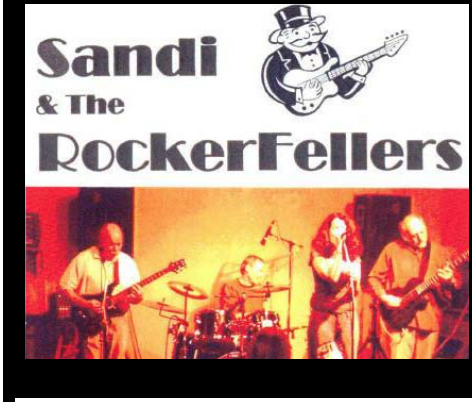
PWCF News

The Newsletter of Prader-Willi California Foundation

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

April-June, 2010 ~ Volume 20, Number 2



Prader-Willi Syndrome Benefit Concert

Craneway Pavilion—Billy Hustace Photography

Get your groove on while you raise awareness of Prader-Willi syndrome and funds for PWCF.

Make it a Date Night! Come out to the extraordinary **Craneway Pavilion**, enjoy a delicious dinner at the **Boilerhouse Restaurant** and a fantastically fun evening of rock 'n roll! Tell your neighbors, invite your friends! **Ticket sales benefit Prader-Willi California Foundation.** For more information contact PWCF 310-372-5053 or 800-400-9994 within California.

Sandi & The RockerFellers

Sandi Snyder - Lead Vocals
Skip Snyder - Lead Guitar & Vocals
Ken Fisher - Bass Guitar
Art Beringer - Drums

Enjoy rock, blues and jazz influences from '70s through today including songs played by bands such as The Pretenders, Sheryl Crow, Bonnie Raitt, Lynyrd Skynyrd, Train, No Doubt, Huey Lewis and many others.

Friday, July 16, 2010 at **8:00 p.m.**

Craneway Pavilion
1414 Harbour Way S
Richmond, CA 94804

Tickets are $5 at the door

Ten minutes from Berkeley
Five minutes from Richmond/San Rafael Bridge
Fifteen minutes from San Francisco Bay Bridge
Craneway.com // CranewayBlog.com

Boilerhouse Restaurant
510.215.6000

In This Issue:

PRADER-WILLI CALIFORNIA FOUNDATION

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514 North Prospect Avenue
Suite 110—Lower Level
Redondo Beach, CA 90277
800-400-9994 (CA only)
310-372-5053 (Phone)
310-372-4329 (Fax)

E-mail: PWCF1@aol.com
Web address: www.PWCF.org
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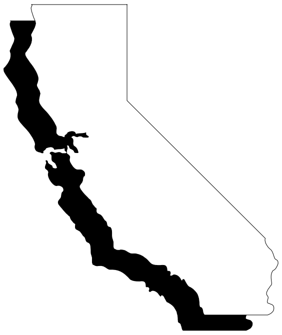

"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families."

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Wendy Young	415-924-7025	wmydmy@gmail.com
Sacramento	Diane Kavrell	530-753-5928	brandon.kavrell@cexp.com
San Luis Obispo Santa Barbara/ Ventura Counties	Hope Liddiard	805-461-0191	The Lidds@charter.net
Santa Clara/Santa Cruz/ Monterey Counties	Elizabeth Kulkowski	408-776-3533	

Central California

Fresno/Kern/Kings Madera/Mariposa Merced/Tulare Counties	Jennifer Rinkenberger (Infants & Children)	559-434-6641	jenrink@mac.com
	Debbie Martinez (Teens & Adults)	559-227-0294	martinezds@gmail.com

Southern California

Los Angeles County	Lisa Graziano	310-316-8243	tlcgraz@aol.com
	Julie Casey	818-843-7321	julie.casey@att.net
Orange County	Jenn Paige Casteel	949-547-1467	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*. When the *PWSProfessionalsExchange* group name appears, click and follow instructions to join.

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

How do you decide whether or what kind of sex education to provide to your child/adult?

I think the answer to this question is really “It depends.” It depends so much on the family and the functional level of the child. For us personally, we gladly had our son participate in any sex ed offered by his public schools. In addition, our church sponsored a program that has different units broken down for different age groups, starting (I think) in elementary school, with very basic concepts and then follow-up sections as the child gets older, going a little more in-depth and giving the kids some tools to consider their own thoughts and feelings on the subject.

My personal feeling is that if the child will spend any time “out in the world,” it’s a good idea to have them have *some* knowledge and teaching around this stuff. Even though our kids can’t always make the proper decision between right and wrong, I think it’s incredibly important to teach them what *is* right so that you always have a baseline to return to when discussing potential issues.

All that being said, I will point out that even after multiple different sessions over the course of his young life, when it comes down to discussing sexuality and the workings of male and female bodies, our son seems to have NO CLUE whatsoever about specifics. The bottom line though is that, if you think that they can handle it, you give them some information and context about respecting themselves and their bodies as well as respecting the same for others. It’s always good to have some agreed upon discussion of right and wrong to minimize the possibility of our children causing an incident, but also to ensure that if anyone tries to prey on *them*, that they know right away when something is wrong and have some tools and language to be able to let us know about the problem. *Anonymous dad of an adult*

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When our son was a young teenager, we took him, as well as his younger sister, to a church-sponsored sex education presentation given by a wonderful doctor who donated his time to different groups. I attended with our son and answered any questions he had about what was discussed. Sadly, this wonderful doctor has passed away. Then later there were some video presentations in health class regarding sex ed at his junior high school which I previewed first and ok'd.

Later, as an adult, he attended a presentation given in connection with requirements for all the young men living in his group home. From what I gathered, it was pretty graphic and included placing condoms on bananas as a demonstration. I did not feel this was the type of instruction our son really needed, given his living situation (in a group home with four other young men and no real opportunity for dealing with the opposite sex). Rather, I felt that instruction on how to be safe if approached in a sexually inappropriate way when out in the community was more important.

Of course as his sisters married and nephews and nieces started being born, he and I discussed again how all this had taken place and what happened in the process of bringing children into the world. He seemed and still does seem satisfied with this information. I don't think he really dwells on why he's not married like his sisters. He seems content with his "girlfriends" which he sees only occasionally. One lives several states away and he says that someday she wants to get married and have ten children! They have not seen each other for about five years now, only seeing each other at PWS conventions.

I realize that each circumstance is different, but our son does not seem to miss what his sisters have in their lives. He is content to enjoy family and friends and is very proud of being an uncle to his five nephews and nieces.

In a terrible way, my concerns about our son being safe in the community proved to be valid. He was molested at his work place when his job coach was busy with another client and didn't check up on him in the restroom. Please ask that your son’s or daughter’s day programs monitor restrooms in the community continuously. None of our sons or daughters need this nightmare in their lives. There is a wonderful program in Orange County called "Get Safe." It has been helpful in showing our son some tactics to use if approached ever again. It also helps young men and women learn these things before anything terrible happens. I strongly suggest a safety program like this for all our friendly, trusting sons and daughters. *Anonymous mom of an adult*

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In my experience with our 30 year old son with PWS, persons with PWS do become sexual and need the information just like anyone else. Since each of our children with PWS doesn't seem to develop as quickly as other children, it is a very individual process. The kids do start asking questions. They see T.V. and may have siblings who talk about sexual things and they become as curious as others. Just be sure that those long periods that they sometimes spend in the bathroom (like other kids in puberty) don't include a stolen bag of candy or something! We found puberty came later in his teen years, but it did come with all the usual adolescent behavior. Our son asked a lot of questions and has had various types of relationships with girls. He has become sexual as he’s gotten older, but not in the same way as my 32 year old son without PWS. He likes hanging out sometimes with the ladies from his supportive homecare group, but he could easily be swayed from that to play a game or watch a movie. When girls pursue him he usually doesn't follow through; maybe the low testosterone count plays into this. He does like to have alone time in his room and has a few sexy movies that he watches, though it’s not often. I think parents generally will have a sense about what and how to present to their child as they need to. My son didn't fit into the traditional timelines of teaching these things, but it did come. *Lynda Larson, parent of a 30 year old son*

Continued on page 13 ...

PWS Family Day at The Painted Turtle

On March 13 PWCF held its third annual, and alas the final, PWS Family Day at The Painted Turtle.

Linda Ryan and **Lisa Graziano** provided the Turtle's expert camp staff and extraordinary volunteers with important training on the evening before the big day. This training is vital to ensuring that everyone at camp knows just how to create a day for our kids and families that is both magical and safe.

Eighteen families enjoyed amazing activities despite the cold and blustery day. There were adventures in woodworking, fishing, cool arts and crafts, singing and dancing, magic and fun with Pun, and even a parents' share session. Parents bonded and shared important information each other all the while experiencing the freedom of knowing their child was safe and having a terrific time.

Unfortunately, The Painted Turtle is not able to offer a week-long camp to children with Prader-Willi syndrome, which has been our long-term goal. Linda Ryan is chairing the new PWS Camp Project, and with the help of PWCF members **Patricia and Don Carlson**, is working hard to identify a permanent PWS Camp that will serve persons of all ages with PWS and provide a magical, memorable and safe camp experience, as well as respite opportunity for their families. Stay tuned for their progress!

A tuckered Wyatt
and Scott Dibble

Fishermen Christie,
Trang, & Dave Nguyen

Artist
Ryan Casey

Warriors Against PWS!

Families enjoyed another fun night on March 13 at the Oracle Arena watching the Warriors shoot hoops as they helped raise awareness of Prader-Willi syndrome.

PWCF member and former Warriors representative **Ashley Hurdle** organized this second annual event with her usual expertise.

Michael Moore, PWCF's Public Awareness Committee chairman, coordinated an interview on KNBR with baseball legend and PWS spokesman **Clint Hurdle**. An unbelievable 2.4 million households heard Clint talk about Prader-Willi syndrome and it's impact upon his youngest daughter, Madison who has PWS, and their family.

Over 500 PWS wristbands and brochures were distributed from PWCF's Awareness Booth.

Our gratitude to the Warriors for their support of this fun awareness-raising event, to the **Ramos Family** who came to the game in full force, and to *all* of the families who came out to support the cause! Thank you to *everyone* involved with making this such a successful event.

Ashley Hurdle

Chloe, Sam & Kristin Cropper

Mike, Kirsta, Ava, Grandpa Dennis, & Lillian Moore

Victor Ramos

Executive Director's Column

Lisa Graziano, M.A.

Eleven years ago when my newborn was transferred to the Neonatal Intensive Care Unit, the nurse there told me something I have never forgotten. She said, "That your baby is in the NICU gives you an opportunity most mothers don't have: someone experienced to teach you first-hand how to care for him."

I'm sure I wasn't so immediately comforted by those words back then when all I wanted was to take our baby home and experience the joys we were *supposed* to be feeling after his birth. But comfort did come. When it was time for his first bath and we had no idea what to do and were absolutely terrified he'd slip through our inexperienced fingers, our nurse was there to show us how to confidently cradle and support him. When we couldn't awaken him for feeds, our wise nurse showed us how to loosen his blanket and gently stroke his cheeks. She was the one who showed us how to tap the bottom of the bottle to keep him awake and interested in feeding. Back then, before the age of online and in-person support groups, these wise tips were not things that we would have been able to learn anywhere else but from this NICU nurse.

I am reminded of our wise nurse every time I speak with a parent who sounds as lost and overwhelmed by how to care for their newly diagnosed baby as I was eleven years ago. I am reminded of the importance of first-hand teaching when I hear a mom or dad express their gratitude for the pearls of wisdom they have just received from our office or from a PWCF Parent Mentor. Every time I attend a Regional Center hearing or an IEP meeting and help a family advocate for their child, I remember the comfort of our NICU nurse standing beside me, gently guiding and sharing her experience and expertise.

This is the same comfort and reassurance that comes with membership in Prader-Willi California Foundation. Through support groups, emails, this newsletter, the website, conferences and events, wise parents, extended family members and professionals share what they have learned over the years and in so doing, help each of us become a better parent or care provider to our child.

Sometimes we find support and connection where we least expect it. Take for example the story of a woman who was recently talked into going for a walk with two of her good friends. This woman didn't really *want* to go for a walk that day, but her friends persisted and so off she went to a beautiful park she'd never before visited. The three friends walked for a distance along a peaceful, wooded path until they came upon a noisy group who were hammering down stakes and posting signs along the walk path. One member of this noisy group asked the trio what the path was like where they'd just been. After answering, the trio inquired about the signs. "We're posting them for a walkathon to raise awareness of Prader-Willi syndrome" was the reply that absolutely stunned the three friends. Turns out the woman who hadn't really wanted to go for a walk that day has a twelve year old child with Prader-Willi syndrome, had never before heard of Prader-Willi California Foundation or our annual walkathons, and didn't know there is so much new and important information about PWS now available.

We have accomplished so much over the years, but this woman's experience highlights how far yet we need to go. No one whose child is diagnosed with Prader-Willi syndrome should be uninformed about Prader-Willi California Foundation and how much information and support we can provide. Each and every one of our many and varied programs and events provides an opportunity to meet someone experienced who can teach us first-hand something we never knew before, something helpful. I encourage you to take advantage of each and every one of these opportunities… you never know whose life you will touch or what wonderful person you will connect with!

Food Tip

This food tip was submitted by Kristen Foley, Representative of Pfizer EndocrineCare

VitaRain is a non-carbonated blend of purified water and natural fruit juice. Each 20 ounce bottle is packed with vitamins, minerals, and nutrients. TalkingRain's product development team worked closely with Roche Vitamins in the research and development process for VitaRain to determine the appropriate level of nutrients for each flavor blend to deliver the greatest health benefit. Each flavor is intended to enhance important functions such as vision, focus, and energy. According to FDA guidelines, each serving of VitaRain offers an excellent source of recommended vitamins and minerals.

There are six delicious flavors of VitaRain: Blueberry, Kiwi Strawberry, Orange Tangerine, Key Lime, Melon Berry, and Passion Peach. Vita Rain is sweetened by Sucralose, an artificial sweetener formerly known as Splenda, and is available under the brand name *Kirkland Signature* at all Costco stores.

Efficacy and Safety of Long-Term Continuous Growth Hormone Treatment in Children with Prader-Willi Syndrome

Dr. de Lind van Wijngaarden
Dutch Growth Research Foundation, Rotterdam, The Netherlands

Reprinted with permission from PWSA (USA). PWSA has Dr. Wijngaarden's permission to share this summary of their research. The full report may be found in The Journal of Clinical Endocrinology & Metabolism Vol. 94, No. 11 pg 4205-4215)

Patients with PWS have an abnormal body composition with increased fat mass and decreased lean body mass, and short stature. Some studies showed normalization of adult height when GH treatment was started before onset of puberty. Although improvement of body composition is considered the most important effect of GH in children with PWS, there are no reports regarding effects of long-term GH treatment on body composition in a large group of patients. We investigated long-term efficacy and safety of GH treatment on body composition, growth, bone maturation, and safety parameters, in 55 children with PWS included in a 4-year national multicenter prospective follow-up study. The mean ± SD age at start of study was 5.9 ± 3.2 years. All children received somatropin 1 $mg/m^2 \cdot day$. The following data were annually obtained in one center: fat% and lean body mass (LBM) by dual-energy x-ray absorptiometry, height, weight, head circumference, bone age, blood pressure, and fasting IGF-I, IGFBP-3, glucose, insulin, HbA1c, total cholesterol, HDL, and LDL. SD-scores were calculated according to Dutch and PWS reference values (SDS and SDS_{PWS}).

Fat%SDS was significantly lower after 4 years of GH treatment ($p<0.0001$). LBMSDS significantly increased during the first year ($p=0.02$), but returned to baseline values the second year and remained unchanged thereafter. Thus, LBM stabilized during long-term continuous GH treatment, which is in contrast to the persistent decrease of LBMSDS commonly observed in untreated children with PWS. Mean ± SD height normalized from –2.27 ± 1.2 SDS to –0.24 ± 1.2 SDS ($p<0.0001$). Head circumference SDS increased from –0.79 ± 1.0 at start to 0.07 ± 1.1 SDS after 4 years. $BMISDS_{PWS}$ significantly decreased. Mean ± SD IGF-I and the IGF-I/IGFBP-3 ratio significantly increased to 2.08 ± 1.1 and 2.32 ± 0.9 SDS, respectively. GH treatment had no adverse effects on bone maturation, blood pressure, glucose homeostasis, and serum lipids.

Our study shows that 4 years of continuous GH treatment with a standard dose (1 $mg/m^2 \cdot day$) had a significant favorable effect on body composition, heightSDS, $BMISDS_{PWS}$, and head circumference SDS, without adverse effects on blood pressure, glucose homeostasis, and serum lipids. Importantly, the favorable effect on body composition persisted during the 4 years of study. Based on our findings, it is recommended to keep IGF-I levels between 2 and 3 SDS for optimal effects in children with PWS, without adverse effects. **In conclusion, long-term continuous GH treatment is an effective and safe therapy for children with PWS.**

* * *

Research Subjects Needed

Endurance and resistance exercise, hormones, and metabolism in youth with Prader-Willi Syndrome (PWS)

Researchers in the Kinesiology Department at California State University Fullerton (CSUF), in collaboration with the Division of Endocrinology at the Children's Hospital of Orange County (CHOC) located in the city of Orange in CA, are investigating the hormonal and metabolic responses during exercise in children with PWS and without PWS. The purpose of this study is to better understand alterations in the endocrinology and metabolism of PWS based on the genetics and body composition particular to PWS.

We are recruiting youth with PWS between the ages 8-18 years old for a three-visit study (1.5 hours for the 1st visit to CHOC, 1 hour for a visit to CSUF, and 3 hours for a 2nd visit to CHOC). During both visits to CHOC the children will complete either an endurance (bike) or resistance (stepping while wearing a weighted vest) exercises. In the 1st visit they will complete a health screening, and in the 2nd visit they will have their blood drawn. The visit to CSUF is for a body composition x-ray scan (DXA). Participating youth will be compensated for their time with gift incentives of $10 and $25 (respectively for visits 1 and 2), and parents/caregivers for mileage and parking

For more information or to participate in this study, please contact the research office at
(657-278-3671) pwstudy@fullerton.edu, Dr. Daniela Rubin
(657-278-4704) drubin@fullerton.edu, Dr. Dan Judelson
(657-278-5423) djudelson@fullerton.edu. Hablamos español.

Dr. Rubin & Cameron

In the Trenches

Vol. 1

by Jessica Patay

Ryan & Jessica

Twenty-nine questions in 10 minutes. It was a typical ride home from an afternoon activity. The car seems to have this affect on children I've been told, but especially Ryan, (my 6 year old with PWS). He is my "high-need-to-know-kid" and is always shooting off questions. A sampling of Ryan's questions on this particular ride home:

- Are the clouds out?
- Do the clouds go away when the sun comes out?
- Do the clouds make it cold?
- Are the clouds in the morning?
- Will it be sunny on Monday?
- Why does the sun come out?

Lately Ryan has been obsessed with the weather. I have had to say to him over and over that "We don't discuss the weather anymore," or "I am not in charge of the weather." I have realized that no matter how many times I answer these questions, they do not go away and his anxiety is not appeased.

Ryan is a prolific question-asker. It is a strength. Curiosity is a good thing. (I keep telling myself that.) His questions, most often though, are fueled by his anxiety and inability to process the world's information around him. He often sees the world in still photographs instead of an ongoing video. His challenges processing information are exacerbated by his impaired short-term memory. Because of course he's asked these questions yesterday, a week ago, a month ago, or even just two minutes ago.

As a mother, I am a teacher to my three children, a teacher of new sounds, words, ideas, concepts, beliefs, values and morals. I enjoy this part of parenting. As a mother, I am called to nurture my children, a role I relish. As a mother, I am called to soothe my children's fears, to settle an anxious thought with answers, with comfort, with love and tenderness. However, how do I do this when I have a child who is *always* asking questions, over and over and over, a bottomless well of them? My child, and probably your children are *always* asking questions until our patience tank is screaming EMPTY in angry red!

Sometimes we keep answering questions. Sometimes we empathize and clarify what it is at the heart of it. Sometimes we answer a few and then disengage. Sometimes we lose our calm resolve and say a little too loudly, "No more questions!" We hope that these tactics work. And sometimes they do. For a few hours or a few minutes.

What helps me in moments like these when I want to pull out my fingernails one by one after Ryan has asked Question #873 that day, is to take a deep breath and say to myself, "It's not his fault. He is not TRYING to drive me crazy. He can't help it. He can't! Ryan loves me. I love Ryan, and I love all his parts that don't work quite right." I take another deep breath.

An "aha" moment came to me today. I have questions too. Lots of them, and all of the time, just like Ryan. Except mine are inside my head and heart. And as a parent of a child with PWS, you do, too. The questions are there, dangling over us, sometimes like twinkling lights or a rain cloud, depending on the day or season of our special journeys. My big ones go like this:

- Will Ryan ever learn to read and write (legibly)?
- When will the food-seeking and stealing behavior begin? Or will it not be as prominent an issue for him?
- What will he be like when he is a teenager? An adult?
- How will others treat him when he is older?
- Will Ryan have any true friends in life?
- Will I lose him prematurely?
- Why was Ryan given to our family? (I ask WHY again…)

I have my own anxiety and angst in living with PWS, as I am sure every parent or caregiver does. Just like Ryan, I have a million questions. *However, I have a choice.* I can stay stuck in my questions and be paralyzed by fear. Or I can tell myself, "I'm all done with these questions today." I can take a deep breath, pray, meditate, smile and remind myself that Ryan was given to me. He's a gift. He is full of goodness and unparalleled gratitude and affection. He is full of priceless treasures and life lessons for me and for our family. And most likely, he will always be full of questions.

Ten Years of *Walking for Prader-Willi Syndrome*!

There were skeptics and there were naysayers, but **Toni Campoy, Renee Tarica, Fran Moss, and Linda Ryan** had a vision for an awareness and fund raising walkathon and persevered. With guidance and help from PWCF members **Lianne Noddle, Henry Tarica** and **Frank Moss**, the first *Walking for Prader-Willi Syndrome* awareness and fund raising event was born in 2001. Of that first *Walk* Renee remembers, "It was pretty exciting, waiting for the unknown. We were quite pleased with the turnout. After the *Walk* Frank, Fran, Henry and I went home to count the monies we'd collected. We were surprised and excited [to have counted $20,600]. The following year we added a *Walk* in Northern California" which grossed a whopping $75,500!

This year marked PWCF's 10th annual *Walk* and now boasts three events spanning the State of California. If you've not yet attended an event, you are sure missing out on a whole lot of fun. Just ask PWCF members **Ivette and Victor Ramos** who brought over 90 of their closest family and friends to this year's *Walk*! There is music, whether it's a live band as those lucky Northerners are treated to by **Austin DeLone** and his now-famous PWS Noisemakers Band, or, it's a fantastically fun DJ. There are family-friendly and exercise-oriented games and raffles. Southerners are treated to a delicious catered picnic lunch. No matter which *Walk* you attended this year, there was a feeling of excitement and connection and a coming together for a common cause – to honor those who have Prader-Willi syndrome and to raise public awareness and funds to help improve the quality of life for all who are impacted by this complex and too-often devastating disorder.

So far we've raised almost $47,000 and because YOU CAN STILL DONATE TO SUPPORT YOUR LOVED ONE OR FAMILY FRIEND you can still help us reach or exceed our $50,000 fundraising goal. Please make your tax-deductible donation today!

PWCF's Board and Walk Planning Committees are already busy planning next year's *Walks*. To keep them fresh and relevant the next decade of awareness *Walks* will likely see some very exciting changes and increased public outreach. Be a part of the next generation of events! Contact PWCF and get involved in planning the 2011 events!

Central California
Debbie and Dave Martinez – Event organizers
Paula Watney – Event organizer
Renee Tarica – Event organizer
Valley Christian Scout Troop 375
Balloon Décor of Central California
Dave Henry, Pfizer Endocrine Care
DJ Rome and DJ "G"

Northern California
Patti and Tom McRae – Event organizers
Maddy Fluhr and Eddie Resendes – Event organizers
Austin and Lesley DeLone – Event organizers
Mary and Paul Hill – Event organizers
Renee Tarica – Event organizer
Wendy Young
Michelle and Kevin Donaldson
Dave Henry, Pfizer Endocrine Care
The PWS Noisemakers Band

Southern California
Renee and Henry Tarica – Event organizer
Jeanine and Mark Milner
Liane and David Noddle
Fran Moss
Carolyn Meyer
Cyndie Kelly
Susan and Russell Quan & Umina Produce
Ronnie Salem and her extraordinary crew
Kristen Foley, Pfizer Endocrine Care
Balloon Factory
Tarzana Subway
DJ Jimmy Rudon

PWCF extends our most sincere appreciation to each and every Sponsor and Donor. Every contribution, from the pocket-sized to the extraordinarily generous, provides a substantial service to persons with Prader-Willi syndrome and their families. We express our gratitude to *everyone* who collected donations and helped increase awareness, and we especially thank this year's **Top Fundraisers** shown below. On behalf of PWCF and the families we support, thank you and see you next year!

Northern California
Kyra Allen
Kristen & Sam Cropper
Michelle & Kevin Donaldson
Maddy Fluhr & Eddie Resendes
Sally & Mark George
Tracy & Roger Goatcher
Mary & Paul Hill
Patti & Tom McRae
Kirsta & Mike Moore
Ivette & Victor Ramos

Southern California
Ken & Maria Knox
Lisa & TJ Graziano
Angela & Robert Lucero
Drew & Lindy Marich
Mercedes Rivera
Renee & Henry Tarica

Central California
Paula & Mike Watney
Jennifer Rinkenberger

> The miracle is not to fly in the air,
> or to walk on the water; but to
> walk on the earth.
> Chinese Proverb


WALKING
for Prader-Willi Syndrome
HELLO OSCAR!
Love,
Uncle Dick & Aunt
RED SOX
NEW YORK

Board Corner

PWCF Board of Directors Meeting May 22, 2010

The Board of Directors met at the PWCF office in Redondo Beach. All members were present except Carl Martens, Chris Patay and Renee Tarica. Consultant Fran Moss and Executive Director Lisa Graziano also attended.

Grant Requests: A group home's grant application for furniture and equipment was reviewed. Partial funding was approved to purchase a television to aid in consumers' exercise regimen. The Board needs more information to make a decision about the remaining funds request.

Treasurer's Report and Finances: Renee Tarica's account summary, submitted in absentia, was reviewed. Given the state of the economy, the Board discussed the earnings and risk of PWCF holdings. To further explore our handling of the PWCF portfolio, we will meet with our Smith Barney representative at the next in-person Board meeting in September. After discussing future educational meetings within California and nationally, the Board pledged $5,000 to help support a PWSA National Conference slated for November 11-13, 2011.

Executive Director's Report: Lisa Graziano reported on the volunteer Grant Writer and PWCF member, Linda Hedstrom, who has been exploring funding sources for PWCF.

Strategic Planning: Led by Drew Marich, the Board reviewed and revised PWCF's goals for 2010.

Fundraising: The following sources have and will provide funds to support PWCF in the near future:

1. Walking for Prader-Willi Syndrome Events*:* A third location in Central California was added this year in addition to the events in Northern and Southern California. The possibility of holding all three *Walks* simultaneously next year, as a state-wide event, was discussed. Additionally, the Board suggested finding new locations to hold these *Walks* in order to promote increased visibility and awareness. Kimberly Pratto-Storr helped create a new DVD which will be made available to families as well as used in a corporate appeal plan. The DVD features photos from *Walk* event*s* and is set to the song, *The Climb.*

2. Opportunity Drawing for Kauai Vacation Condominium*:* Renee Tarica donated one week in a luxurious condominium to be used for fundraising purposes. The Board discussed selling tickets online.

Residential Training DVD Project: Fran Moss reported that although the June completion deadline has to have been extended, much of the filming is complete. Fran Moss anticipates that the DVD will be finished and available for distribution at the November GEM meeting.

Improve PWCF Website: Tom McRae reported that the revision of the site is in progress. The Board discussed appearance, content, and committee member training to allow for web updates in the future. The goal is to present the revised website at the GEM meeting.

Improve Public Awareness: Julie Casey presented an update on activity on PWCF's Facebook page (424 positive responses to date). PWCF will also set up a Twitter account.

General Education Meeting (GEM) Organization: Lisa Graziano reported that planning is complete for the 2010 GEM meeting. PWS experts Linda Gourash, M.D. and Janice Forster, M.D. will present at the San Jose Hilton Hotel on Saturday, November 6. Planning has begun for the 2011 GEM meeting.

Residential Services Liaison Committee Report: Fran Moss reported that openings exist at a Griffin Home located in Northern California, Arc of San Diego, and a Marjan Home in Corona. PWS Residential Staff Training Consultant Theresa McGrath issued a report on recent training sessions. The Board agreed to suggest that she offer training sessions to Regional Centers, and produce a DVD of her training session.

Public Awareness Committee Report: Mike Moore reported on the Warriors Event and the Clint Hurdle interview on KNBR in which Clint discussed Prader-Willi syndrome for a full five minutes for a listenership of approximately 2.4 million households. About 100 tickets were sold under the auspices of PWCF and the organization will receive $10 per ticket. Since Clint Hurdle is a national spokesman for PWSA, the Board agreed to grant 50% of these proceeds, after expenses, to PWSA. The Board discussed holding a 2011 event with the Warriors and perhaps another athletic organization. Lisa reported that the Rockerfellers, a Bay Area band that has connections with PWCF member Jackie Lindstrom, will hold a benefit concert for PWCF on July 16, 2010 at the Craneway Pavilion located in Richmond, California.

Program Committee Report: See also notes above regarding the GEM. Lisa reported that The Painted Turtle camp has indicated they will not offer a weeklong session to serve children with PWS. Linda Ryan, who chairs the new PWS Camp Project, is working with PWCF members Patricia and Don Carlson, to explore other camp / respite options. They have researched the beautiful Tuolumne Trails and Easter Seals' Camp Harmon and are making good progress toward producing a camp to serve persons of all ages with PWS.

Nominating Committee Report: Lisa reported on behalf of committee chairperson Kim Morgan that three Board members' terms expire at the end of this year: Michelle Freier, Tom McRae and Betty Olson. The committee has made good progress identifying candidates to run for the 2011-2013 term.

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

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

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

What will you gain by participating at the Board level?

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

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

- Three to four Saturdays per year to attend Board meetings (most held at the 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.

To run for a vacating seat on the Board or to nominate someone else, submit in writing the name and contact information to Kim Morgan, Chair, Nominating Committee, PWCF, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277 or via email at PWCF1@aol.com. **The deadline to submit nominations for the 2011-2013 Board of Directors is August 6, 2010.**

Volunteer Recognition Corner

PWCF recognizes the following individuals for their work to mail the *Walking for Prader-Willi Syndrome* brochures:

Renee Tarica
Henry Tarica
Bill Morgan
Fran Moss

Hasmukh Amarasekera
Kevin Amerasekera
Cameron Graziano

PWCF thanks **Angela Lucero** for her PWS presentation at Albertson's grocery stores on March 24 which helped raise awareness of PWS and support for the *Walking for Prader-Willi Syndrome* events.

PWCF is grateful to **Linda Ryan** for providing critical training to the volunteers and staff at The Painted Turtle to help make PWS Family Day on March 13 so successful and fun.

PWCF is grateful to **Kimberly Pratto-Storr** for her work to create a new DVD that will be used to increase public awareness and seek corporate donations via the *Walking for PWS* awareness and fundraising events. Kimberly also helped secure copyright permission to use the song, *The Climb*, for this new DVD. Kimberly also volunteered in the office contacting and providing support to families.

PWCF thanks **Cameron Graziano** for his help to affix postage to the Los Angeles County Support Group meeting notices.

PWCF thanks **Jessica Acosta** for her work to staff the PWS Information Booth at the San Gabriel/Pomona Parents' Place Family Resource & Empowerment Center's *18th Annual Information Fair & Festival* on April 25.

PWCF thanks **Cynthia Stokes** and **Jessica Oestreich** for providing administrative assistance in the office.

One Family’s Experience with Depo-Provera

by Grace Navalta

Many of us parents who have daughters with PWS may notice that their teenage or adult daughter’s behaviors get worse before their periods. You may be directed by doctors, home administrators and others to give them medication to stop their periods in order to avoid severe pre-menstrual outbursts during the week before their periods.

But before you decide on a chemical method to stop your daughter’s period, please consider our story and the severe side effects such medication had on our daughter.

My daughter, Arianna, lives in a group home and we were asked by our group home administrators if we’d consider stopping her periods because she would have such severe tantrums every month during the week before her period. They spoke to her psychologist who then told us to ask her medical doctor if getting Depo-Provera shots would be a good alternative for our daughter.

I went with one of the administrators to Arianna’s medical doctor. I was told that Depo-Provera was a good alternative with very few side effects. I asked the nurse who administered the shot and she also said that there weren’t any side effects except for light periods before my daughter’s period disappeared.

Arianna got the shot a week before Thanksgiving. During Thanksgiving vacation, she was in high spirits, talkative social and generally her sweet self. A week later, when we picked our daughter up for a visit, her home administrator said she was acting “spacey.” When asked what she meant by that, she said Arianna was not paying attention and seemed “spaced out.”

That evening, we took Arianna to a large Christmas party put on by our cultural organization. Arianna took no interest in the Santa or to her old teacher, which was very uncharacteristic of her. By that evening, she informed me that Santa Clause had a gun and wanted to hurt her and that she was afraid of him. Her father and I were extremely alarmed, because she has never had delusions before. We informed her group home and psychologist. We also noticed that when we called Arianna at home, she became extremely quiet and wouldn’t speak with us.

That week, I arranged to meet with Arianna, her psychiatrist and care-givers at a psychiatric appointment. I was very alarmed to see that Arianna could not speak, had a look of terror in her eyes, was not responding, and even wet her pants (which she had not done since she was five years old). The psychiatrist was at a loss as to what was causing Ari’s problems. I told her that all her problems started shortly after she received her Depo-Provera shot. She said that she thought the shots were a poor choice because the medication stays in Ari’s body for a full three months. I told her that I thought the doctor had recommended the shots. She said no, that she had seen potential problems, but had advised the administrators to seek council with Arianna’s medical doctor. I was flabbergasted to know that this medication had not been a recommendation by her psychiatrist but a suggestion to consult her medical doctor. This was a tragic miscommunication between the psychiatrist, administrators and myself.

The psychiatrist said that Arianna appeared to be going through a psychotic break. She said she recognized the psychotic break from the fear showing in Arianna’s eyes. I was heartbroken and felt the terror of a parent whose child has something going terribly wrong but had no power to help her child.

Shortly after leaving the psychiatrist’s office, I received a call from Arianna’s psychiatrist; she didn’t want us to go home. She insisted that I take Arianna to Emergency. I was stunned and didn’t want to put Arianna in a traumatic situation, but her doctor insisted.

I finally agreed because I was worried that Arianna might be having a stroke, or severe physical reaction to the Depo-Provera. She had also complained of a stomach ache earlier and was rubbing her stomach. I panicked that Arianna wouldn’t regain her speech, and that she would lose all the hard-fought physical and mental developments she’d made over the years, such as her level of speech and her ability to read at a second grade level. The child I loved seemed to be slipping away from me. I felt overwhelmed, but I forced myself not to cry or show how distraught I was so that Arianna wouldn’t become even more upset.

After several hours of tests, the doctors in emergency couldn’t find anything physically wrong with Arianna. She was at this point, almost comatose. The emergency room doctors agreed that the timing was right and they concluded that it was probably the Depo-Provera shot that had most likely caused a reaction in Arianna. Although extremely rare, they believed that the hormone boost from the shot had most likely caused her strange reaction.

It was very hard to do, but I knew I wasn’t able to provide 24 hour care, so Arianna returned with her care givers to her group home. I went home and was unable to sleep. I broke down for the first time that night in my own bed and my husband and I talked into the night about what had happened. I felt an overwhelming sense of guilt for allowing the doctor to give the Depo-Provera shot in the first place.

The next day, I returned to the psychiatrist’s office with my husband. Arianna was already there with her care giver. When Arianna went in to see her doctor, things went from bad to worse. Arianna began to have delusions and began crying, saying she was afraid of the snakes and that she was having a baby. The sight of my daughter, terrified and seeing and feeling things that weren’t there, was almost more than I could bear.

Continued on page 13 ...

Depo-Provera continued from page 12 ...

We dug deep and made the best decision we could. We decided to move forward and put Arianna on an anti-psychotic drug called Geodon. Very slowly, Arianna's delusions disappeared, but there were other side effects of the medication such as involuntary movements, and a sedated state. After three long months we finally began reducing the Geodon. After five long months, Arianna is finally off of all drugs.

I wrote this story so that parents would be aware of what can possibly go wrong and not have to suffer like my family did. Putting your daughter on hormones to prevent premenstrual tension can have serious, unintended effects. Please consider our story before you decide to give this medication.

* * *

Parent to Parent continued from page 3 ...

With our typically developing daughter who is now 19, we wanted her sex education to come first from us as her parents. We knew sooner was better than later. She was already reading sexually oriented words that had been carved on her classroom desk in second grade. So we had "the talk" with her at age 8. Our son, Jesse, with PWS became familiar with the word "sex" by watching reruns of the TV show 7th Heaven. As the children in the show became teenagers, sexual standards became an issue for discussion. At that time Jesse was 10-12 in age. We told him that "sex" was what happened between a husband and wife that allowed them to have a baby. He was quite satisfied with this. This is Jesse's freshman year of high school and he is 15. Last fall in his exercise-nutrition science class which is required for all freshmen, we knew at the end of the semester the class would have a unit on sex education. Although Jesse is 15, developmentally he is more like a fourth grader. But again we wanted him to hear the sex education talk first from us. He took it in stride and our fear that it might become a matter of public discussion for him has not happened. I think God gives parents a sixth sense of when it is the right time to discuss sexual issues with their children. The timing may differ with each child, but I think it is important that they hear it first from the parent and that leaves the lines of discussion open for whatever else they might hear from school or friends. *Wanda Faivre, parent of a 15 year old son*

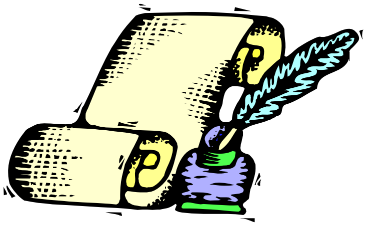
Next issue's Parent to Parent question is, ***"How do you handle it when you see a child or adult in the community who you believe may have Prader-Willi syndrome? Do you approach the parent and ask or not?"***

To submit your response to this question or to send
a new question, email, fax or send it to PWCF!

Congress Established Prader-Willi Syndrome Awareness Month

Last December, House Resolution 55, in the House of Representatives by California Representatives Ed Royce and Jane Harman, was passed in a majority vote with bipartisan support and established Prader-Willi Syndrome (PWS) awareness month. The resolution recognized PWS as a rare life-threatening genetic condition affecting one in 15,000 people and the most common known genetic cause of life-threatening obesity that has been identified. The resolution also recognized the importance of early diagnosis and the efforts and commitment of patient advocacy groups.

"This is a significant development for those affected by Prader-Willi syndrome," said Kim Weinberg, former executive director of Prader-Willi Syndrome Association (USA). "PWSA (USA) is a strong advocate for national recognition of PWS, launching PWS Awareness Month, and will continue to promote the agenda of the PWS community." Janalee Heinemann, M.S.W. and PWSA (USA)'s director of research and medical affairs, said, "PWS research has wide ramifications beyond the PWS community and is a significant key to unlocking the mystery of obesity as well as to gaining a better understanding of autism."

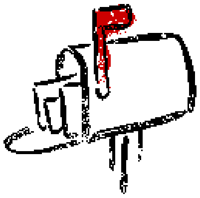


In June, Heinemann co-chaired the First International Conference on Hyperphagia (the uncontrolled desire to consume food) bringing together multi-disciplinary experts studying hyperphagia across different syndrome groups, government and pharmaceutical representatives to accelerate discoveries of new, effective treatments and a cure. "This Congressional recognition shines a light on an important area of study for a perplexing disease and on those who are dedicated to finding answers, such as the NIH and others in the scientific world," Heinemann added.

"House Resolution 55 is a great step toward a brighter future for those with PWS," said Weinberg. "The entire PWS community is appreciative to Reps. Royce and Harman for their work and support."

PWS is a complex genetic disorder affecting appetite, growth, metabolism, cognitive function and behavior. Although considered a rare disorder, PWS is one of the most common conditions seen in genetics clinics. Currently there is no cure and, to date, no medications or procedures are successful in staving off the relentless hunger, although growth hormone treatment has great benefit. PWCF was proud to sponsor our annual *Walking for Prader-Willi Syndrome* within PWS Awareness Month.

PWCF Gets Mail…



Dear PWCF: Thank you for your most recent donation to CHOC Children's Prader-Willi Syndrome Clinic. With your support we are able to achieve our mission – to nurture, support and advance the health and wellbeing of children. We appreciate your generosity and would welcome the opportunity to share first-hand the impact your contribution makes. Please contact me if your Board is interested in a tour.
Sincerely, *Leah Nosek, Grants Officer*

Dear PWCF: Please accept our gratitude for your generous contribution to [support PWS Family Day and] keep The Painted Turtle's year-round camp programs free of charge to children with serious medical conditions. We very much enjoy serving your community of children and families and appreciate your partnering with The Painted Turtle.

We have a full calendar of programs planned for this year in order to create life-changing experiences for more than 2,100 children and family members at camp. In addition, our Hospital Outreach Program will regularly visit six hospitals throughout the state to bring doses of camp magic to more than 1,200 children during their hospital stays.

We are able to provide these life-changing experiences thanks to generous partners like you.
With much appreciation, *Michael L. House, PhD, CEO The Painted Turtle*

Yvette Tarica

Dear PWCF: Many thanks for your email [informing us that our request for a grant to support the PWS Clinic at Rady Children's Hospital in San Diego was approved]…. It is rewarding for us to help some families "see the light" and discover for themselves how much better life can be when food security is provided and behavior is managed effectively. It has taught me never to give up on any family, that everyone is capable of enacting positive change if we give them the encouragement and tools they need. On behalf of the entire team, thank you for your continued support that allows us to serve individuals with PWS and their families.
Lynne Bird, M.D., Director, PWS Clinic, Rady Children's Hospital at San Diego

Dear PWCF: Thank you so much for participating in our 2010 California Association of Superior Court Investigators conference. Your presentation on Prader-Willi syndrome was very informative.
Yours truly, *CASCI Board and Members*

Dear PWCF: Thank you so much for all your support. All the ladies [are] so happy having the [new] treadmill and the elliptical. It was a big help for all to have it.
Thank you again, *Jowella Chico Care Home*.

PRADER-WILLI CALIFORNIA FOUNDATION

2010 Annual General Education Meeting

November 6, 2010
San Jose Hilton Hotel, San Jose, California

Featuring PWS Experts

Janice Forster, M.D. and Linda Gourash, M.D.

All things Prader-Willi syndrome will be covered
including behavioral and psychiatric interventions

You DON'T want to miss this conference!

Laughter Through Tears:
Creating a Strong, Supportive, Healthy Marriage and Family

Lisa Graziano, M.A., MFT

Part II

As we read in Part I of this series, the four key components of a healthy and strong marriage are a deep friendship, a shared sense of purpose, staying connected with each other, and maintaining shared authority. We learned that despite the extraordinary challenges that having a child with Prader-Willi syndrome presents, if we can strengthen and maintain a healthy marital relationship, raising our child and our family as a whole becomes a much easier undertaking. The trick is overcoming the challenges that face all marriages, and especially those complicated by PWS.

Statistically, most marriages fail within the first seven years. At the same time, most children are born within the first seven years of a marriage, which means that *more than half of kids will grow up in a divorced family*. All children are negatively impacted when parents divorce – even the most civil divorce creates stress – but children with PWS especially need an even *greater* degree of stability, routine and low stress environment. While no couple ever *wants* their marriage to end in divorce, we often place the focus on our marriage at the very bottom of the priority totem pole, underneath all of the things we *have* to do for our child or children. And all too often we view our spouse as just another *cause* of our stress.

But it doesn't have to be this way. If not for the sake of our marriage, then for the sake of our child it behooves us to work *together* with our spouse to create a strong marriage and a supportive family atmosphere. And in the end, once we practice the skills and techniques that will help improve our relationship and place importance, emphasis and value on our spouse and our marriage we will reap the benefits of a mutually satisfying, loving, healthy relationship and strong family.

Common Stressors on the New Family

Each of us reacts to stress differently depending upon our own individual character makeup, temperament, and learned coping strategies. No matter what the circumstances, the birth of a baby is stressful on any marriage. For the parents of a child with Prader-Willi syndrome, the amount of stress each parent feels is compounded by the degree of trauma associated with their baby's delivery and the severity of the child's symptoms. While the couple may share the experience of learning together that their child has a serious medical disorder, each individual may react quite differently. Recognizing and bearing in mind some stressors and coping reactions typically experienced by new parents may help you have a deeper understanding of and more compassion for your spouse, thereby strengthening the intimacy between the couple. It is my belief that *in a loving relationship, it is the responsibility of each partner to take some supportive action when we believe our partner is experiencing a stressor.*

We all empathize with new mothers' lack of sleep, but it is important to remember the new father's lack of sleep as well. Lack of restful sleep keeps *both* parents from reacting as calmly as they might normally.

What follows are very genetic, stereotypic descriptions of stress reactions exhibited by men and women. Regardless of gender, people will exhibit a more typically "male" response or a more typically "female" response to stress; neither response is more "right" or "wrong" than the other.

Men typically react to stressful events by trying to *do* something about them. In order to be in a ready state to "do," whether it be making phone calls, signing papers, speaking with physicians, comforting his wife, men frequently believe they must not allow themselves to become emotional. For many fathers, "doing" is working hard *not* to become emotional. He may fear that turning to his wife and sharing his feelings will cause him to feel too vulnerable and push him over the emotional edge. As a result, he may choose more emotional distance from his feelings and from his wife in order to sustain his ready-to-do-state (to which she may feel additionally stressed by her perception of being neglected, shut out, emotionally abandoned).

Not being able to *do* anything to correct the "problem" can create even *more* stress on a father. He may try various strategies to "fix" things: reassure his wife that everything will be okay (to which she may feel additionally stressed by her perception that he is in denial, doesn't understand the situation at all, and therefore she will have to do *everything* by herself); or he may choose to focus on securing the family's financial and health insurance status by working more hours or more intensely (to which his wife may feel abandoned, overwhelmed, and resentful); or because he may feel afraid to physically handle the baby, he may look for something else *useful* to do such as work more hours, focus on house or car repairs, research the syndrome, etc. (to which his wife may feel additionally stressed by her perception that he is not physically present to help her).

Women typically react to stressful events by wanting to talk it out… literally. Women often feel a physical relief while sharing stressful feelings. New mothers often feel intense feelings of vulnerability and dependency upon her husband and will look for reassurances from him that he will "be there" for her. She may want to talk about her experiences in order to relieve her stress (to which her husband may feel additional stress at the perception he needs to "do" something to help her). Women often expect their husbands to be as solid as a rock and when their husband is not as solid as expected, especially during times of stress, she may feel scared or angry and protect herself by turning or pulling away from her spouse.

Continued on page 16 ...

Laughter Through Tears continued from page 15 ...

Common situations in new families often become intensified when the child has PWS. The demands upon the couple to make constant adjustments and negotiations are intensified; nighttime feeds are not the typical simple nighttime feeds, etc. Post-partum depression symptoms may need even greater and more intense intervention. Maintaining employment and health insurance benefits become paramount and may place even greater stress upon the working spouse.

New fathers in particular can feel intimidated to hold and care for his young infant. He may feel afraid he'll somehow injure his child, either by holding the baby in such a way it will be smothered or receive injury to the neck, or by feeding it in such a ways that it will aspirate or choke. Embarrassed to express his fears or insecurities, he may simply not participate in these activities, to which his wife may react by feeling overwhelmed and exhausted by having total responsibility for the child.

New mothers, whether or not they experience an initial period of feeling incompetent, often develop a sense of expertise over the care of their baby. Already less confident in his own nurturing abilities, the young father's confidence may take more hits when his wife corrects – or worse, ridicules – his caretaking skills. Simply redoing a diaper tells Dad, "You did it wrong. You are not competent" to which he may respond by doing fewer diaper changes, to which she reacts by feeling even more overwhelmed and exhausted by having total responsibility for the child, and so the cycle continues.

Power struggles can develop, especially as couples become more comfortable handling their child or more knowledgeable about the syndrome. It is not uncommon for couples to engage in the Right-Wrong Battle, not only about childcare but about many other aspects of the relationship. More on the Right-Wrong battle in Part III of this series.

These unhealthy patterns may continue for years and overlap onto many other areas within the marital dynamic as the child grows or as more children enter the family.

But all it takes to make a more positive move toward change is for one of the couple to do something different.

Table I on page 17 shows typical stressors experienced by new fathers and new mothers and some possible strategies that can be taken to create a change toward a healthier relationship.

Part III in this series will appear in the next newsletter edition and will look at typical stressors experienced by established families, and, as outlined by Janalee Heinemann, M.S., PWSA(USA) Director of Medical Affairs and Research, sibling issues and other complicating factors inherent in raising multiple children.

Gadget Tips

As we enter the summer months, you may find these cool products helpful.

The Chilly Pad ($14.95) and **The Chilly Dana** ($12.95) by Frogg Toggs are made from a hyper-evaporative material that retains water while remaining dry to the touch. Both of these items are innovative ways to cool down while enduring outdoor heat. When wet, the towels begin to evaporate and cool, providing cool, soft comfort to the user. When it stops cooling, simply re-wet the towel in hot or cold water and wring it out. Within minutes, it's cool again. To purchase these products go to www.chillypad.com

Fatwheels by the Equipment Shop

Serious training wheels for bikes. Built by an industrial machine design company, Fatwheels are rugged and long lasting and use heavy duty pneumatic tires just like those on a bicycle. Fatwheels add great stability to any standard bicycle with solid rear axles. Always wear a helmet and appropriate protective gear while riding.

Equipment Shop was established to bring affordable equipment to families, schools, and agencies to enhance the development of children with disabilities. Everyone at Equipment Shop is glad to be part of the lives of these special kids. For more information visit www.equipmentshop.com or 800-525-7681 EST.

Laughter Through Tears:
Creating a Strong, Supportive, Healthy Marriage and Family

Table I

Typical Stressors on New Fathers	**Strategies Toward Change**	**Typical Stressors on New Mothers**	**Strategies Toward Change**
Lack of rest, lack of sleep.	Nap whenever possible. Be tolerant of a little more mess.	Lack of rest, lack of sleep.	Nap whenever possible. Don't try to do *everything*. Allow for a little more mess.
Feeling helpless to do anything to "fix" the problem or improve the situation.	Be involved in child's daily care and routine to extent possible. Ask wife what would be helpful to her that you could do. Learn about the syndrome. Connect with other fathers.	Feeling exhausted and/or resentful being primary caretaker.	Ask for help from spouse. Be specific about tasks. Express appreciation for help. Don't criticize/correct spouse's care of child. Share thoughts and feelings with others who are good listeners.
Feeling incompetent to care for baby. Believing you may accidentally hurt the baby.	Ask questions! Develop confidence in your childcare skills through practice.	Feeling overwhelmed by medical and therapy schedules	Remind self that things will get easier. Build in as much time as possible to transition from place to place.
Being corrected – directly or subtly – by spouse regarding care or handling of baby.	Calmly assure wife that though you may do things differently than she does, you're not doing them wrong.	Feeling home is "invaded" by therapists, phone calls, well-intentioned relatives who don't understand or "get it."	Screen phone calls. Schedule times during day to return phone calls, make appointments, etc. Protect the off times by not answering or returning calls.
Feeling like an "outsider" in your own family.	Ask wife what you could do that would be helpful to her and for the household. Don't take "Nothing" as an answer!	Feeling resentful of husband's time away from home, still having a "normal life." Feeling socially isolated, alone.	Share thoughts and feelings with spouse. Let him know you are not looking for answers, just a good ear. Schedule brief time away from home when you play and your husband does the Dad thing. Schedule time with girlfriends. When you're gone, presume he will do good job keeping his child safe and entertained. Connect with other parents who have a child with PWS. Join a support group either live or online.
Fear of not being able to provide adequately for family and child's current and future needs, i.e., medical insurance, estate planning, etc.	Work as team to gather information. Don't take on whole task alone.	Fear that the closeness couple once felt toward each other will disappear. Fear that the marriage will suffer.	Tell him how much you need him. Tell him how much you appreciate his commitment to the family. Share your personal hopes and dreams for the future. Listen to his.
Feel jealous of spouse's attention toward baby. Fear that the closeness couple once felt toward each other will disappear. Fear that the marriage will suffer.	Tell spouse when you feel lonely for her attention. Tell her how much you love being with her. Tell her how close you feel to her when the two of you make love. Share your personal hopes and dreams for the future. Listen to hers.	Feeling stressed, angry, etc. at relatives or friends who don't "understand" or "get it."	Create a good support network for yourself and husband. Remind yourself relatives and friends don't know *how* to support you. Calmly continue to educate about the syndrome. Limit/eliminate sharing with people who are not good listeners. Eliminate relationships that are destructive to you or your family.
Blame: Either oneself (especially if child has a deletion or father has prior drug history), or spouse (especially if child has UPD or if mother has prior drug history), or blame the universe.	Join a support group either live or online. Call other parents on the phone. Remind yourself that there is no "cause" of PWS, it just happened and you and your family will do all that you can to create a good family life and build new dreams.	Blame: Either oneself (especially if child has UPD or mother has prior drug history), or spouse (especially if child has deletion or father has prior drug history), or blame the universe.	Join a support group either live or online. Call other parents on the phone. Remind yourself that there is no "cause" of PWS, it just happened and you and your family will do all that you can to create a good family life and build new dreams.
Feeling sad, hopeless about the future.	Negative thoughts promote negative feelings; positive thoughts promote positive feelings. Force yourself to change negative thoughts into more positive ones. Become a "possibility thinker." Create new dreams with your spouse and build them together.	Feeling sad, hopeless about the future.	Negative thoughts promote negative feelings; positive thoughts promote positive feelings. Force yourself to change negative thoughts into more positive ones. Become a "possibility thinker." Create new dreams with your spouse and build them together.

Ride the Wave

by Elizabeth Greskovics

GiGi

It's Christmas in Costa Rica. Our family - ten of us in all - is sharing a rented house on the beach. The water is warm and inviting and the waves close to shore are gentle and playful. All three of our girls love being in the water and try out the surfboard.

GiGi, our oldest of three girls, greets each new day with enthusiasm. She is the first one dressed and is eager for whatever the day holds. Of course she wants to know numerous times exactly *what* the day holds and in what order, but it is her willingness to try and her enthusiasm that we love and appreciate. Give her a day filled with a beach walk, an ocean swim, checking out shops, a boat cruise on the river and scheduled meals and snacks and she will have her day bag packed and lead the charge.

Flash back ten years this April. Weighing just 3 lbs, 4 oz at birth GiGi was delivered via emergency C-section at 31 weeks and spent her first six weeks in the hospital. She now stands at almost 5 feet (tallest in her class) and weighs around 90 pounds. I look back at pictures from her first years and I see the twinkle in her eyes and the playful smile across on her face. I also see the strabismus that was mostly corrected through two eye surgeries and recall the endless appointments and therapies. I reflect on uncertainty and our many questions.

Flash forward to today. GiGi is in third grade in a class with her typical peers. She attends the Resource Room for language arts and math and has speech, occupational therapy and, less often, physical therapy. She loves school and looks forward to it just as much as the snack and lunch we pack each morning. She knows all of the teachers – not just hers – by name and greets them with a hug often asking how their dog is or how their daughter is doing away at school. Genuine and enthusiastic, she keeps the conversation going. And going, and going… "Enough questions GiGi – time to go." The interactions with her typical peers are few. Despite all of the social groups, modeling and facilitators there are no "natural" play dates and I long for the day GiGi has a true friend.

Outside of school, GiGi belongs to a Girl Scout troop. She takes lessons in swimming, gymnastics and yoga. She participates in Friendship Circle activities including the Challenger League seasonal basketball and baseball teams. She has informed me that she would like to take karate (like her friend Cameron Graziano) and horseback riding (like her sister Maya). I think to myself "When? How?" and hope she does not ask again. She also has a keen interest in cooking (we're talking specific ingredients and herbs to enhance the flavor and presentation of a guacamole or piece of fish) and home décor. Never fond of any children's programs or videos, she now enjoys the Food Network, and even more so the House & Garden channel. I am thankful – for my sake!

It's hard to believe it has been ten years since GiGi's birth. Is life with PWS what I expected? Yes and no. How does one know what to expect? It's like surfing the waves in the ocean – whether at home in Manhattan Beach or in Costa Rica. Some days it is lovely and the waves are warm and inviting. Other days the seas are rough. Days when I've been thrown to the bottom of the sea floor trying to remain calm, not gasping for air while I determine which way is up. And days that I've had really good rides that put a big smile on my face.

I can't control the waves or the tides and I am learning to ride each wave as it comes. Yes, the weather forecast helps. Forecast: likelihood of increased anxiety and need for food security. *It's always good to be prepared*. When the waves are too big, don't enter the storm: wait for things to settle down. Swim near a lifeguard. *Learn to ask for help and schedule breaks.* I've also learned that I will probably be learning this all of my life. That I must plan and forecast, but also enjoy each day and take the time to not just ride the waves but *enjoy* the ride.

Our family is convening again for a Sunday night dinner. We try to make this happen weekly – much more regular than a Costa Rica trip. GiGi is the first ready: showered, dressed in a well-thought-out and coordinated outfit with matching jewelry. It's not just that dinner is an occasion worthy of dressing up, it's that GiGi celebrates and appreciates life's "events" – big and small. I am in my uniform sweats, hair in a pony tail. GiGi asks, "Is that what you are wearing?" I quickly put on a nicer shirt, some blush and earrings. GiGi smiles and hugs me. I actually feel a little better, too. For now, I will not think about the appointments that need to be scheduled or the numerous notes I need to send to her "team." I will enjoy this moment, being with my precious husband, kids and family.

MEMBERSHIP ACTIVITY

April-June, 2010

Please note that because we are fortunate to have the majority of our families renew their membership each year and in the interest of space, effective January, 2009 we will no longer list renewing Individual and Family members. We will continue to list all new members and all renewing Extended Family, Family Friends, and Professional Members.

New Individual Members

Marilyn Shimel
Liliana Zepeda

New Auxiliary Members

Jamie Calvert for Ryan Patay
Richard Cortez, Supported Living Staff for Austin Jobe
Dawn French for Ryan Patay
Jeremy Frend, M.D. for Ryan Casey
Janet & Joel Goldberg for Ryan Patay
Gayle Haberman for Ryan Patay
Jennifer Haberman for Ryan Patay
Stan & Barbara Haberman for Ryan Patay
Julie McLaughlin for Ryan Patay
Jen Saliba for GiGi Greskovics
Linda Smith for Ryan Casey
Jeannette Wagner for Ryan Patay

Renewed Extended Family Members

Dolores & Gene Albaugh
Lisa Bonk
Terri Canales
Carina Chaij
Mary Culver
Joseph DiFilippo
Laura & Ray Esau
Suzanne Fluhr & Steve Albelda, M.D.
Mary & William Graziano
Pat Grey
Sandra Hansen
Sharri & George Marich
Betty McBroome
Linda McGee
Carolyn Meyer
Kathleen Minor
Judy & Bob Morgan
Lynn & Chuck Morrow
Lianne & David Noddle
Kathy & Ralph Paige
Stephen Patay
Nancy & Christopher Rohan
Mark Savit
Judy Schlafer
Frances & Dave Sim
Joyce & Norman Smith
Margaret & Bill Spinelli
Celeste & Tom Von Der Ahe

Renewed Family Friend Members

Valerie Gellner
Mel Goldberg & Dolores Horn
Irene & Kyle Kaiser
Nancy & Kim Kaiser
Regina Livingston
Joan & Chuck Partain
Tyna & Ray Triggs

Renewed Professional Members

Jim Burton, Regional Center of the East Bay
Mary Lane Carlson, MPH, RD, Registered Dietitian
Suzanne Cassidy, M.D.
Dan Clark, San Diego Regional Center
Gayle Cronic, Puckett Residential Services
Ida Dacus, South Central L.A. Regional Center
Lynn DeFreece, North Valley Services
Evan Farrar, PWSA (USA) Crisis Counselor
Linda Hamilton, Lee Street Homes
Virginia Kimonis, M.D., MRCP
Ken Krieger, San Diego Regional Center
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Tom Montesonti, Area Board I
Kathleen O'Connell, Pfizer Endocrine Care
Rosary Oliva, Lucky Homes
Pradeep & Sujata Rawate, Rawate's Group Home
Daniela Rubin, Ph.D., CSU Fullerton, Dept of Kinesiology
Joe Tontodonato, The Arc of San Diego
Sara Utsler, North Bay Regional Center
Paul Wurst, Manager, Options in Supported Living LLC

We cannot direct the wind;
we can only adjust our sails.

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

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We work hard to recognize all donors who wish to be recognized. If you do not 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

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Penny Eilders' May 10th birthday
Marie-Claire Leon's May 12th birthday
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June & Bob Reifeiss' Christmas present

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