact Person:
Parisa Salehi, MD
Office: (323) 361-8816
Email: psalehi@chla.usc.edu

Study Location:
Children's Hospital Los Angeles
4650 Sunset Blvd
Los Angeles, CA 90027

The Tao of Special Needs Parenting

by Lisa Peters, Massachusetts

"It is as we expected," the Geneticist said to me, "your son has Prader-Willi Syndrome."

And suddenly, like my new born infant, I too began a difficult new journey.

My son's birth was traumatic and frightening. It was as if someone had maliciously thrown me into the cold, deep end of the pool, knowing I could not swim.

Instinctively, I realized, that in order to survive, I needed to keep my body in a constant state of motion.

And although this survival technique of treading water did indeed save my life, after many years of thoughtless, continuous movement, I began to realize, I wasn't really getting anywhere. More importantly, I was starting to become fatigued and dispirited.

As a parent of child diagnosed with PWS, I am accustomed to chaos.

It is not unusual for my son to experience unexpected surgeries, unwelcome lab results, unusual seizure activity, poor cognitive testing and additional diagnoses. I am not complaining since it is this unusually high level of stress that has enabled me to understand the true meaning of the word resiliency.

But the greatest difficulty I face amidst all this hardship and stress, is my inability to find a sense of peace.

How do I disassociate my son from his syndrome, seeing him as a delightful boy and not a devastating diagnosis?

How do I stop living in the past, reflecting on his traumatic birth?

How do I stop fearing the future, and what life will be like for him when I am gone?

How do I help my family and I to live in the now, happy and unaffected by what may lie around the next corner?

In trying to answer these difficult questions, I have discovered that my spiritual path has somehow become fast-tracked. It is as if someone pressed the fast forward button, hurling my life forward at break-neck speed allowing me to ask those difficult life questions sooner than expected, enabling me perhaps to quickly discover my one true path.

Perhaps not coincidentally, I stumbled upon the word Tao, a word Chinese philosophers use to describe this spiritual journey.

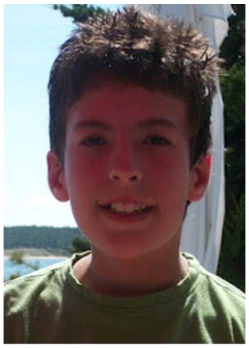
In Taoism, the object of spiritual practice is to harmonize one's will with Nature in order to achieve effortless action. This involves meditative and moral practices, focusing on the concept of virtue.

Can you coax your mind from its wandering
and keep to the original oneness?
Can you let your body become
supple as a newborn child's?
Can you cleanse your inner vision
until you see nothing but the light?
Can you love people and lead them
without imposing your will?
Can you deal with the most vital matters
by letting events take their course?
Can you step back from you own mind
and thus understand all things?

The Tao philosophy also embraces the concept of "The Interdependence of All Things". Taoist philosophers determined that everything has its complementary opposite. More than this, they saw that everything can only be understood by comparing it to its opposite.

Day is only day in relation to night, cold only cold in relation to heat, and soft only soft in relation to hard. Looking deeper still, they realized that these relationships are in a constant state of flux: Day flows gradually into night and back again.

All things, then, are interdependent. By observing the processes of Nature, the Taoists say, we can come to some understanding about the meaning of our lives and about our place in the world.



Ironically, my "disabled" son has always seemed to possess an "abled" and enlightened spirit. His kind and gentle nature is incongruous to the harsh and chaotic lifestyle that we lead. I can't help but wonder if this too holds some significance?

Are the answers to my questions buried somewhere beneath these opposing influences?

Do I impose my will, making extra appointments with therapists and specialists, or do I need to embrace nick's gentle nature, release my fear, accept our life and just enjoy the time we share together.

Perhaps to help my son, I must allow him simply to be?

Lisa Peters shares her adventures in special needs parenting at www.onalifelessperfect.blogspot.com
Visit her blog to learn more about Prader Willi Syndrome, ADHD, Aspergers and their "crazy life trying to find happiness amidst all the chaos."

Prader-Willi California Foundation 2012 General Education Meeting

Putting the Pieces Together

Friday, November 2, 2012
Meet & Greet Mixer 7:00 p.m.

General Conference
Saturday, November 3, 2012
8:00 a.m. - 5:00 p.m.

Hilton San Jose
300 Almaden Boulevard
San Jose, CA 95110
PWCF Group Room Rate of $119 plus taxes if Reservation Made by October 2
408.287.2100

Teaching Social Thinking Skills
Michelle Garcia Winner, MA, CCC-SLP

Medical Management of Prader-Willi Syndrome
Suzanne Cassidy, M.D.

Overview of PWS Research
June-Anne Gold, M.D.

Menu Creations by Mamma Deb
Debbie Granger of Easter Seals

PWCF Business Meeting

Share Sessions

Youth & Adult Program

PWCF 2012 General Education Meeting
Registration Form

Register online at www.PWCF.org or by check or credit card

Early Bird Discount: **Register by 10/14 and deduct $10 per person/couple!**

PWCF Member:	$50 / $80 per couple
Non-PWCF Member:	$60
Professional:	$85

Fees May Be Reduced or Waived Upon Request

○ I'm not a PWCF member. Please send membership information

Please Print:

____
Name(s) of All Persons Registering for General Education Meeting

____
Mailing Address *City* *State/Zip*

____
Telephone *Email*

Number of Vegetarian Lunches Requested: _______________

Youth & Adult Program "YAP" Registration

PWCF Members	$10/child or adult
Non-PWCF Members	$12/child or adult

Fees May Be Reduced or Waived Upon Request

Names & Ages of Persons Enrolling in YAP Program:

Name:________________________ Age:_____ PWS? ○Yes ○No
Name:________________________ Age:_____ PWS? ○Yes ○No
Name:________________________ Age:_____ PWS? ○Yes ○No
Name:________________________ Age:_____ PWS? ○Yes ○No

Fee Calculation

Total Amount Due for General Education Meeting: $__________
Total Amount Due for Youth & Adult Program: $__________
Total Tax Deductible Donation Amount: $__________
Total Amount Enclosed: $__________

○ I have enclosed my check made payable to "PWCF"

○ Please charge my: ○Visa ○MasterCard ○AmExpress

Name on card ____
Credit Card No. ______________________________________
Email ____
Expiration ____
Security Code (on back of card) _______________________
Billing Address ______________________________________
(if different from mailing address above)

Signature ____

Mail Registration Form with payment to:

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

Questions? Contact PWCF 310.372.5053 / PWCF1@aol.com

The Wedding Day and PWS

by Katherine Crawford

As wedding planning got down to the final two weeks, Jackson and I realized that there was a final element that we hadn't particularly planned for: the incredible heat wave hitting the Midwest, where our wedding was taking place.

In the final pre-wedding meeting, Jackson and I told our officiant that we had a temperature cut-off for our outdoor wedding. If the temperature was going to be over 90°, the wedding would be set up in the alternate indoor location. He immediately gave a sigh of relief. Just a weekend earlier, he had officiated an outdoor wedding in the blistering heat. The couple had insisted it be outdoors, regardless of temperature, and regardless of their parents' (or anyone else's) recommendations. So, outdoors it was, in over 100 degrees of stick-to-your-chair humid heat. And then, in the middle of the wedding, one of their grandparents passed out. The ceremony was stopped as family members and the officiant himself attended to the poor grandparent, who recovered after care.

My brother Michael, like many individuals with PWS, has trouble regulating his core body temperature. About ten years ago, this nearly resulted in catastrophe for him when, during a family trip to Florida, he developed such advanced heat stroke that he fell into a coma and was hospitalized for a week. This was a catastrophe that I would not repeat.

Incredibly, in the early hours before sun up on our wedding day, a light rain shower passed over our city. The temperature dropped and the sky was still slightly overcast from the clouds by the time I left with my mom to the gardens. Against all odds, it was going to be a pleasant temperature. Before we knew it, I was waiting with my dad for our big entrance cue. My usher Michael gave us a nod saying "It's time." He guided my dad and me around the corner in the garden and proudly gave my train a final *floof* so it trailed behind me just so. I began the final walk up the aisle.

Everyone was in high spirits after the wedding. Our caravan of cars headed towards the next stop: the mid-day cruise. The lake breeze was refreshing. Michael sat with his caretaker, Brian, during most of the cruise. This was the hardest part of the event for Michael, due to the buffet-style hors d'oeuvres which the captain was cheerfully pushing everyone to try. Brian handled so many of the little challenges; anything from food spills to well-needed pleasantly distracting conversation.

After the cruise was a two hour break before the evening reception. Brian took Michael back home for a rest. When Michael arrived at the reception, he came up fifteen minutes after the original scheduled Grand March in borderline tears. He'd thought he missed being part of it because he slept in. He felt terrible. But what had actually happened was that once we arrived at the reception Jackson and I realized we needed to re-arrange the schedule of the Grand March so everyone had a chance to arrive. But… no one told Michael. As he stood in front of me sniffing back tears, I gave him a big hug as I told him, "Michael, we couldn't have a Grand March *without* you!" and he smiled with relief.

The dinner was exquisite. It was not a buffet; each plate was delivered person by person. Coincidentally, this is also a good way for brides and grooms to avoid missing out on dinner. Unlike so many of our married friends, Jackson and I ate quite well during our wedding day. We had one surprising complication come up in the weeks before our wedding with regards to the cake. It turns out there *were* multiple layers of flavor to account for allergies and preferences. Whoops. My dad was worried that Michael would insist on eating one of each, but I told dad that I'd take care of it. I called Michael three weeks beforehand and asked him "What slice would you like: vanilla, lemon poppy seed, or double chocolate cake with peanut butter cup whipped filling?" Of course he picked chocolate (just like my husband!), and furthermore had no problem with eating only one slice because he had advance notice.

Day-of, I discover that the "double-chocolate cake" included two vanilla layers of cake. I hear Michael start to get upset: he'd ordered double-chocolate cake, not chocolate and *vanilla* cake. Suddenly, a moment of brilliance occurs to me. There's a thin strip of chocolate frosting in between the two vanilla layers. "Oh, Michael," I say, "it *is* double-chocolate. Look: chocolate *here"* I point to the chocolate cake part, "and chocolate *here"* I point to the chocolate frosting between the vanilla layers. For once, I was saved by a technicality!

The Grand March was a big hit and kicked off a lively dance. Michael was particularly exuberant in his dancing, singing along with the Elvis songs and spinning around the dance floor. Midway through the dance, Brian noticed that Michael was overheating. Brian took Michael aside to sit down, and convinced him that it'd be alright if he took off the outer jacket of his tux for a while. He then got Michael a cool compress for his forehead, and a half hour later Michael was already feeling better. Once again, Brian saved the day by being a helping hand with Michael.

As the dance was winding down, Michael goes up to the DJ to ask for the microphone. He gave the final toast of that evening, dressed to the nines in his tailed tux and red vest, standing tall and strong. Tears of happiness welled up in my eyes. I thought of all that we'd been through together as siblings. Years of mischief and make-believe, successes and failures, laughter and sorrow all went through my mind. Above it all, I am so proud Michael is part of my family. He's the best brother I could have ever asked for.

Clarification Regarding the Article
IEP or IPP Meeting Suggestions

The April – June, 2012 issue of *PWCF News* included an article titled *IEP or IPP Meeting Suggestions* (page 7) which advised against being open and honest about the negative behaviors exhibited by your son or daughter with PWS in front of your son or daughter during the IEP or IPP meeting in order to avoid a behavior outburst during the meeting.

PWCF received a call from a Regional Center Service Coordinator who suggested that it was not clear enough that withholding this information should *only* occur when the individual with PWS would exhibit a negative behavior that would interfere with the progress of the meeting *and* if the Service Coordinator is already well aware of the negative behaviors exhibited by the individual they serve.

The Service Coordinator advises that *all behaviors*, *both negative and positive, should be discussed in full and that no detail should be omitted because the service coordinator needs to know as much information as possible about the individual they are serving.* The same would be true for sharing information with representatives from In-Home Support Services or any other support agency. Share the individual with PWS' most challenging days. Share what, on a typical day, parents must do to assist Junior in the shower. Share what parents need to do when Junior is at his/her most challenging. If the service coordinator does not know about their client's/ consumer's problematic behaviors or what the most challenging situations look like, that service coordinator will have a far more difficult time providing the individual or family with appropriate assistance and support.

Our Service Coordinator advises that she wouldn't want to trigger anyone with PWS into tantrum behavior, however if the family believes that the service coordinator or (any other support agency personnel such as medical insurers, school staff, etc.) truly do not understand what the family is trying to convey in regards to intensity, severity or duration of a behavioral issue, the family must do what they believe will most effectively communicate the reality of their lives. When beginning a conversation about negative behaviors with the person with PWS in the meeting room, the service coordinator may see how quickly or how strongly a person with PWS can progress into exhibiting a negative behavior. It can be extremely helpful to have first-hand experience regarding a tantrum behavior, as a PWS tantrum generally differs from a non-PWS tantrum in general intensity and duration. It should be noted that people with PWS typically don't enjoy feeling such strong negative emotions and often feel embarrassed or shameful after a tantrum.

Advises the Service Coordinator, "In order for supporting individuals or agencies to provide the appropriate level of services or support, it is critical that they *fully* understand the individual's propensity toward behavioral outbursts so that they better understand the individual and the family they are serving."

Great Fun Had by All at PWCF's 2012 Camp Session

Over sixty people enjoyed another fantastic experience attending PWCF's Camp. Under the extraordinarily able direction of Easter Seals' Camp Director **June Stockbridge**, each camper received exceptional care from their Camp Counselors. This year, in addition to the core activities of daily swimming, arts & crafts, tie-dying, basketball, and cabin play, campers were treated to Nerf sharpshooting and other fun indoor games, Olympic relays and other fun outdoor games, two campfires complete with entertaining campfire songs, an exhilarating horseback ride through the woods, and an end-of-camp dance. Old friends reunited; new friendships were forged. Camp food was healthy, low calorie, and absolutely *delicious*! More than one camper was overhead pondering how they could *live* at camp in order to enjoy chef Mamma Deb's food *every* day! Many thanks to PWCF member **Linda Ryan** for providing training to all camp staff prior to camp. Stay tuned for the dates of the 2013 PWCF Camp session!

PWS' White House Adventure Continues...

Last issue we reported that the video produced by the Foundation for Prader-Willi Research (FPWR) and entered into First Lady Michelle Obama's *Let's Move!* Communities on the Move Video Challenge, had received the most votes and that two PWS representatives would visit the White House to receive congratulations by the First Lady herself.

Then we learned that even though the PWS video had receive the most votes, the video was not deemed the winner of the contest and therefore PWS representatives would not be invited to the White House.

Here is the latest announcement from Keegan Johnson, FPWR's Executive Director regarding the video contest and Prader-Willi Syndrome's representation at the White House:

FPWR's video is now re-posted and the USDA has selected us as a winner under the "Exceptional Achievement" category. The USDA has released an official statement and will be inviting us to the White House. At the end of the day, here's what happened:

~ The Let's Move video challenge was not intended to focus on a single syndrome
~The USDA acknowledged to me that this rule was not clearly written and they could have identified their concern before the contest started
~The USDA has apologized for the mistake and are inviting us to the White House as an Exceptional Achievement category because we got the most votes

The situation has been frustrating, however the USDA has been working with us to resolve the issue. In the end, because of your passion, hard work and voting we have achieved what we set out to accomplish. In addition, this event has significantly raised the profile of PWS. We have caused a lot of people to realize the passion of the special needs community and how much we can help in the fight against obesity.

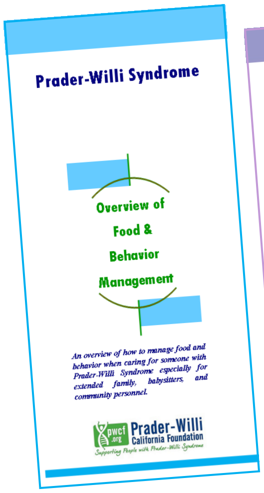
Prader-Willi Syndrome will be going to the White House!"

Stay tuned for more information about PWS' White House adventure!

New Brochures Available

PWCF has created two new brochures. An *Overview of Food & Behavior Management* provides insight into the connection between food and behavior and provides behavior management strategies for all care providers, grandparents and other extended family members, babysitters, teachers, therapists, etc.

The second brochure introduces the strengths possessed by many persons with PWS and outlines some common challenges and behavior management solutions. This brochure is designed to be helpful to introduce the syndrome to friends, neighbors, and other care providers.


Prader-Willi Syndrome

Overview of Food & Behavior Management

An overview of how to manage food and behavior when caring for someone with Prader-Willi Syndrome especially for extended family, babysitters, and community personnel.

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

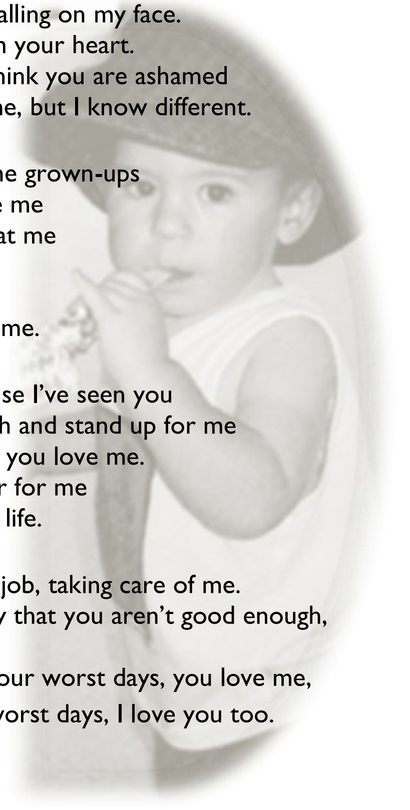

Prader-Willi Syndrome

It takes a village to raise a child, or so the saying goes. As parents, family, friends, teachers, babysitters, and caretakers, we are each a part of that village.

We're all in it together.

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

I Know Different



I have felt your tears falling on my face.
Those tears pour from your heart.
Someone else might think you are ashamed
of having a child like me, but I know different.

You are ashamed of the grown-ups
The adults who ignore me
The adults who stare at me
The adults who judge
without knowing
everything you do for me.

I know different because I've seen you
raise your head up high and stand up for me
because I'm yours and you love me.
I have heard you cheer for me
every single day of my life.

I know you have a big job, taking care of me.
And I know you worry that you aren't good enough,
but I know different.
I know that even on your worst days, you love me,
and that even on *my* worst days, I love you too.

Board Corner

PWCF Board of Directors Meeting
June 9, 2012
by Whitney Bras

Board Members Present: Julie Casey, Chris Patay, Kimberlee Morgan, Whitney Bras, Paula Watney, June-Anne Gold, M.D., Roger Goatcher, Renee Tarica, Tom McRae. Others Present: Lisa Graziano, Executive Director; Fran Moss, Consultant. Board Members Absent: Julie Tauscher, Don Carlson

Public Awareness

- Julie Casey gave an update on the social networking (Facebook and Twitter)
- The board discussed improving the directions to the SoCal walk-a-thon as well as an alternative walk path. June-Anne Gold offered to look into PWCF becoming an official Charity for 2013 L.A. Marathon.
- Paula Watney updated the board on the success of the Putt for PW Golf Tournament.
- Drew Marich has agreed, with assistance from Julie Casey, to organize a PWS Family Day with the L.A. Galaxy. The dates discussed were 8/26/2012 or 9/16/2012.
- The board decided not to pursue holding a Family Day the Warriors.
- No one was able to organize a Family Day with the Oakland As.

Program Committee

- PWS 2012 Camp Session Update - Lisa Graziano informed the board that 65 campers had confirmed registration.
- 2012 PWCF Conference update - Lisa has signed the contract with the San Jose Hilton and the date is set for November 3rd, 2012. Suzanne Cassidy, M.D. will be one of the main speakers.
- Behavior Management Training Series – Lisa is writing the presentations.
- Website update – Progress continues to be made to the new website. Renee, Treasurer, wrote a check for half of the balance due to Web Site Design & Maintenance, the company designing our new site.
- Research Update - June-Anne Gold, M.D. and Lisa Graziano will attend the hyperphagia conference October 17-21, 2012 in Baton Rouge, Louisiana. The Children's Hospital of Los Angeles plans to start a new research study of a medication and needs 20 individuals with PWS.

Residential Services Liaison Committee

- Fran Moss and Paula Watney updated the board on the status of California residential facilities and discussed openings in each facility. Lisa Graziano will mail each facility our new *PWS Residential Staff Training* DVD along with the PWSA (USA) book, Supporting Adults with PWS in Residential Settings.
- Residential Facilities Checklist - The board reviewed the new *Facilities Checklist* created by Fran Moss and Paula Watney. Suggestions for improvement were collected and a final checklist will be ready at the next board meeting.

Executive Directors Report

- Lisa introduced Katherine (Girdaukas) Crawford, PWCF's newly hired Family Support Coordinator. Katherine gave a brief summary of her work history, as well as her vision for her new role. Her hours are Mon-Thurs 9am-2:30 / 3:00 pm.
- Lisa updated the board on her activities since the last board meeting which included the creation and mailing of Thank You cards for the walk-a-thon.

Treasurers Report

- The board reviewed and discussed the 2012 income statement.
- Steve Takeda from Smith and Barney, PWCF's investment firm, gave an overview of PWCF's investment and operating accounts and the investment strategy behind each account. He will provide the board with further material.

Strategic Planning

- Katherine (Girdaukas) Crawford will research the cost of a portable exhibit signs and a display.
- California Partnership Discussion and Strategizing – A Vocational Work Sites Coalition Meeting was discussed, with the goal of the coalition to work with Regional Center case workers and local employers in order to improve upon exciting vocational and day programs serving persons with PWS, and identify and train up new potential sites.
- Long Term Strategic Planning - The board discussed how many years of operating expenses we should save, and came to the determination of two years. The board decided on the account that we will use to fund our long term projects. A formalized statement will be developed that can be provided to potential grantors and included in our grant applications.

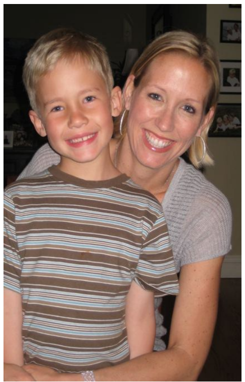
New Business

The board would like to explore an awareness event to run in the 2014 L.A. Marathon. 25 runners will be needed.
Julie Casey informed the board that two new programs are available to benefit PWCF, eScrip, and Ralphs Community Partnership. Information on the programs will be announced on Facebook as well as in the newsletter.

In the Trenches

Vol. 9

by Jessica Patay



Ryan & Jessica

I'm a group-y kind of girl. I always have been.

I love the village of my girlfriends that I get to live in from time to time. Were it not for my girlfriends or fellow mom friends, I would not be as validated, or as encouraged, as I need to be. In fact, you probably would not want to be around me. Because my true girlfriends challenge me to be the best me, at the same time they accept and love me as I am…a flawed mother just trying to do the darn best I can.

And I must say—I have a fantastic-keeper-of-a-husband, but husbands are not girlfriends, and they are not meant to be. It's just not fair to expect that from them. Women need women. Mothers need other mothers. The friendship of fellow women and fellow moms, the camaraderie, and the i-get-you-and-you-get-me-ness is absolutely priceless. There is a warm, friendly feeling when we girls commune and gab, gab, gab, uninterrupted by children screaming in the background, like when on a phone-call with a friend. We feel understood and we offer validation to one another. Not to judge or compare or criticize. (We do that enough to ourselves don't we?)

ESPECIALLY in this special needs game we are in.

And in the same vein, couples need couples in their corner. Families need other families. I say this, again, especially as parents of children with special needs. We just "get" that all families with special needs kids have gone through some excruciating journey. Without having to say much, there's an instant bond, as "we're fellow survivors." Like being in a foreign country and running into someone from our hometown, and there's this huge moment of comfort and identity all wrapped together.

Although each of our journeys may be a little different, or a LOT different, there is a bond of compassion and empathy. We all understand the cycles of grief, of blow-your-mind frustrations and stresses. And oh, the victories in achieving milestones…how they mean so much, vastly more than in our "typical" children sometimes. (And we don't want to admit it, but we feel it inside…).

I am eternally grateful for my two special needs moms groups—one within the PWS community and one within my school district. Neither one is formal. There are no dues required. No rules. Anyone is welcome. We don't have to ACCOMPLISH anything. We schedule a dinner out periodically at a very yummy restaurant (this part required) and just *be*. Together. "Moms' Night Out."

And maybe these nights out *feel so good* because they are nights **OFF**. A break from the intensity, the demands, the needs, the food schedules, the questions, and the nighttime GH shots.

We share laughs sometimes till our drinks come out our noses…then we share tear jerking stories till *you know what* comes out of same noses. Venting, sharing, encouraging each other along. We snort and make snarky comments…about the thousands of questions our children are ALWAYS asking. We have drinks and delicious entrees. I learn and grow so much from the other women and their savvy in getting what their child needs, through the school or the regional center. I am inspired anew to be more calm, calm, CALM, and patient in my hectic hamster-wheel life.

Every time I drive away from a "Moms' Night Out," I relish in the feeling that I am not alone. We are not alone.
THANK GOODNESS!!

PWS Awareness at Summer Concert Event

In keeping with the Prader-Willi California Foundation's mission to improve the lives of those living with PWS, we proudly participated as a community partner with the Levitt Pavilion, a non-profit agency located in Pasadena with a strong commitment to contribute to the well-being of families through the arts and entertainment environment at their summer concert series.

We raised the public's awareness of PWS with a PWS Education Booth at the concert on June 27.

PWCF's President **Julie Casey** and Board member **June-Anne Gold, M.D.** worked the Education Booth and distributed PWS brochures and wristbands to concert goers.

We Get Mail

Dear PWCF: I wanted to let you know that Theresa [McGrath, PWCF's Residential Training Consultant] performed her training with our staff today and she did an excellent job. We have one new QMRP and a handful of new direct care staff and they were commenting on Theresa's insightful ideas and strategies. It seemed as though several light bulbs were lit today. I am sure our homes will benefit from this immediately. Thank you again for your support and providing this important outreach service to our staff. Sincerely, *Joe Tontodonato, Director of Operations, Community Living Services, ARC of San Diego*

Dear PWCF: Just dropping by to tell you how much I enjoy reading about the progress PWCF makes. I know it is not fast enough for you but it is something. *Love and God Bless, Nancy Kaiser, Family Friend,*
PS: I am so glad that we are part of the PWCF family

Dear PWCF: Just received my electronic version of your newsletter. Just wanted to tell you how much I enjoyed your opening remarks [in the Executive Director's column]. I have also wondered from time to time, how my son feels having to live with PWS. Your conversation with Cameron really resonated with me. I try to have these types of discussions with both of my boys in the hopes of always building their self esteem (as you mention in your piece.)

I love reading your newsletter. It is always filled with just the right balance of helpful info, important studies and lots of family perspectives. [PWCF does] such a fine job with it. Thank you also for sharing my Neuro Psych story with your readers. I hope they can find some comfort in knowing we all share similar hopes, dreams, fears and inspirations. *Love, Lisa Peters*

Dear PWCF: I just wanted to thank you on behalf of my 6 residents that attended this year's [PWS Camp] session. Everyone had a great time! If it was not for the scholarships that you guys provide my guys would not be able to attend - so thank you so much! *Linda Hamilton, owner and operator of Lee Street Homes*

Dear PWCF: Mr. Walter B. McDonald died on Tuesday, May 8, 2012 at the age of 63. Walter had Prader-Willi Syndrome. Walter does not have any living family members, and was under the care of North Bay Regional Center in Napa; his conservator is Mr. Randy Kitch. It is the desire of his caregivers, social worker, and conservator that Walter be remembered and honored in a special way. Rather than having a memorial service, all agreed that a living legacy to Walter might best be done through a memorial contribution in his name to the Prader-Willi California Foundation. Please accept the enclosed check… to sponsor a Prader-Willi camper at your summer camp… *Cordially, Christopher Donhost, Manager, Fairmont Cremation Services*

Dear PWCF: Thank you for sending the PWCF information/donation brochure. Also, a special thanks [to Katherine Girdaukas Crawford] for your personal note – you are a *wealth* of information. I was very pleased to view the Mission Statement and Objectives of PWCF. I can only imagine how ecstatic one must feel when a connection is made! Thank you for your energies, hard work and dedication. May be future of PWCF be rich in success and hope. *Sincerely, Jane Oclassen*

Dear PWCF: I was at the [PWS Behavior Training Series] training this Saturday in Redondo Beach. I just wanted to say that I really enjoyed your talk! You certainly are a wonderful resource for parents and providers of individuals with PWS, so thank you so very much for all of the information. I also want to thank you for allowing me to make my announcement for our studies.
Pam Wright, Research Assistant from CSUF

Volunteer Recognition Corner

Volunteers are unpaid not because they are worthless, but because they are priceless.

Thank you to **Julie Casey**, PWCF's President, and Board member **June-Anne Gold, M.D.** for their work to increase public awareness at PWCF's Information Booth at the Levitt Pavilion Children's Concert in Pasadena on June 27.

Thank you to **Jackson Crawford,** Katherine Crawford's newly wedded husband, for working so hard moving furniture, books, bookshelves, and computer equipment out of the PWCF offices to make room for the installation of new and badly-needed carpeting (included in lease negotiations).

From *Trick or Treat* to '*Tis the Season*: Tips and Techniques for the Holidays

by Katherine Crawford

HALLOWEEN

-Discuss your expectations in advance. Any rules (like one piece of candy per house, visiting just these ten neighborhood houses, the child and parent trick-or-treat together, etc) must be made when both parent and child can calmly go over them. This is also a great opportunity to teach your child "please" and "thank you".

-Decide on post-Halloween candy rules beforehand. Some families plan out a one-candy-per-day rule. Other families allow the child to exchange all the candy collected for a highly desired toy (also known as the "Great Pumpkin" exchange). If you are visiting just a few homes, you may decide to give each house a pre-prepared Halloween bag to give your child including little toys or a healthy treat, preventing candy battles from the beginning.

- Plan your child's costume and candy collection bag. Avoid costumes with lots of pockets or sweatpants with elastic at the bottom of the legs; both offer easy opportunities for the child to smuggle away candy. Having glow-in-the-dark bracelets on both of your child's wrists are not only good for safety, they also increase visibility of where their hands are to prevent them from palming candy without your knowledge. Fabric candy bags can be modified to have Velcro-secured openings so you can hear when it is opened, and plastic trick-or-treat containers offer good visibility of what goes in and out.

- Teach your child what to expect. Tell them how to react to "tricks" like motion-activated spiders or people dressed up as scarecrow decorations that jump out at trick-or-treaters. Talk through what behavior is acceptable in response to being spooked.

- Prepare the child to transition out of trick-or-treating. This transition is made easier when they are primed in advance. Deciding on a cut-off age can be useful. However, just because they are no longer going house-to-house doesn't mean they have to miss out on all the fun: they can always hand out treats… under good supervision, of course!

THANKSGIVING

- "If everyone is watching then no one is watching". This applies to food-centric holidays as well as it does to swimming safety. Make sure there is an explicit understanding of who is supervising the person with PWS and when. You can tag-team so that no single individual is overburdened with responsibility. If a relative is educated and aware of the challenges and techniques, include them in the tag-team chain as well.

- Plan your visits strategically. Control the environment to control the stressors. If Grandma hosts a buffet followed by an open dessert table, you can plan your visit to include one or the other, not both. Be sure to keep the lines of communication open with her. You could also instead invite Grandma to Thanksgiving dinner at your house where food security can be more easily maintained.

- Foreshadow the schedule with your child (no matter their age). Discuss the schedule of the day in terms of order of events rather than specific times. The chaos of the holidays make it hard to predict that dinner will happen at 6 o'clock on the dot, but easier to predict that dinner will happen after the family card game.

- Foreshadow the food routine with your child (no matter their age). If the dinner is a buffet, walk through how you and your child will go through the line in unambiguous terms. "Pick reasonable portions" is open to subjective interpretation and by extension, open to arguments. "Pick ½ cup of mashed potatoes, one slice of meat, ½ cup serving of cooked vegetables, and one slice of pie" is precise and *not open to interpretation or subjective opinions*. If you are preparing your child's plate (which is always a good option), you will have told them well in advance that this was the plan, and you'll have reassured them of your criteria for plate design ("Don't worry, I'll be sure to include a little bit of everything offered"). If this creates anxiety, it might be necessary to stipulate that the person wait politely at the table rather than stand next to you as you make up their plate in the buffet line.

- Have a clear plan in case behaviors take a turn, and make sure that the plan is communicated with your child. Punishments are not effective in a population that has a hard time connecting cause to effect. Treat "leaving early" the same way you would a fire drill: a necessary precaution. You can also include a certain amount of cool-down time in the car prior to leaving. If the person can get themselves back into thinking-mode, they may not have to leave early. If they do calm down, be sure to praise them.

- Reward good behavior. Sitting patiently at the table while the parent or guardian prepares the meal, cutting food into small pieces before eating it and practicing turn-taking in conversations are all specific examples of behaviors to target with rewards. Praise and attention are often the best rewards: they are given immediately and have an immediate effect. Avoid major rewards ("if you follow your behavior plan, we'll go to Disneyland") which can create stress and anxiety if the child starts worrying that they might not get to go to Disneyland. Smaller rewards ("if you follow your behavior plan, we'll go to see a movie Tuesday") are more manageable.

Continued on page 17 ...

We Remember

Walter B. McDonald

June 18, 1948 – May 8, 2012

Mr. Walter B. McDonald was fun to be around. He loved people, loved to make people laugh, and loved to give a playful pinch now and again. And he absolutely loved holding his newspapers.

Walter became ill in 2010 and succumbed to a stroke that took his life on May 8 of this year. Walter was 63 years old.

Walter did not have any living family members. He was under the care of North Bay Regional Center, had a conservator, and lived at the Griffin Family Care Home. It was the desire of his caregivers, social worker, and conservator that Walter be remembered and honored in a special way. Rather than having a memorial service, all agreed that a living legacy to Walter might best be done through a memorial contribution in his name to the Prader-Willi California Foundation.

The Prader-Willi California Foundation is honored to have created the Walter B. McDonald Memorial Camp Scholarship which will be awarded to one special camper to attend the 2013 PWS Camp session.

Olympic Torch Runner Has PWS

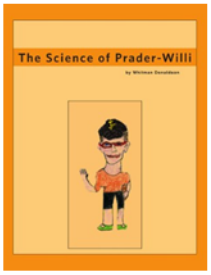
Stuart Mitchell, a 20 year-old with Prader-Willi Syndrome, carried the Olympic Torch through St. Ives, U.K. on July 8, 2012.

Way to raise awareness of PWS & support Prader-Willi Syndrome Association UK!

The Science of Prader-Willi

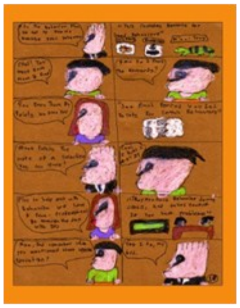
Written by PWCF Member Whitman Donaldson

This personal, informative, creative, and easy-to- understand graphic novella about Prader-Willi syndrome is written by our very own **Whitman Donaldson** who has PWS.



Writes Whitman, “This book is dedicated to my California Prader-Willi Family: Duncan, Emma, Felix, Grace, Hayley, Kelsey, Lillian, Oliver, Oscar, Richard, Safiya, Timmy, Trevor, and in loving memory of Paige, who will be dearly missed by all those who knew her. Also, thanks to my everyday heroes, my parents, who have given their strength, love, encouragement, protection, and advocacy skills throughout my life to be the best I can be, and have the most successful and independent life.”

This book will help you gain first-hand insight into Whitman’s life as a 23 year old young man affected by PWS. Its comic strip format makes it an ideal tool to introduce the syndrome to your older child, teen or adult with PWS, as well as other family members.



Published by Creativity Explored, $20. Order your copy online today! http://www.magcloud.com/browse/

Continued from page 16 ...

CHRISTMAS, HANUKKAH, AND NEW YEAR’S EVE AND ALL OTHER HOLIDAY CELEBRATIONS

- Stockings hung by the chimney with care don’t need to include candy. Little toys and seasonal knick-knacks are great stocking stuffers that don’t cause any extra anxiety. Be sure to prime expectations though!

- For the dreidel game, use non-edible markers like poker chips instead of chocolate coins.

- For a champagne toast (or any serving of alcohol) be aware of potential drug interactions. If in doubt, check with a pharmacist. This is easy to do when you pick up your adult child’s prescriptions. The pharmacist can then take into account all of the medications and give you an informed recommendation.

- Include food-free activities in your plans. Arts, crafts, puzzles, and games are all great fun and encourage social interaction.

- Take the time to take care of yourself. No one expects a car to run on empty, and the same is true of people. Step back, take a walk, or spend time with friends: do what it takes to refuel your energy. When you are at your best, you are better able to help your child.

(Thanks to Latham Centers’ Top Ten Strategies to Survive and Thrive During the Holidays article which served as useful inspiration on many points)

Residential and Vocational Providers Receive Special Gift from PWCF

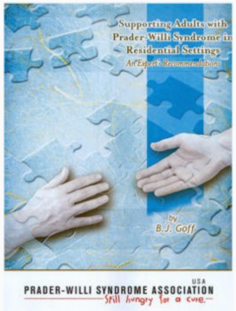
by Katherine Crawford, Family Support Coordinator

Anyone providing a home to an individual with Prader-Willi syndrome will be faced with questions. *How do I deal with food security? How can I prevent behavioral outbursts? How can I reduce skin picking?* Though common, these challenges can be anticipated, lessened, and in some cases prevented.

PWCF's DVD *Prader-Willi Syndrome Residential Staff Training* and PWSA (USA)'s book Supporting Adults with Prader-Willi Syndrome in Residential Settings aim to address these concerns. Both are written from residential providers' backgrounds.

The book's author, B.J. Goff, Ed.D., worked in general group homes before moving to PWS-specific group homes. As a result, the book is insightful into the differences between both types of homes, and why some techniques that work for persons with general disabilities are disastrous for persons with PWS. It also includes personal stories which highlight the rewards of successfully supporting people living with PWS.

The DVD shines in staff training situations. Staff can watch the entire DVD straight through, pause to focus on specific areas, or view segments at a time and have a discussion together afterwards. This DVD is especially useful for staff with limited experience with PWS: behavioral problems that staff may have previously assessed as the individual being "spoiled" or "stubborn" can be seen from the broader perspective of the syndrome. The DVD was filmed at real PWS group homes. Seeing real-life examples of behavioral outbursts from a variety of people with PWS may take the wind out of the sails of a staff member who had previously blamed the individual.



Alone or together, the *Prader-Willi Syndrome Residential Staff Training* DVD and the *Supporting Adults with Prader-Willi Syndrome in Residential Settings* book are vital training tools for residential staff, vocational and day program staff, and families. For this reason, the Prader-Willi California Foundation's Board of Directors mailed a complimentary packet with both the DVD and the book to all California PWS residential and vocational providers serving individuals with Prader-Willi syndrome. Thanks to the help of a donation received from the Richard DeLone Special Housing Project, we mailed over forty packages. With the right tools and training, everyone can experience success.

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

PWS Staff Training Materials

Order Form

USA PRADER-WILLI SYNDROME ASSOCIATION Still hungry for a cure.

Please send me ___________ PWS Residential Staff Training DVD(s). PWCF Member Price $25 · Non-Member Price $35

Please send me ___________ Supporting Adults with PWS in Residential Settings book(s). Price $15 · 2 or more $12 each

Shipping Fees: $5.00 for orders $10.00 – $20.00 | $10.00 for orders $21.00 – $49.99 | $12.00 for orders $50.00 – $99.99

Name: ______________________________ Telephone: ___________

Shipping Address: ______________________________

City, State, Zip: ______________________________

Total $ _________ ☐I have enclosed my check made payable to "PWCF" ☐Please charge my ☐Visa ☐MasterCard ☐AmEx

Name as it appears on card ______________________ Email: ______________________

Credit Card No.______________________ Expiration _________ Security Code *(on back of card)* _________

Billing Address ______________________________
(if different from shipping address above)

Signature ______________________________

Mail Order Form with your payment to Prader-Willi California Foundation
514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277

Office Use Only
Date Rcvd: ___________
Amount: ___________
Ck/CC#:___________
Date Sent:___________

IEPs by Dr. Seuss

Do you like these IEPs?

I do not like these IEPs
I do not like them, Jeeze Louise
We test, we check, we plan, we meet
But nothing ever seems complete.

Would you, could you
Like the form?

I do not like the form I see
Not page 1, not 2, or 3
Another change, A brand new box
I think we all have lost our rocks.

Could you all meet here or there?

We could not all meet here or there.
We cannot all fit anywhere.
Not in a room, Not in the hall
There seems to be no space at all.

Would you, could you meet again?

I cannot meet again next week
No lunch, no prep
Please hear me speak.
No, not at dusk. No, not at dawn
at 5 pm I should be gone.

Could you hear while all speak out?
Would you write the words they spout?

I could not hear, I would not write
This does not need to be a fight.
Sign here, date there, mark this, check that
Beware the students ad-vo-cat(e).

You do not like them
So you say
Try again! Try again! And you may.

If you will let me be,
I will try again
You will see.

Say!

I almost like these IEPs
I think I'll write 6003.
And I will practice day and night
Until they say
"You've got it right!"

MEMBERSHIP ACTIVITY

July-September 2012

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

New Family Members
Renée & Brent Snyder

Renewed Extended Family Members
Dolores & Gene Algaugh
Sandra Hansen
Nancy & Christopher Rohan
Jenn Shallvey
Celeste & Tom Von Der Ahe

Renewed Family Friend Members
Stacy Mason

Renewed Professional Members
Lulu & Oscar Cachuela – Marjan Homes
Diane Campbell Anand – Frank D. Lanterman Regional Center
Lynne Bird, M.D. – Rady Children's Hospital, San Diego
Sarah Bishop – North Bay Regional Center
Phil Bonnet – Alta California Regional Center
Danielle Borut, M.D. – White Memorial
Mary Lane Carlson, EdD, MPH, RD, CDE
Vicki Cox, M.S. – UCSF Genetics Office
Gayle Anne Cronic – Puckett Residential Services
Lynn W. DeFreece – North Valley Services
Janet Foos – Redwood Coast Regional Center
Ken Krieger – San Diego Regional Center
Larry Landauer – Regional Center of Orange County
Laura Larson – Far Northern Regional Center
Duane Law – Kern Regional Center
Phillip D.K. Lee, M.D. – Univ of Texas Med Branch
Lota Mitchell – PWSA (USA)
Nancy Harjani Muirhead, Psy.D., ABPS
Roberta Newton – Area Board X
Michael Rosenberg – Area Board III
James L. Shorter – Golden Gate Regional Center
Julie Tauscher – PRIDE Industries

We Goofed!

We neglected to acknowledge Shannon Watney who volunteered at the Central CA *Walking for Prader-Willi Syndrome* event. Thank you, Shannon!

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

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

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

DONATIONS ~ July ~ September 2012

General Donations
Dolores & Gene Albaugh
Anonymous Donor via Cars 4 Causes
Kathleen Dignan
Laura & Ray Esau
Keith Fromelt via Johnson & Johnson
Cameron Graziano
Carrie Hassanzai
Janice & Neil Hubberth
Jason Huck via HSBC Philanthropic Programs
Bonnie & Richard Keeley
Stacy Mason
Fran Nicholson
Marty & Arlin Paaren-Fletcher
United Way California Capital Region
Paula & Mike Watney via Church Fundraising
Sharon Wedegaertner

Donations in Honor of Samantha Morgan
Suzanne Privette

Donations in Honor of RJ Lucero
The Foothill Civitan Club of Burbank

Donation in Memory of Walter B. McDonald
Donation sent from Walter's caregivers, North Bay Regional Center Social Worker, and Conservator Mr. Randy Kitch to sponsor an individual with Prader-Willi Syndrome at PWCF's PWS Camp

Donations in Memory of Manuel Resendes
Isabel Matos and the Resendes Family

Donations in Memory of William Graziano
Wells Fargo

Donations in Memory of Josephine Fresquez and in Honor of Peyton Snyder
Anita Snyder
Gary Snyder

Donations in Memory of Christine Applegate and in Honor of Nolan Bonk
Gina Ayllon and Giuliana Halasz, PACE, & HSMC
Nadene Bergmann
Nolan Bonk
Paul Bruschera
Janice & Peter Celli
Lavina & Paul De Natale
Gloria & Louis Dradi
Jennifer Esposto
Sumita, Michael & Sabrina Fleming
Lisa & Fred Greenstein
JoAnn & Robert Hellman
Marie Hellman
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Rosenda M. Jardin
Joan & Richard Klasens
Carol Loughlin
Richard Lynch
Joanne & John McGlothlin
Ginny & Tom McGraw
Jane & Don Oclassen
Katherine Randall
Josette & Timothy Reid

Donations in Memory of Ronald F. Higgins and in Honor of Lexi Higgins
Anonymous Donor via the National Christian Foundation of Wisconsin
Debra Jamin Heller & Family
Marjorie & Carl Lundgren
Christina & Randy Maxwell
Emily Moore
Ronald E. Opera and all of the other members of the Winthrop Couchot Professional Corporation
Sue Phelps
The Rubin Family
Russ & Pat Swigart

Donations in Memory of Aunt Mary Houston Culver
Libby and Rob Fuller
Mary Culver

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).