PWCF News

The Newsletter of Prader-Willi California Foundation

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

July-September, 2010 ~ Volume 20, Number 3

PWCF Wins APX Alarm Gives Back Project Regional Award

Thanks to the many people who voted for PWCF in the national *APX Gives Back Project*, PWCF won $30,000!

The contest began last June when Utah Prader-Willi Syndrome Association president **Lisa Thornton** entered her chapter into the contest's Mountain Region and encouraged PWCF to enter to compete in the Pacific Region. PWCF's Board of Directors immediately approved, and we were off and running encouraging and collecting votes. In total, close to 400 charities received nominations with over 375,000 total votes received since the campaign was announced. Tensions were high toward the very end of the contest as PWCF's one-time healthy lead slipped as our competitor charity increased their votes. In the end, though, families enthusiastically responded to PWCF's constant email reminders and PWCF Secretary **Julie Casey's** continuous Facebook reminders to vote. By only 143 votes, PWCF won $30,000.

Utah PWSA won the grand prize of $100,000!

With these newfound monies, vital programs and services will be completed that will assist persons with Prader-Willi syndrome not only in each organization's home state but throughout the country. PWCF will fund the completion of our new residential staff training DVD, and Utah PWSA will fund several projects, the main one being the completion of their new internet-based software program, Careful Steps, that will detail all the steps of care for a child with Prader-Willi Syndrome, including providing all related PWSA(USA) Gathered View articles, text excerpts, and journal abstracts.

The company who sponsored this major contest is APX Alarm Security Solutions Inc. (www.apxalarm.com), a nationwide full service residential security company that deploys geographically-focused teams of sales representatives and installers to markets around the United States and Canada. APX Alarm was established in 1999 and its customers have access to the broadest and most comprehensive product offerings in the industry. The company has enjoyed remarkable growth, due to its innovative products and strong commitment to their customers. The company's mission and focus: Protecting families. APX Alarm takes this commitment seriously, as the company generously provides assistance and resources to help people in need within the communities they live and work.

APX Alarm Family Foundation President, **Josh Houser** presented PWCF with our winner's check at a news conference held on September 14. It was an extraordinary event, one that reflected APX executives commitment to and passion for supporting charitable organizations like PWCF in our work to improve the quality of life of families. We were thrilled that a number of PWCF family members came to the ceremony to celebrate, as did representatives from the offices of **Congresswoman Jane Harman** and **Representative Jenny Oropeza**. Attendees were treated to an array of appetizers, APX Alarm t-shirts, and a whole lot of celebratory fun!

Thank you, APX Alarms, for giving us the opportunity to raise a *massive* amount of PWS awareness throughout the country and for generously awarding us $30,000. And thanks to all of *you* who helped us win!

In This Issue:

PRADER-WILLI CALIFORNIA FOUNDATION

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Vice-President - Chris Patay

Secretary - Julie Casey

Treasurer - Renee Tarica

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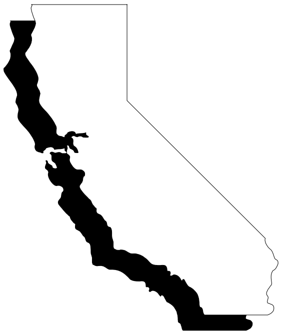


"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families."

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

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

Prader-Willi California Foundation Wants YOU to Win!

Win a Vacation Condo in Kauai
or a Laguna Beach Getaway
or $150!

www.PonoKai.com

1st Prize – *Soft sandy beaches. Warm, soothing winds. Beautiful ocean front views.* All this can be yours! Win seven glorious nights at the Pono Kai Resort located directly across from the beach in Kauai, Hawaii! This gorgeous two-bedroom condo sleeps six and is fully furnished complete with full kitchen, BBQ, swimming pool, and tennis court. Available almost any time of the year, from a Wednesday through Wednesday, or Saturday through Saturday. Approximate value $1,500. Airfare and all other transportation are not included.

2nd Prize – Two nights at *Laguna Riviera Resort on the Beach* in Laguna Beach. Ocean View Room sleeps up to four. Full kitchen, outdoor seating area. Continental breakfast for up to four. Unlimited access to beach equipment, indoor pool and sauna. Single boogie board rental on one day of your choice. Complimentary wired and wireless internet access. Daily/nightly self-parking. All taxes and fees included (winner will not pay any taxes or other fees at check-out). Package valid from 9/12/10–5/27/11. Reservations subject to availability at time of booking and may not be valid during holidays and special event periods. Retail value $521.

3rd Prize – $150 MasterCard/Visa Gift Card

$20 per ticket or 10 tickets for $180.

Sell tickets to family, friends, neighbors and co-workers.

To order your tickets, contact PWCF at 310-372-5053

Net proceeds benefit the programs and service provided by Prader-Willi California Foundation which include education for parents, care providers and professionals, support groups, advocacy services, residential staff training, educational materials, grants to group homes and vocational work sites, camp scholarships, support of multidisciplinary PWS clinics, and so much more.

Drawing will be held at PWCF's General Education Meeting on November 6, 2010 at the San Jose Hilton. Winner need not be present.

Mail-in entries must be received by November 3, 2010. Tickets may be purchased at the General Education Meeting in San Jose, CA. Contact the PWCF office at 310-372-5053 for condo/hotel reservation information. All travel arrangements are the responsibility of the winner. All arrangements are subject to availability and blackout dates may apply. Additional Drawing Tickets available by contacting PWCF. Only official opportunity drawing tickets will be drawn. No facsimiles permitted. Void where prohibited or restricted by law. All federal, state and local laws and regulations apply. There are no substitutions on any prizes. No conversion to cash prizes.

RACE with Us

for Prader-Willi Syndrome

PWCF members **Chris and Jessica Patay** are searching for 5 additional runners ***(all levels welcome)*** and a support crew to participate in the **Ragner Relay Los Angeles.** It is a 200-mile relay race split between 12 runners from Huntington Beach to Coronado Island, San Diego.

WHEN:	**April 2011**
WHY:	**To Raise FUNDS for PWCF and AWARENESS of Prader-Willi Syndrome**
COST:	$100 to register for the race Each runner will be encouraged to raise donations. TEAM GOAL is $50,000!!
WANTED:	**3 Female runners, 2 Male runners, 2 Drivers, and alternate runners, support crew, and more!!**
HOW:	Contact Chris and Jessica Patay for an application: patays@cox.net or call 310-489-6605

We hope that you will consider being a part of this challening and exciting event!

Food Tip

The following food tip was submitted by Wendy Young of Mill Valley

Here's a little food tip for a wonderful snack that is nutritious, delicious, portable, and non-perishable: Sensible Foods "Crunch-dried" snack. Individual packets come in flavors of "Orchard" (apples/peaches/apricots), "Tropical", and "Corn". They contain no added sugar, no additives (as the ingredients list might read: "corn, sea salt, and Nothing Else), are low fat gluten free and less than 85 calories per pack, are Kosher certified and are fun to eat. All our kids beg for them (and I can attest as well they are delicious).

Whole Foods carries them, or you can buy a box of mixed or specific flavor direct from the company on their website http://www.sensiblefoods.com/. Phone 888-222-0170.

Gadget Tip

New Weighted Therapy for Children with Prader-Willi syndrome!

The Miracle Belt™ is a pediatric weighted therapy belt which promotes self-calming, balance, and increased body awareness by enhancing proprioceptive feedback. Within minutes of wearing the Miracle Belt™ your child will feel more grounded, focused, and secure! Therapeutic weighted belts have been found to benefit infants and children with Prader-Willi syndrome and many other diagnoses which cause developmental delays. Using the latest in foam technology we have created the most comfortable, safe, and durable line of weighted therapy products for infants and children with Prader-Willi syndrome.

The Miracle Belt™ is a pediatric weighted belt providing sensory processing benefits for infants and children weighing less than 75 pounds. The Sensory Belt™ is a weighted belt providing sensory processing benefits for children, teens, and adults weighing more than 75 pounds.

Miracle Belt™ is $45.95. The Sensory Belt™ starts at $53.95. Every purchase includes a 30 day Money Back Guarantee. For more information or to order call 888-813-4365 or visit www.miraclebelt.com/prader-willi.html

PWCF does not endorse nor recommend these products. Talk with your child or adult child's physical or occupational therapist about the appropriateness of this product for your loved one.

Executive Director's Column

Lisa Graziano, M.A.

I always look forward to summer. Summer inspires images of fun, relaxation, vacationing, sleeping in, slowing down, and taking it easy. Summer days are supposed to be luxuriously long, followed by even longer summer nights. While my family and I did experience *some* of these states of being, they lasted all too briefly and then, just like that, summer was over and there wasn't nearly enough relaxing or slowing down or taking it easy. And time absolutely did *not* pass slowly. I hope you had more luck extending your summer days into long, luxurious ones!

The passage of time is often all too closely related to the amount of activity and action one submits or commits oneself to. PWCF has been quite active throughout these summer months. Since June, we have been involved in a whirlwind of activity participating in the APX Alarm national charity contest, *APX Gives Back Project*. Who knew at the start of summer that we'd have a giant check hand-delivered to us – and I mean 'giant' in every sense of the word. As you read on the front page of this newsletter many, many people cast their votes for PWCF over a span of many, many weeks and because of their dedication, PWCF won a $30,000 prize! Sometimes it takes but a few to make a huge difference; this time it took many to make a huge difference… along with a whole lot of luck! To each and every one of you who took the time to vote for PWCF in this contest, I extend my personal gratitude. The winnings will fund the completion of the professional residential staff training DVD that PWCF has been working on so hard and for so long under the leadership of PWCF member and past executive director **Fran Moss**. PWCF is extraordinarily grateful to all of our voters, and so very grateful to APX Alarm for sponsoring the contest that helped us win so much money, but just as importantly helped us raise so much awareness of PWS throughout the country!

Our PWS Benefit Concert on July 16 where ***Sandi and the RockerFellers*** played at the **Craneway Pavilion** was a great success. About 100 people attended, almost all of whom had never before heard of Prader-Willi syndrome and now have a much better understanding of the disorder. PWCF is indebted to the band's members **Sandi and Skip Snyder**, **Ken Fisher** and **Art Beringer**, and to the Craneway Pavilion located in Richmond for their *fantastically* fun and generous help to increase the public's awareness of PWS.

Seven families have received a new PWS diagnosis just since last June's publication of the newsletter. Clearly, we are making progress toward educating our physicians about how to recognize the syndrome. We have a long way to go, though as one of those newborns remained in the hospital for months and underwent numerous and probably unnecessary tests before receiving her PWS diagnosis, and another young woman has waited *18 years* for her diagnosis.

Without a doubt, stressors on families are enormous, whether we're just receiving our child's diagnosis or we've been 'In the Trenches' for any length of time. California's dismal financial status only adds additional stressors as families struggle to maintain their jobs. Health insurance benefits are like gold and the sacrifices families make to get or keep them are often enormous. It is so very important to do anything and everything we can to reduce our own stress whenever and wherever we can, as well as do what we can to help reduce the stress on our spouse or partner. Part III of the series *Laughter Through Tears: Creating a Strong, Supportive, Healthy Marriage and Family* is designed to help increase awareness, understanding and empathy of the struggles we are experiencing, as well as provide helpful suggestions to alleviate them.

As the new school year begins it's time once again to prepare all of our child's teachers on the subtleties and complexities of teaching a student with PWS. To help families and educators, inside this edition is an order form to receive the DVD *Understanding the Student with PWS: Strategies for Success*. We're very proud of this DVD which was created under the direction of PWCF member **Michelle Donaldson**.

To assist your teen or adult in their residential setting or place of employment, we've included an order form for the DVD *Food, Behavior and Beyond: Practical Management for the Child and Adult with PWS.* Actually, this DVD is helpful for *anyone* and *everyone* who cares for or comes into contact with someone with PWS, and it is therefore highly recommended to keep at least one copy in your PWS library.

As we've seen over and over, the enormous efforts of a few can significantly benefit the many. We hope such is the case again as PWCF members **Jessica and Chris Patay** coordinate their *RACE with Us* and work toward achieving their established team fundraising goal of $50,000, the proceeds of which will benefit PWCF. Jessica and Chris are recruiting more runners, drivers and support crew members so check out their announcement on page 4 and join in their efforts. Jessica and Chris and the rest of your team, we wish you Godspeed and good luck!

Continued on page 17 ...

Urinary Incontinence in Persons with Prader-Willi Syndrome

von Gontard A, Didden R, Sinnema M, Curfs L.

Radboud University Nijmegen, Behavioural Science Institute, Nijmegen, and Trajectum, the Netherlands
PubMed.gov 2010 Jun 24 http://www.ncbi.nlm.nih.gov/pubmed/20575983

Abstract

STUDY TYPE: Symptom prevalence (non-consecutive cohort) Level of Evidence 3b. OBJECTIVE: To assess and identify the frequency and type of urinary incontinence (UI), as well as associated symptoms in persons with Prader-Willi syndrome (PWS). PWS is characterized by mental retardation, short stature, obesity and hypogonadism. The behavioural phenotype includes eating problems, temper outbursts, affective disorders, stereotypies and speech abnormalities. UI is common in children with mental retardation in general, but has not been reported systematically in children with PWS so far. MATERIALS AND METHODS: The Dutch version of the 'Parental Questionnaire: Enuresis/Urinary Incontinence' was completed by 118 parents of children with PWS. This questionnaire includes items referring to day- and night-time wetting, toilet habits, observable voiding behaviours and reactions, urinary tract infections, stool habits and behavioural symptoms. RESULTS: The rate of nocturnal enuresis in persons with PWS was 13.6% (16) at a mean age of 15.1 years. 3.8% (5) had additional daytime urinary incontinence, and 3.3% (4) had faecal [fecal] incontinence. Lower urinary tract symptoms were commonly indicative of overactive bladder, dysfunctional voiding and postponement. Also, the rate of internalizing and externalizing behavioural problems was high. **CONCLUSION: Urinary incontinence is more common in persons with PWS than in typically developing children, adolescents and adults. As lower urinary tract symptoms are common, detailed assessment and specific treatment of UI should be part of the care of all persons with PWS.**

* * *

Research Subjects Needed

New Clue for Understanding the Hunger of Prader-Willi Syndrome: Research Volunteers are Needed for Further Studies

In the July 2010 issue of *The Journal of Clinical Endocrinology & Metabolism*, Dr. Joan C. Han, a pediatric endocrinologist at the National Institutes of Health (NIH), and her colleagues reported the results of a small pilot study of 13 patients with PWS. They observed that patients with PWS appear to have lower blood concentrations of brain-derived neurotrophic factor (BDNF). BDNF is a protein that is believed to play an important role in controlling appetite and may provide some answers to understanding the insatiable hunger of PWS and other conditions associated with hyperphagia. Dr. Han and her colleagues recently received a grant from the PWSA (USA) to conduct further studies on BDNF, and they are seeking patients with PWS (ages 0-18 years old) for this research. Participation involves providing medical information and a blood sample. For more information, please contact Dr. Han at (301) 435-7820 or hanjo@mail.nih.gov.

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 resistance exercises while wearing a weighted vest, 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 certificates, 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.

Prader-Willi California Foundation
2010 General Education Meeting

The Pittsburgh Partnership

Janice L. Forster, MD & Linda M. Gourash, MD

The Behavior Toolbox

A Cosmic Understanding of PWS:Food & Behavior
Food Security
Sensory Integration
The TRAIN
Low Expressed Emotion
Anatomy of a Tantrum: Optimal Responses
Incentives, Consequences and Common Errors of Behavior Management and Making Changes
Interactive Behavior Workshop
Q&A Panel with the Pittsburgh Partnership
PWCF Business Meeting

Friday, November 5, 2010
Meet & Greet Mixer 7:00 p.m.

General Conference
Saturday, November 6, 2010
8:00 a.m.— 4:30 p.m.

***What's Up Doc?* Dinner with the Speakers**
Saturday, November 6, 2010 6:30 p.m.

Hilton San Jose
300 Almaden Boulevard
San Jose, CA 95110
$109 Reduced Room Rate (plus taxes)
if reservation made by October 6
408-287-2100

PWCF 2010
General Education Meeting
Registration Form

Register online at www.PWCF.org

General Education Meeting Registration

Early Bird Discount: Register by 10/30 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 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 Youth & Adult Program:
Name:_____________________ Age:___ PWS? ○Yes ○No
Name:_____________________ Age:___ PWS? ○Yes ○No
Name:_____________________ Age:___ PWS? ○Yes ○No
Name:_____________________ Age:___ PWS? ○Yes ○No

What's Up Doc? Fundraiser Dinner with the Speakers

Dine with PWS experts Drs. Linda Gourash and Janice Forster after the conference and ask *all of* your PWS-related questions! Reservation fee $150 per diner (includes meal) Space is limited - reserve early!

Dinner choice: [A] Grilled Salmon [B] Grilled Chicken [C] Pasta

Name of Each Diner:
Name:____________________________ Dinner Choice:____
Name:____________________________ Dinner Choice:____
Name:____________________________ Dinner Choice:____

Fee Calculation

Total Amount Due for General Education Meeting: $_________
Total Amount Due for Youth & Adult Program: $_________
Total Amount for *What's Up Doc?* Dinner: $_________
Total Tax Deductible Donation Amount: $_________
Total Amount Enclosed: $_________

Mail Registration Form with check made payable to:
Prader-Willi California Foundation
514 N. Prospect Avenue, Suite 110-Lower Level
Redondo Beach, CA 90277
Questions? Call 310.372.5053 or toll-free in CA 800.400.9994

PWSA (USA) and FPWR Hold Joint Board Meeting

Alice Viroslav, President of the Foundation for Prader-Willi Research, and John Heybach, Board Co-Chair of the Prader-Willi Syndrome Association-USA announced there was a very successful joint board meeting on September 11, 2010 in Washington, DC. The purpose of the meeting was to strategize about the future needs of individuals with PWS, their families, and their care providers, and to identify potential solutions in the areas of both care giving and research. They also focused on how the two organizations can work together to meet these future challenges. The leadership of PWSA and FPWR are excited about the outcome of the meeting and the opportunities it will create to work together to accelerate progress in serving the Prader-Willi syndrome community.

GoodSearch for PWCF

What if Prader Willi California Foundation earned a donation every time you searched the Internet? Or how about if a percentage of every purchase you made online went to support our cause? Well, now it can!

GoodSearch.com is a new Yahoo-powered search engine that donates half its advertising revenue, about a penny per search, to the charities its users designate. Use it just as you would any search engine, get quality search results from Yahoo, and watch the donations add up! Just enter www.goodsearch.com in your browser. Type Prader-Willi California Foundation where it asks Who Do You GoodSearch For?

GoodShop.com is a new online shopping mall which donates up to 30 percent of each purchase to your favorite cause! Hundreds of great stores including Amazon, Target, Gap, Best Buy, eBay, Macy's and Barnes & Noble have teamed up with GoodShop and every time you place an order, you'll be supporting your favorite cause. And if you download the GoodSearch – Prader Willi California Foundation toolbar, our cause will earn money every time you shop and search online - even if you forget to go to GoodShop or GoodSearch first! Add the Prader Willi California Foundation toolbar at:

http://www.goodsearch.com/toolbar/prader-willi-california-foundation

PWSA (USA) Appoints New Executive Director

PWSA (USA) Board Co-Chairs John Heybach and Ken Smith have announced the appointment of **Evan Farrar** as PWSA's permanent Executive Director by unanimous vote of the Board of Directors on August 26, 2010 effective immediately.

Evan is no stranger to the PWSA community. Since being hired as a Crisis Intervention Counselor in the summer of 2007 he has served in a variety of management capacities for PWSA (USA) including as the Acting Executive Director and more recently as a member of the Executive Management Team that has guided the agency for the past several months. These experiences in management of day to day operations at PWSA – alongside his extensive experience working with families through the Crisis Program – uniquely qualifies Evan to lead PWSA (USA) into the future. In applying for the position, Evan identified these strengths he brings to this position: continuity, PWSA experience, an understanding of PWS, knowledge of staff and providers, experience with the international PWS community, professional and personal strengths matching PWSA's current needs for an Executive Director, and an ability to hit the ground *still* running. Most importantly, he wrote:

> *I have a vision for this organization that builds on our past rather than replaces it – a pivotal distinction. We have a proud history. An amazing history, really, as an organization that started small and now has a global outreach which was unimaginable when PWSA was first formed by a few parents desperate for community and support. It is that original vision of effectively serving people and families living with PWS that inspires me to want to step into the role of Executive Director. Through working in our Crisis Program, I've learned firsthand the pain and struggle some of our families experience. But I also know the joy our families experience as well. I will carry this knowledge into every conversation I have, and decision I make, as the Executive Director of PWSA (USA). I believe I am uniquely qualified – at this time – to provide the executive leadership PWSA needs in collaboration with you and others who care so deeply about our mission.*

PWSA (USA) hopes you will celebrate with them the advancement of one of their own staff into this important position. With Evan's appointment as Executive Director PWSA (USA) also looks forward to hiring quickly a new Crisis Intervention Counselor so that PWSA (USA) continues to provide high-quality responsive services to meet the needs of families.

The PWSA Board of Directors thanks members for supporting the work of PWSA (USA). They continue to grow in strength and influence because of members and friends like you and passionate staff, leaders and volunteers who are dedicated to those affected by PWS. Together we will continue to strengthen and develop the mission of PWSA (USA).

I’m No Expert

by Lisa Peters, Massachusetts

I am not an expert at anything.

I am not a fine-tuned athlete with golden trophies lined on a shelf in my living room. Music and art are like foreign languages to me. I am not a banker, a lawyer or a CEO. I have trouble just balancing my checkbook. So when my son Nicholas was born with PWS, I found myself completely unprepared for the job.

Physicians from Children’s Hospital handed me my tiny infant amidst a flurry of complex medical terms. Words like hyperphasia, scoliosis and cryptochidism were thrown at me like icy snowballs hurled from some anonymous attacker. Geneticists and endocrinologists surrounded my bedside like nervous advisors briefing the president on the latest global crisis. Critical medical decisions were now presented to me for immediate answer. Did I want my son to have a tube placed in his nose or stomach? Do I want to consider giving my child growth hormone injections? Here is your list of upcoming doctor appointments.

My role in life was now clearly defined and my son’s precious life depended on it.

My easygoing life was officially over. Treading water was no longer an option. A clear life’s purpose with devastating consequences had been thrust upon me. It was almost as if since I had not bothered to define who I was, God decided to do it for me. And while I wasn’t wearing red spandex tights and leaping tall buildings in a single bound, I suddenly realized that like it or not I had become a superhero.

Suddenly, I could relate to the hardships of the likes of Clark Kent, Peter Parker and Bruce Wayne. These colorful cartoon caricatures now held the key to my success as a parent of a child with special needs. Like them, my new responsibilities felt uncomfortable and overwhelming. It would take me some time to embrace these new found abilities and fine-tune them into helpful skills capable of deterring the most fearsome of foes. My identity as superhero was cleverly concealed under the disguise of a mild mannered stay-at-home mom. And although the future of the world did not rest in my hands, the quality of life for my child most certainly did.

My superpowers are even more difficult than slinging a few spider webs or running faster than a train.

I can thread a feeding tube faster than a speeding bullet.

I understand acronyms like IEP, AFO’s, GH, UPD, CoQ10, ABA, IGF-1, BP-3, FISH and MEM.

I can recall all 11 names and phone numbers of all the 11 specialists we see at Children’s Hospital.

I am able to comprehend complex medical terms in a single doctor’s visit.

I am able to negotiate the harrowing halls of the parking garage at Children’s Hospital in Boston with my eyes closed.

Wielding my magic PWS booklet, I have singlehandedly educated countless ER doctors, dentists, anesthesiologists, primary care physicians and nurse practioners on all the medical complexities of PWS.

I can calculate the number of calories in a lunchtime meal faster than you can say “pass the butter please.”

I can divert a full-blown temper tantrum just by singing a song or asking a question.

I wear an invisible force field perfectly designed to repel thoughtless comments and ignorant remarks like, “I think I have PWS”, “He won’t have it that bad,” or “Just a snack won’t hurt.”

I have a monthly schedule of appointments that rivals the secretary of state.

I can lock a cabinet faster than you can say, “Who was the dope who left it unlocked?”

I spend more time speaking to teachers, therapists, physicians and psychiatrists than I do speaking with my own family members.

I can design an IEP that reads like an owner’s manual.

I can activate my superhero laptop, and like the bat phone to the commissioner’s office, I can instantly connect with fellow superheroes from around the world who share the same evil arch enemy as me.

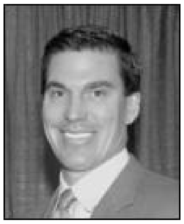
And like the lone superhero misunderstood by the world, I too feel a sense of loneliness that comes from living a life few can understand. I too feel unappreciated for the mentally and physically exhausting role I play in saving a life.

When my son Nicholas was first diagnosed with PWS, I wondered how the world would change his life. What I never realized was just how much his diagnosis would change mine. And while I don’t have shiny blue black hair and ride in the bat mobile, caring for my son has made me a wiser, stronger, more resilient human being. Who just happens to have a new job as a superhero.

Board Corner

PWCF Board of Directors Meeting – July 20, 2010

Summarized by Drew Marich



The highlights of the meeting were:

Relationship with Foundation for Prader-Willi Research ("FPWR")
In early June a member of FPWR contacted PWCF to request that PWCF promote to PWCF members an upcoming FPWR fundraising walk. There was discussion about whether advertising this event represents a conflict of interest with PWCF's fundraising efforts, how any such advertising might be communicated to minimize potential confusion by PWCF members who might think it's a PWCF event, and what, if any, official position PWCF should take with respect to FPWR. A suggestion was made that each Board Member independently research FPWR to get more information in order to discuss again at the next meeting. In the meantime language will be drafted by Lisa Graziano, with Chris Patay's help, which can be sent immediately in response to any information on FPWR events or any other organization that are sent to PWCF members via the PWCFmembers email group to clarify that an event/activity is not PWCF sponsored.

2011-13 Board Candidates Update
On behalf of Kim Morgan, Nominating Committee chairperson, Lisa reported that there are 3 candidates confirmed for 3 spots and 2 additional interested parties who responded to the solicitation in the newsletter. The Nominating Committee is currently contacting the additional interested parties.

Financial Review
Renee Tarica, PWCF's Treasurer, is working with the accountant to finalize the 2009 taxes.

At the next Board meeting Morgan Stanley Smith Barney, PWCF's investment manager, will provide an overview of the Foundation's historical investment performance against key benchmarks.

Fundraising Update
Walking for PWS Events – Lisa presented a report detailing the online Walk donations per location and per solicitor which highlighted that not a lot of people are using the online system. It was noted that many members had difficulty creating their own fundraising page which may be contributing to the low utilization. The Fundraising team will research pricing and features for alternative products and make a recommendation based on their findings to the Board regarding which product to use for next year's Walks.

Alternative Walk Locations in 2011 – The Board discussed alterative sites for the Walks in 2011. Board Member Michael Moore reported on a couple of possible locations in the San Francisco Bay area, including Crissy Field in San Francisco which has a flat location which seemed like a particularly interesting possibility. Mike will continue to research this option to find out 1) if music is allowed (as a band typically plays at the Northern CA Walk); 2) cost; and 3) dates available in April/May. Board Members Michelle Freier and Julie Casey will look into alternative locations for the Southern California Walk, including Griffith Park, Marina Del Rey, Rose Bowl, and Long Beach area options.

APX Family Foundation Gives Back Project Update – Julie updated the Board on the APX Gives Back contest. APX is donating $250,000 to local charities through a Facebook contest. PWCF is currently in the lead for the Pacific Region which would mean winning $30,000 if we can sustain this position through the end of the contest on August 21st.

Raffle Contest – Led by Renee Tarica, PWCF will hold an opportunity drawing contest with the winners selected at the annual General Education Meeting in November. Several Board members have been investigating using the internet to better promote and conduct the contest, but it appears that legal and other concerns will make that not possible. Lisa has taken the lead in drafting the flyer. Prizes include a week at condo in Kauai, a hotel stay in Laguna Beach, and a gift card.

Residential Services Update
Fran Moss updated the Board on the progress of the new residential staff training DVD. She noted that completion of the filming was taking place late in July at a couple of homes.

Grant Requests – The Board denied a request for funding at a home that has only one PWS client resident. The Board approved a grant request for entertainment equipment at a group home. A new letter of agreement has been created for all approved grants.

Regional Center Trainings – The Board is offering to conduct in-service training to Regional Centers around the state by funding Theresa McGrath, a training consultant, to conduct the trainings for Regional Centers that are interested. Lisa is drafting a letter to send to the Regional Centers promoting this training.

Awareness Update
Facebook & Twitter Update – Julie noted that Facebook "fans" have continued to increase since the last meeting and that a Twitter account is still pending. For more information go to www.facebook.com/pwcf1

Continued on page 17 ...

Start the School Year with Powerful Tools!

Order PWCF's DVD *Understanding the Student with Prader-Willi Syndrome: Strategies for Success*, created under the direction of PWCF member Michelle Donaldson.

Strategies for Success provides teachers with an introduction and overview of the issues associated with PWS, and demonstrates and describes pragmatic strategies that school staff can use to support the success of a student with PWS in their classroom. Interview footage with PWS experts and classroom teachers provides a coherent explanation and demonstration of the issues involved in teaching a student with PWS, and various strategies that can be used to support him or her.

Viewers have the choice to watch successful strategies for lower grades or upper grades, allowing the DVD to be most relevant to its audience. This concise production is a user-friendly tool for busy educators, serving to empower and inspire school staff to create their own successful strategies.

Make this DVD available to your child's teachers, related services staff, principal, and everyone else with whom your child comes into contact at school. Request your IEP Team to purchase the DVD to help improve your child's learning, facilitate your child's teachers' ability to teach, and improve the overall efficiency in the classroom.

With each DVD order, you'll also receive the following handouts and brochures:

✓12 Steps to a Successful IEP Meeting
✓Sample IEP Addendum
✓Addressing Food Issues at School
✓Do's and Don'ts When Teaching and Playing with the Student Who Has PWS
✓Information for School Staff
✓Health Concerns and the Student with Prader-Willi Syndrome
✓Food is *Never* OK in the Classroom
✓Helping with Diet Management
✓Positive Behavior Strategies: Tips for Educators
✓Homework… a Lesson in Frustration

Brochures: About PWCF; PWS Synopsis; Food Security at School; Core Therapeutic Interventions; Speech and Language Therapy for the Child with PWS.

Understanding the Student with Prader-Willi Syndrome: Strategies for Success
DVD Order Form

Office Use Only
Date Rcvd: _________
Check #:___________
Date Sent:__________

Please send me ______ DVDs at a cost of $20 each.	$________
Please add $5 shipping fee	$ 5.00
Total Amount Enclosed:	$________

Name: ________________________________ Telephone: __________________
Address:____
City, State, Zip: ____

Mail this form with your check made payable to **Prader-Willi California Foundation** to:
514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277

Questions? Call the PWCF office at 310.372.5053 or toll-free within California at 800.400.9994

DVD Provides Crash Course / Reminder Session on PWS Management Strategies

If you haven't yet viewed this information-packed DVD or if there are new care providers on your child or adult child's treatment team, then you need this DVD! Designed to provide a deeper understanding of PWS and effective strategies to manage many of its behavioral symptoms, this DVD is an *invaluable* tool.

PWS experts Linda Gourash, M.D. and Janice Forster, M.D. provide vital information on such topics as:

Nutritional Basics
Food and Behavior
The Behavior Toolbox
Cognitive and Behavioral Traits
To Medicate or Not to Medicate

Linda Gourash, M.D. is a developmental pediatrician with extensive clinical experience caring for children and adults in medical and behavioral crises related to Prader-Willi syndrome. Janice Forster, M.D. is a child and adolescent neuropsychiatrist with more than ten years experience managing hospitalized persons with complications of Prader-Willi syndrome. Together they are the Pittsburgh Partnership (www.pittsburghpartnership.com).

This DVD should be made available to *everyone* who helps care for your child or adult child, including extended family members, babysitters, Regional Center case workers, residential staff providers, vocational work site employers and staff.

It was updated in 2008 with Spanish subtitles for the benefit of all Spanish speaking parents and providers.

With each DVD order, you'll also receive the following handouts and brochures:
✓Home-Study Examination Note-Taking Guide
✓Home-Study Guide Answer Key
✓Food Security overview created by Drs. Gourash and Forster
✓Brochures: About PWCF; PWS Synopsis

Food, Behavior & Beyond: Practical Management for the Child and Adult with PWS
DVD Order Form

Office Use Only
Date Rcvd: ________
Check #:__________
Date Sent:_________

Please send me ______ DVDs at a cost of $20 each.	**$**________
Please add $5 shipping fee	**$**<u> 5.00</u>
Total Amount Enclosed:	**$**________

Name: ____ Telephone: _________________

Address:____

City, State, Zip: ____

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In the Trenches

Vol. II

by Jessica Patay

Ryan & Jessica

It appears so far that Ryan has escaped "middle child syndrome." Granted, he is only 7 years old, but let's be optimistic. He is sandwiched between older brother Luke, 9 ½, and younger sister Kate, age 5. Each of my children has their own unique place in the family. Ryan receives the benefit of stimulation, modeling, and social play of his siblings, as well as the love, affection, irritation and annoyance.

And yes, these last two—irritation and annoyance—are benefits as well. I have always said that Luke will be a better husband and Kate will be a better wife because they've had Ryan as their brother. They will be better friends, classmates, and citizens because they've come face to face with a brother who is different, disabled, and who does not experience the world and people the same way they do. They will learn early to cope with disappointments: "Why won't Ryan play Legos with me?" "Why can't we go out to eat?" "Why do we have to go to so many doctors' appointments?" "Why can't I/we…?" They will have first-hand experience with tolerating differences and appreciating abilities versus disabilities. Hopefully they will adopt a perspective of gratitude for what they *do have* and what their bodies and minds *can* do.

As a parent who is watching Luke and Kate grow up with Ryan, I am banking on their growing up to be sensitive and compassionate. I'm hoping they can bypass long-standing resentment, anger or bitterness that could be expressed in a multitude of ways. I am hoping they do not grow up jaded or cynical after experiencing some disappointments or hardships in their childhood. I re-read something recently that impacted me, yet comforted me:

"Children don't have problems just because their brother or sister has a disability. They may develop problems if their own special relationships with their parents are interrupted, if their lives are affected by stresses in the family, or if their own childhood is impinged upon too greatly. They will react in different ways depending on their ages, how their lives are affected right now, their own personality styles, and how you behave around them. Brother-sister relationships in typical families aren't perfect, so you shouldn't expect they will be perfect in your family either."

This quote comes from Nobody's Perfect: Living and Growing with Children Who Have Special Needs by Nancy B. Miller, a book I highly recommend to all parents and caregivers of children with special needs. It can be read and re-read as you experience different phases of life.

There are moments when Luke or Kate may complain about Ryan or fight with him. I instantly jump into worry-mode and fear long-term ramifications of their growing up with a disabled and sometimes very difficult and anxious brother. Then my rational and loving husband reminds me, "They're kids. They fight. They annoy each other. They push each other's buttons. Try not to let it push all of yours."

I have syrupy sweet moments, too. And these are the ones I hold so closely and dearly like my kids' school pictures in my wallet. Two stand out in my mind. The first was with my son Luke. He was about 8 at the time. He had just stepped out of the shower and was in our bedroom cozily wrapped up in his towel. Out of nowhere he said, "Mom, I would give my life for Ryan."

I was so shocked but managed to respond calmly, "What do you mean, Luke?"

He said, "If we were on a boat that was drowning and there was only one life preserver, I'd give mine to Ryan."

Where in the world did this come from? What a huge weight he must feel for his brother! I got choked up immediately and hugged Luke and praised him for his amazing heart. (Of course I didn't say, "Oh honey, that would never happen. You do not need to ever worry about something like that…" I wish I would have but I was so stunned I did not think of it.) He's an old soul, my Luke. I affectionately call him my-deep-thinker-deep-feeler-guy. Ryan is so very lucky to have him as his older brother leading the way.

I'm still kicking myself over the other event because I did not record it on our video camera. It was a Sunday afternoon in May this year. My husband Chris was hosing down the driveway and attending to backyard needs. Kate asked if she could put on her swimsuit and run through the sprinklers. She asked Luke and Ryan to join her. Luke was engrossed in his Wii game, but Ryan actually said yes. The fact that he said yes was significant because he'd been in a phase of not wanting to get water on himself. Getting sprinkled or splashed *by* water required a different tolerance than swimming or bathing *in* water. Anyhow, they changed clothes and ran outside into the grass. Back and forth they chased the water waves and each other. At one point Kate turned to Ryan and exclaimed joyfully, "Ryan, lets hold hands!" And he did. Which is a small miracle considering his persistent aversion to holding hands with anyone, including his siblings. They squeezed hands, giggled at each other and ran through the water again and again. Together. Happy. It felt like a blissful *normal* childhood moment. And I said to myself: The kids will be ok. The kids will be ok. And they will.

Ryan may be in the middle, but he is in the middle of the fierce and devoted love of his siblings.

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

Lisa Graziano, M.A., MFT

Part III

As we read in Parts I and II of this series, there are four key components of a healthy and strong marriage: the development of a deep friendship, a shared sense of purpose, staying connected with each other, and maintaining shared authority. It goes without saying that all children need a stable family, but children with PWS are especially in need of stability, routine and a low stress environment to help keep behavioral problems to a minimum. In Part II we reviewed the more common stressors facing the new family who is raising an infant or child with PWS and reviewed strategies to help manage those stressors.

In Part III, we will now focus on some of the more common stressors that the established family faces and offer strategies to help manage these stressors.

Common Stressors on the Established Family

Too often the unhealthy patterns and habits developed in the early years of the marriage permeate other aspects of the relationship. While it can be difficult to alter negative feelings, resentments, patterns of reaction and protection, it can be done. Even if currently out of sight, intimacy, emotional connection and closeness can be resurrected; indeed *must* be resurrected for the sake of the marriage and family.

Daily Demands As the child with PWS continues to grow up it can sometimes seem that there is never a “resting” period before the next “task” or “phase” needs attention. The demands of daily life, the demands of the child with PWS, and the demands of other children may leave little to no energy to do much of anything else at the end of the day. Each spouse may feel completely spent, feeling he or she does the lion’s share of the family’s work, particularly if one spouse has not yet adjusted to the child’s diagnosis and special needs. Couples may find themselves competing with each other for the “Most Exhausted” or “Most Stressed” award.

Mothers often feel overwhelmed with having sole or almost-sole responsibility for the child’s medical, therapeutic, educational and social needs, as well as all things related to running the household – cooking, cleaning, laundry, bill paying, repairs, etc. If there are multiple children, these tasks become intensified. Fathers frequently feel overwhelmed by extraordinary financial pressures, feel a tremendous “pull” to take care of job responsibilities as well as home responsibilities. Many fathers talk about wanting to be home more with their family but not being able to. When either or both parents are also trying to work outside the family home, taking care of all of the family’s needs can quickly become overwhelming and impossible to adequately manage. The marital relationship may very well have taken second, third, or last position on the priority totem pole. “Balance” may be difficult or impossible to find… everything boils down to levels of priority.

Support Issues Lack of an adequate support network can become glaring. There can be real or perceived lack of support from a spouse, from extended family members, or friends. As parents come to learn who is “dependable” and who is not, there can be a “weening” out of friends and family member support. Chronic grief and exhaustion may keep us focused more upon what we’re not getting, making it more difficult for us to see our *partner’s* needs or pain.

Financial Issues Couples may disagree about how much of the family’s resources should be devoted toward the child with PWS. A parent can sometimes erroneously equate how much money or resources their spouse is willing, or not willing, to spend on the child with PWS with how much they love that child. Husbands, typically the main financial provider, often feel overwhelmed with financial stressors, trying to provide not only for the family’s needs and wants today, but also trying to plan and save for the future needs as well, including college education costs, retirement, residential needs for the child with PWS, etc. Blaming and power struggles may become more common.

Childrearing Issues Issues related to the couple’s individual childrearing philosophies and styles may begin to become problematic. It’s not uncommon that one parent perceives the other as being too “soft” on the child and compensates by being “tougher” or vice-versa, causing problems not only in the marital relationship but in the family structure. Soon the child may learn how to “play one parent against the other.”

One parent’s emotional reaction to having a child with PWS may elicit that parent’s “mercy,” prompting the parent not to “push” the child too hard, to just let the child have what he wants, or to cater to the child’s “whims.” This may be in stark contrast to the other parent’s emotional reaction to “push” the child even harder. This dynamic is complicated even more when siblings perceive unfairness.

Sibling Issues Managing the needs of multiple children poses even more challenges. Having insight into some common sibling experiences provides parents the opportunity to proactively help their children understand and manage those feelings. Janalee Heinemann, M.S., PWSA(USA)’s former executive director and current Director of Research and Medical Affairs and a parent herself, provides insight on typical family dynamics where there are multiple children.

Continued on page 15 ...

Laughter Through Tears continued from page 14 ...

Common feelings siblings feel include:

- resentment, guilt, love, jealousy, anger
- a desire to protect
- feeling left out from being told what is going on
- a fear of the disability being contagious or inherited
- embarrassment, compassion, loneliness
- feeling parents love the disabled sibling more
- seeing the siblings disability as a stigma on themselves
- a desire to be "sick" themselves to get attention

Younger Children may be at risk because:

- They have a limited understanding of what is wrong.
- They are egocentric thinkers and wonder "*Will I catch it?" "What will happen to me?"*
- They have magical thinking, i.e. "*It's all my fault because I said…" "Did I cause it?" "Will God make it happen to me if I'm bad?"*
- Their parents are the most important people in their world, and their parent's attention is often diverted to the disabled child.
- In their great desire to please their parents, they may willingly take on too much responsibility.

Pre-Teens and Early Teens are more focused on the following:

- They are much more aware of their sibling's differences and much less willing to be different themselves, thus they are more likely to be embarrassed or ashamed of how their disabled sibling looks or acts.
- They feel guilty for various reasons, e.g. because they are healthy and their sibling isn't; because they resent their sibling; because sometimes they wish their sibling was dead.
- They feel isolated, i.e., "*My parents don't understand me." "My friends don't understand what I have to go through*."
- They are acutely aware of their parent's double standard for their sibling on discipline, chores, achievements, and tolerated behavior.
- They may resent having to "take care" of their disabled sibling.
- They are the least sympathetic and understanding of their disabled sibling at this age - but that's true in "normal" family situations also.

Older Teens often begin to feel more comfortable with themselves and their situation but parents needs to be aware that:

- If the disabled sibling's problems cause too much home disruption and alienation from parents, this is the age when the sibling will "escape" by being away from home a lot.
- Sometimes a parent sees a way to "escape" [and too frequently asks the older teen to babysit or otherwise supervise or care for their sibling with PWS] and expect the teen to become overly responsible.
- They feel a need to "make up" for their disabled sibling by being an overachiever.
- They may question more the justice of why God let this happen.
- They feel a need to protect their sibling from the world.
- They begin to become concerned about who will take care of their disabled sibling if something happens to their parents.

Besides forgiving ourselves for being human, and the siblings also, other steps parents can take after realizing we have done or said something inappropriate are:

- Acknowledge to your child that you made a mistake
- Let your child vent his/her feelings and admit you also have some of the same feelings regarding your child with PWS, or to the situation the disability creates, i.e., "We don't hate Matt [who has PWS] for the problems of living with locked cupboards and refrigerator, but we do hate the syndrome at times."
- Do some problem-solving with your child regarding how you can both deal with the situation, i.e., We decided that although it wouldn't be fair to Matt to allow his sister Sarah to eat in front of him, the compromise is to allow her to snack after he is in bed.
- Find some special time away from *all* your children, so you can come back feeling more refreshed and less sorry for yourself.

Janalee adds, "Although it may be hard to believe at this point in your life, when it is all said and done and the siblings are grown, they will most likely become more loving, responsible, and compassionate than the average adult."

Continued on page 16 ...

Continued from page 15 ...

Creating a Strong, Supportive, Healthy Marriage and Family – Part III
Table of Common Stressors on Established Parents and Strategies Toward Change

Common Stressors on Established Parents	Strategies Toward Change
Fathers often serve as "bad guy discipline enforcer," may "play" less with child/ren. Belief that spouse is "too hard" or "too soft" on child Disagreements regarding childcare philosophies, spanking v. no spanking, etc. Child's behavioral issues related to PWS increasing.	Speak privately with spouse about your concerns. Determine spouse's perception of and motivation for being "hard" or "soft" on child. Explore your partner's goals/dreams for child. Determine partner's philosophies about discipline. Work with spouse to strategize day-to-day disciplinary methods both agree upon. Work toward discipline compromises. Take parenting class together or consecutively if child care is an issue. Share stories with each other regarding family-of-origin child-rearing philosophies to gain deeper understanding of each other. Utilize tag-team approach. Connect with other parents regarding strategies.
Feel like an "outsider" in one's own family. Feel "not enough" for spouse, for family, etc. Feel lonely, isolated, neglected, abandoned by spouse. Fear marital relationship is suffering. Fear closeness couple once felt will disappear forever.	Get more information about spouse's daily activities. If important event is to occur, call to see how it went. Call spouse during the day just to say hi. On drive home from work, focus thinking on spouse and kids. Initiate ritual where hugs are shared as soon as you walk in, before anything else occurs. Share your wish to feel closer. Work with spouse to find/create trustworthy babysitter. Plan a date, or plan a date in your bedroom after the kids are in bed.
Fear not being able to provide adequately for child and family. Fear spending too much income on child with PWS which precludes care of other children or other family goals. Fear how to plan for retirement *and* potential life-long care of child.	Don't take on whole burden of family's financial stability by yourself. Talk with spouse about your concerns. Create a budget together, determine where family can reduce expenses. Create an estate plan and Special Needs Trust.
Disagreement regarding treatment philosophies i.e., growth hormone, sex hormones, supplements, orthotics, etc.	Do as much research as possible with professionals and other parents. Explore in-depth spouse's thoughts, experience, objections, concerns, etc. Work toward compromise if possible.
Guilt	Don't try to "make up for" or overcompensate.
Not enough time alone and/or enjoying activities or hobbies once enjoyed. Feeling emotional and/or socially isolated.	Get back in touch with your preferred activities/hobbies. Schedule play time with girl friends/guy friends while spouse parents in your absence. Express appreciation for spouse's care of kids.
Knowing child has daily challenges and feeling unable to "do" anything to "fix" it.	Remind yourself that by providing a stable, loving home you *are* doing the very *best* for your child.
Feel completely spent, exhausted. Resent partner who appears to have "normal" daily life, free of concern for child's moment-to-moment needs. Feel overwhelmed with daily needs of child/ren, spouse, household chores, employment responsibilities, etc.	Ask for more help from spouse and/or others. Be specific about tasks you'd like help with. Express appreciation for help. Determine if family budget can afford housekeeper. Tell spouse when you're feeling irritable or impatient and ask him/her to be more patient with you. Utilize tag-team approach. Change negative statements to positive ones. Fake it if it feels unnatural.
Feel hopeless about the future: marriage, child, family, etc.	Assess level of depression: Comes and goes? Higher than usual? High level all the time? Share feelings with spouse. Seek professional counseling.
Blaming spouse for our sadness, grief, fear, etc.	Blame helps us manage our sadness, grief, fear, etc. Remember, your spouse is simply a human being who has vulnerabilities, fears, patterns of reaction, etc. No one is infallible. Shortcomings do not make or break a marriage.

Board Corner continued from page 10 ...

Benefit Concert Update – Michael Moore reported that on July 16th the band Sandi & The RockerFellers produced a benefit concert at the Craneway Pavilion in Richmond, CA with the proceeds benefitting PWCF. The net proceeds were minimal, but a great deal of public awareness was raised with more than 100 people attending the concert, most of whom knew nothing about PWS. PWS awareness wristbands and brochures were distributed to all attendees.

Website Update
We are in the process of updating the PWCF website, led by Board member Tom McCrae. We've hired a new web designer and Tom is working with him to design and prioritize the changes to be made in the coming months.

Long Range Planning
The key next step in developing longer term fundraising goals is for the Board to agree on a single long-term objective or project. Over the last two years the Board has explored a number of long-terms goals and has focused the list down to six. Currently the Board is going through a voting process to determine the primary objective to pursue, with the next step to begin doing in-depth analysis of the resources and time required to achieve the goal. The Board will share with the membership at the November General Education Meeting the long-term goal and the high-level plans in place to achieve it.

Executive Director's column continued from page 5 ...

As important as it is to look to the past to observe progress, so too is it important to look ahead to the leadership who will help propel us to accomplish even more goals. This year's Slate of Candidates brings a new and different skill set to the Board. Acquaint yourself with each and cast your vote using the enclosed Ballot. Voting will conclude at the **General Education Meeting on November 6 at the San Jose Hilton**.

And you really do *not* want to miss this year's conference which will feature PWS experts **Linda Gourash, M.D.** and **Janice Forster, M.D.** Check out the meeting's program and use the Registration Form to take advantage of the Early Bird Discount. Make your hotel reservation to stay Friday night and participate in the Meet & Greet before the conference. Stay for the *What's Up Doc?* dinner just following the conference and dine with Drs. Forster and Gourash as you have the opportunity to ask them all of your PWS related questions. Without exaggeration I can safely say that the information that will be presented at this conference is absolutely life-changing and life-enhancing.

Be sure to enter to win a fantastic vacation condo in Kauai, a romantic getaway in beautiful Laguna Beach, or $150 gift card. Each of these prizes was generously donated by PWCF members **Renee Tarica**, **Julie Casey** and **Drew Marich's** company Luxury Link. While I'm absolutely buying my own book of tickets and hoping that *I* am the lucky winner of one of these exciting prizes, I do - although I must admit with some reluctance - wish you good luck as well! And for those of us with a child born with Prader-Willi syndrome, we absolutely know that sometimes, it all just simply comes down to luck.

We Remember

Ashleigh Lininger

10/26/1989 – 5/16/2010

Last Thoughts of Ashleigh
By Christopher Lininger,
brother to Ashleigh

It is time. Time for time.
Time gone for mother's breast and
mother's hand and father's teaching.
The ice cream shops are closing, the toy
stores have the lights off, and it
is too late to go for a walk around the park.
But for you, little sister everything is open.
Open.
For much seemed closed to you in your life, but all you saw
was the opening you created.
Time is open for you now.
The plum blossoms are falling. Each blossom honored life.
You have honored life, little sister.
You have honored us all.
From every question to every smile.
You gave us much. You gave us everything.
And now you take the journey, so take it well.
Know that you are loved. Take your journey well.
"Death is the remedy that all great singers sing of."
Take the new dream, leave your mind in the grass of
your choice, it's all the same.

Those we have held in our arms
for a little while,
We hold in our hearts forever.

PWCF Gets Mail…

Dear PWCF: This is my opportunity to officially thank the Prader-Willi California Foundation's generous gift to the Endocrine [department] at Children Hospital Orange County. As you know, our Prader-Willi clinic continues to grow with many new infants and children this year. Your gift will help us continue to provide comprehensive care to these children and their families.
Sincerely, *Susan J. Clark, M.D., Director, Endocrinology*

Dear PWCF: I would like to take this opportunity to express my deep gratitude for helping me with my financial needs in opening a [PWS] board and care facility here in Orange County. It was indeed a great help! More power on your organization!
Sincerely yours, *Zylnna A. Oliva, New Life Homes*

Executive Functioning Skills

The Council for Exceptional Children defines Executive Functioning (EF) as “the cognitive processes that enable individuals to engage in goal-directed or problem-solving behaviors. Thus, executive functioning may include goal setting or identifying a problem, developing a plan, the ability to execute the plan, flexibility, attention and memory systems to guide the individual (*e.g*., working memory), and evaluation or self-monitoring.”

In an article on the website of the Council for Exceptional Children (www.cec.sped.org), “Executive Function problems can also manifest themselves through behavior problems. Failure to plan, to inhibit behavior despite intentions, and to evaluate can all lead students to act inappropriately, according to Philip David Zelazo, professor at the University of Toronto, in his AboutKidsHealth series on EF. For example, some children may act inappropriately because they do not plan or anticipate the consequences of their behavior. In other instances, children who cannot inhibit their actions may continue to behave inappropriately even when they understand the consequences of those actions; children who have difficulty evaluating may not be able learn from punishment and will therefore repeat inappropriate behavior.

“Specific Executive Function impairments appear to affect particular disabilities. Children with learning disabilities have difficulty with numerous facets of executive function, according to Meltzer and Krishnan. These include self-regulatory activities such as checking, monitoring, and revising when learning as well as weaknesses in cognitive flexibility, sorting, organizing, and prioritizing information.”

Executive Functioning skills appear to be weak in most persons with Prader-Willi syndrome.

The Encyclopedia of Mental Disorders (EMD) notes that executive functions can be difficult to assess directly because they are high-level abilities that influence more basic abilities like attention, memory and motor skills. However, many of the tests used to measure other abilities, particularly those that look at more complex aspects of these abilities, can be used to evaluate executive functions. A person with executive function deficits may perform well on tests of basic attention, but have trouble with tasks that require divided or alternating attention. Verbal fluency tests that ask people to say a number of words in a certain period of time can also reveal problems with executive function. One commonly used test asks individuals to name as many animals or as many words beginning with a particular letter as they can in one minute. A person with executive function deficits may find the animal naming task simple, but struggle to name words beginning with a particular letter, since this task requires people to organize concepts in a novel way.

According to the EMD, “Executive functions are important for successful adaptation and performance in real-life situations. They allow people to initiate and complete tasks and to persevere in the face of challenges. Because the environment can be unpredictable, executive functions are vital to human ability to recognize the significance of unexpected situations and to make alternative plans quickly when unusual events arise and interfere with normal routines. In this way, executive function contributes to success in work and school and allows people to manage the stresses of daily life.

“Executive functions also enable people to inhibit inappropriate behaviors. People with poor executive functions often have problems interacting with other people since they may say or do things that are bizarre or offensive to others. Most people experience impulses to do or say things that could get them in trouble, such as making a sexually explicit comment to a stranger, commenting negatively on someone's appearance, or insulting an authority figure like a boss or police officer; but most people have no trouble suppressing these urges. When executive functions are impaired, however, these urges may not be suppressed. Executive functions are thus an important component of the ability to fit in socially.”

Unlimited Learning maintains a website which contains an **Executive Function Checklist** at http://www.unlimitedlearning.biz/executive_function_checklist.html While copyright laws prohibit us from reprinting the list in its entirety, we have included a few items and encourage you to research further should you find that 5 or more items apply to your child/adult child:

___Cannot stay focused
___Does not learn from consequences
___Has trouble generalizing and applying information
___Is a literal thinker
___Does not plan ahead
___Cannot follow plan
___Poor judge of time concepts
___Has 'in the brain - out the mouth' problems
___Does not inhibit reactions
___Cannot control temper
___Rigid in thinking
___Cannot 'shift gears' when circumstances change
___Tends to blame others for problems
___Uses strategies that have a history of not working
___Overly trusts everyone
___Moody
___Does not do well on tests where application of knowledge is needed
___Only does well on factual tests where questions match the study guide
___Does poorly on tests where questions are re-worded or out of order
___Has trouble maintaining relationships for extended periods of time
___Smokes or uses tobacco products
___Likes or always seems to have conflict in relationships
___Is easily frustrated or angered

Many of these symptoms are also symptoms of many different medical conditions.

Continued on page 19 ...

Executive Functioning Skills continued from page 18 ...

Strategies to Strengthen Executive Functioning

The Council for Exceptional Children states that "executive functioning strategies can—and often are—taught in one-on-one settings or in small groups, some recommend that all students be taught EF strategies in general education classes. "We need to teach executive function strategies so students can plan, organize, prioritize and use their working memory effectively," says Meltzer. "Then students become efficient and successful; their self-esteem improves and their effort becomes more goal-oriented. All students benefit from the strategies, and some students must have them. If we embed the strategies in the curriculum, all students benefit."

"A few models of classroom-based EF strategy instruction are available, including the Kansas intervention model, Benchmark model, and Drive to Thrive, according to Meltzer in her book, *Executive Function in Education*. All of these models share common principles:

Strategy instruction should be directly linked to the curriculum.
- The strategies should be taught explicitly, including teacher modeling and extensive practice.
- Strategies should be taught in a structured, systematic way.
- Strategy instruction should address students' motivation and effort.

Cogmed Working Memory Training (www.cogmed.com) is a computer-based tool to address attention problems caused by poor working memory, one of the executive skills. Cogmed claims to "combine cognitive neuroscience with innovative computer game design and close professional support to deliver substantial and lasting benefits to their users."

On their website, Cogmed provides a checklist to help identify weaknesses in working memory. They note that an individual may be constrained by their working memory capacity if he/she:

1. Is easily distracted when working on or doing something that is not highly interesting.
2. Has trouble waiting his/her turn, for example in a conversation or when waiting in line to get help.
3. Struggles with reading comprehension and has to read through texts repeatedly to understand.
4. Struggles with problem solving that require holding information in mind, for example mental math calculations.
5. Is inconsistent in remembering math facts.
6. Struggles with completing tasks, especially multiple step tasks.
7. Has difficulty remembering long instruction given in several steps, for example following recipes, directions or school/work assignments.
8. Struggles to understand the context in a story or a conversation.
9. Has difficulties when planning and organizing something that needs to be done in separate steps.
10. Has difficulty staying focused during cognitive demanding tasks but attends well when cognitively demands are minimal
11. Has difficulty integrating new information with prior knowledge.
12. When called on, forgets what he/she was planning to say.
13. Has difficulty taking notes and listening at the same time.

For more information about Cogmed Working Memory Training, visit www.cogmed.com

Volunteer Recognition Corner

PWCF recognizes **Cameron Graziano** for his work to mail letters and Support Group meeting notices.

Every day
we decide who we will be
by the actions we take.

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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For 2010 APX Gives Back Project Winner

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MEMBERSHIP ACTIVITY
July~September 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
Kevin Liddiard

New Extended Family Members
Verona Murray

Renewed Extended Family Members
Tod Holdorf
Joyce & Norman Smith

Renewed Family Friend Members
Patrick Maxon
Patricia Morgan

Renewed Professional Members
Julie Tauscher, PRIDE Industries
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Prader-Willi California Foundation is a nonprofit, 501 (c) (3) corporation established in the state of California in 1979. Prader-Willi California Foundation is an affiliate of Prader-Willi Syndrome Association (USA) and shares in their quest to serve individuals and families affected by Prader-Willi syndrome. PWCF's vision is that people with Prader-Willi syndrome may pursue their individual hopes and dreams to the full extent of their talents and capabilities and that we will help them achieve their goals.