PWCF News

The Newsletter of Prader-Willi California Foundation *An Affiliate of*

January-March, 2011 ~ Volume 22, Number 1

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

California *Walks* and RACES for Prader-Willi Syndrome!

This year, California will see *two* major walk and run events that will help raise awareness of Prader-Willi syndrome and funds to support the programs and services that Prader-Willi California Foundation provides to individuals with PWS and their families. First, the **RACE for PWS** will be held April 15-16. This extraordinary relay race is organized by PWCF members **Jessica and Chris Patay.** Read all about it and how you can support the PWS Team on page 7.

Then, PWCF will hold its 11th annual ***Walking for Prader-Willi Syndrome*** events on:

May 1 in Southern California
May 1 in Central California
May 14 in Northern California

New Video & DVD tools make it even *easier* to raise awareness and funds! The new *Walking for PWS* video is now available! This video is set to the song *The Climb*, sung by Miley Cyrus, and was created by PWCF members **Kimberly Storr** and **Lisa Graziano.** You can introduce your potential donors and sponsors to Prader-Willi syndrome and the importance of supporting a *Walk* by referring them to PWCF's website to view the video, or refer them directly to YouTube at www.youtube.com/watch?v=UMr7qGUNZuI or send them a DVD! The DVDs are free with a $5 donation suggested to help offset production costs.

The *Walk* events are fun! Organized exercise-incorporated games, arts-and-crafts activities, face painting, and music to dance to at every event. Meet with other families in an atmosphere of fun, collegiality, and kinship. A hosted picnic lunch will be served in Southern California; bring your own picnic lunch to the Central and Northern *Walks*.

Your support of the *Walk* events is absolutely vital. Invite your extended family, friends, co-workers, your child's therapists, physicians, teachers, employer to support you. Honor someone or a family with a Footprint Sign to be posted along your designated *Walk* path.

Not able to attend a *Walk*? You can still make a big difference! Collect tax-deductible cash, check or online donations. Create your own personalized website to spread the word online. Remember, every time you speak with someone about the *Walk* you're increasing PWS awareness!

Your brochure will reach your mailbox soon, but you can get started today at **www.pwcf.org/WalkingForPWS.htm**

Funds raised through the *Walking for Prader-Willi Syndrome* events support PWS Clinics; PWCF's Camp; PWS group homes; residential and vocational work staff training programs; Support Groups; educational conferences; educational articles including this newsletter, books, brochures, and DVDs; local and national research, IEP and Regional Center advocacy; medical crisis support, and a statewide toll-free line, and so much more. **With your help we will continue to do all that we do!**

WALKING for Prader-Willi Syndrome

Support your loved one, family friend, student, or patient by supporting this year's *Walking for Prader-Willi Syndrome* events!
Have fun, honor your loved one or friend and… *Walk* with us!

In This Issue:

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
Facebook: www.facebook.com/pwcf1

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

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Wendy Young	415-380-0721	wmydmy@gmail.com
Sacramento	Diane Kavrell	530-753-5928	brandon.kavrell@cexp.com

Central California

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

Southern California

Los Angeles County	Lisa Graziano	310-316-8243	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 case-workers, 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 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?

While it can be awkward, there are settings when it can be appropriate to ask (as I've done); "Excuse me, would you mind sharing your child's diagnosis with me?" Worst case, they say "No" but on the few occasions I've asked, I've always gotten a response. After that, it is easy to lead the conversation to Prader-Willi by sharing that "my child has similar physical/emotional qualities, so I was just curious" or something similar. *Linda Ryan, mother of Trevor, age 21*

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There have been occasions when I thought perhaps someone had PWS but I have never approached the parent and asked. I would have to feel *very* confident to do that – and I feel that I can't be 100% certain as many PWS characteristics could be something else. (However, if they had a "Stop the Hunger" hat or t-shirt on, I wouldn't hesitate!) *Elizabeth Greskovics, mother of GiGi, age 10*

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I would not approach the family. As genetic professionals, we often see people in the community who seem to have a recognizable condition but it is not our role to intrude on people's privacy. Just as I would not approach someone who looks like they have PWS, I would not approach someone who looks like they have Down syndrome, achondroplasia or any other condition. Just my thoughts! *Jamie Fisher, M.S., Certified Genetic Counselor, Genetic Medicine Central California*

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This scenario happened to me not too long ago. My son and I were attending a bike camp to help him learn how to ride a bike independently. Every child at the camp had some sort of disability. A young lady walked into the room and my immediate thought was that she has Prader-Willi syndrome. I asked the girl's mother, "Do you mind if I ask what disability your child has?" Her answer surprised me because she said her daughter has Down syndrome. I felt a bit stuck: I didn't want to be any *more* intrusive, but I was pretty sure her child has PWS and by virtue of being given another diagnosis, was not receiving PWS-specific interventions and management strategies. On the last day of camp I decided to offer the mom a couple of PWCF's awareness-raising cool glow-in-the-dark wristbands in hopes she just might check out the website. Whether she ever looks up the information, at least she was excited to wear the wristband for that day and spread a bit more PWS awareness! *Lisa Graziano, mother of Cameron, age 12*

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Funny you should ask, but just last week at UCLA Fitness program clinic for older teens and young adults we had a girl and her mother sit right next to us. She had small hands and feet and the almond shaped eyes and was quite overweight. I almost asked her mother but couldn't get the nerve up. If I ever see them again, I will ask her. So my answer is no. Best Regards, *Renee Lovern, mother of Kim, age 19*

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Yes, I would, without hesitation approach the parent! I actually have done this just recently. In a large Mall here in San Diego, I saw a mom feeding her toddler through a g-tube and of course Hayden was in his stroller (can't walk for long periods of time!). The mom and I made eye contact and we both smiled at each other. I told my sister-in-law, "Watch Hayden. I need to go talk to that Mom." I walked up to her said hello, told her my son is disabled and he had a g-tube for the first 18 months! I asked her if her son had a syndrome. It turns out that her son has liver disease and he is waiting for a transplant. I wished good luck to them and God bless them! I gave her my number and told her if she ever needed someone to talk too, please call. I feel we are all in this journey together, besides you can never have too many friends!!! *Hope Liddiard, mother of Hayden, age* 9

Next issue's Parent to Parent question is, *"What supplements do you find most helpful and how do you determine the correct dosage?"* To submit your response to this question or to send a new question, email, fax or send it to PWCF.

The trail is the thing, not the end of the trail.

Travel too fast and you miss all you are traveling for.

~Louis Lamour
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Food Tip

This food tip was submitted by Linda Ryan of Newhall

I tried **Walden Farms Whipped Peanut Spread** this week, and while nothing will take the place of real peanut butter on an apple, this is actually pretty good in a PB & J sandwich! Use Sarah Lee's 45 Calories and Delightful bread, and Walden Farms calorie free Fruit Spreads and you've got a great sandwich for only 90 calories.

The Whipped Peanut Spread has 0 calories, 0 fat, 0 cholesterol, 0 sugar, 0 carbs, is gluten free, and has a natural fresh roasted peanut flavor.

Walden Farms Fruit Spreads are sugar free, calorie free, carb free, and are sweetened with Splenda. Flavors include Apple Butter, Apricot, Blueberry, Grape Jelly, Orange Marmalade, Raspberry, and Strawberry. Walden Farms Calorie Free specialties are endorsed by the American Diabetes Association.

I purchase mine at Sprout's, but Whole Foods and some Pavilions carry all of these items.

Do you have a Food Tip you'd like to share? Send, fax or email it to PWCF!

Gadget Tip

Submitted by Jennifer and Patrick Jones of Dallas, Texas

Alarms - We've had trouble with our four year old son getting out of his room since he was 2. We've tried numerous solutions to keep him from getting out and into the kitchen without us knowing. We've done some simple things: place something against the door (our son is *very* smart and at 2 years old he would reach out and catch the things against the door before they fell), hang coat hangers and noise makers on the door. Well, we moved to a new house and now his room is all the way across the house. What were we to do? My brilliant husband began looking into alarms, and instead of a doorbell or another noise maker, he found a system that uses the lights in our bedroom to alert us when our son opens his door. The best part is he doesn't even know how we know he's opened his door!

As soon as his door opens, the lights in our bedroom flip on and off which wakes us up and helps us get to him before he makes it down the hallway and out to temptation. Most of the time he just wants to use the bathroom, but this way we know and can prevent any unwanted kitchen time.

It's gone very well and the system seems to be unbeatable as long as we don't lose power. In the event that we *do* lose power in the middle of the night, we have other things in place like locks on the fridge and such, but we want to train him as best we can to *not* go into the kitchen. So, catching him in the hallway is very helpful. The light system can be done for under $500 which, in the long run, is worth the price of keeping our son safe.

Below are some links to the products that can be used. We're really excited about this option and we hope that it helps other people keep their kids safe! My husband is willing to discuss programming the devices with anyone who has questions. Feel free to contact me: jennifer.jones@mayodev.com

ISY Controller
http://www.smarthome.com/12231DB/ISY-99i-INSTEON-Compatible-Automation-Controller-with-Dual-Band-PLM/p.aspx

TriggerLinc
http://www.smarthome.com/2421/TriggerLinc-INSTEON-Wireless-Open-Close-Sensor/p.aspx

Lamp Module *
http://www.smarthome.com/2856S3B/ICON-Relay-INSTEON-Appliance-Module-3-Pin/p.aspx
* - The Lamp Module is the cheapest device you can get to control a light. There are a plethora of in-wall switches, outlets, etc. that can be purchased that can be controlled by the ISY Controller. (There are also more expensive versions of the ISY, but you can do what you need with the one listed above.)

Executive Director's Column

Lisa Graziano, M.A.

Here we are at the beginning of a new year, when all things are possible. Is *this* the year when scientists will discover the heretofore elusive treatment to manage the irrepressible food drive that distinguishes Prader-Willi syndrome? Could this be the year when some pharmaceutical company perfects a medication that reduces the anxiety *and* eliminates obsessive-compulsive-perseverative symptoms *and* smoothes out mood and provides for more emotional stability? Oh, do I ever hope so! And yes, while I do admit to feeling disappointed that more dramatic breakthroughs haven't already occurred, I continue to hope, like you, that the hard work of the past has paved the way for *this* year's exciting new medical breakthroughs.

At the same time, I know that there *have* been advances in our understanding of Prader-Willi syndrome and the development of some very *real* strategies to help parents and care providers in our day-to-day interactions with our loved one with PWS. Some of these advances, strategies, and tools can now be viewed on PWCF's **new DVD*, The Brain & Behavior in Prader-Willi Syndrome*** (see Order Form on page 17) featuring PWS specialist **Janice Forster, M.D.** And I know that this *is* the year that PWCF opens **its new PWS Camp** with Easter Seals' Camp Harmon to *exclusively* serve persons with PWS, providing great *and* safe fun for our special campers and a week of respite for their families (registration forms will be available soon; (see page 11) for more information). I also know this *is* the year we do more outreach to our Spanish-speaking families, and that other important, long-labored-over projects will be completed and rolled out by year's end.

As you will read in the Board Corner, your Board continues to work hard to support existing programs and create new activities that will raise the public's awareness of PWS, that will educate families and professionals, provide advocacy and support services to families, and support research efforts. While the Board works collectively, it relies heavily upon the individual efforts of very dedicated, creative, and enthusiastic people. Many of us tend to believe that there's not much that we alone can do to improve the circumstances of many, but I *know* it is through the efforts of *single* individuals that monumental things happen. I know this because I see it all the time.

"Monumental" like the 200 mile **RACE for PWS** (see page 7) being organized by former Board of Director **Jessica Patay** along with her husband and current Vice President **Chris Patay**. And **Lance Spellman's** vision-come-to-life to create a Turtle Park at a PWS group home in San Diego where residents can interact with and care for these exquisite creatures (see page 13). And there are twenty-two monumentally dedicated individual women who are currently serving as a Parent Mentor for a newly-diagnosed California family who take time out of their own very busy lives to help make the life of someone else just a little less scary.

"Monumental" comes in smaller packages too. It's the $5 donation we receive from someone on a fixed income who sacrifices their limited funds for something they deem greater than themselves. It's the individual who takes the time to write an article for the newsletter to share important information they believe will help other families. As you'll read in *PWCF Gets Mail,* 12 year old **Abraham Hill** is a monumental leader of generosity, as is, I am proud to brag, my own 12 year old son, **Cameron Graziano,** who recently asked me if we were still collecting Shining Star donations, and then promptly handed me all of the $70 cash he had received for his birthday. There are individuals too numerous to list, some going *way* back to the beginnings of PWCF, who make monumental contributions because they *know* the efforts of but a single person can make a world difference.

I can only imagine how hard each and every one of you works for your family and for your loved ones. I applaud you for your efforts and encourage you to take a moment to recognize and acknowledge the efforts of those around you who are likewise working just as hard, though in different ways. And then as we progress through this New Year, I want to encourage you to be ever vigilant for an opportunity where *your* single efforts just might make a world of difference in the lives of other families who are affected by Prader-Willi syndrome.

Now, if we could just accelerate that monumental leap in researchers' discovery of those new medications…

Only those who will risk going too far
can possibly find out how far they can go.
~Author Unknown

The Beginning of a Long Conversation

by Mary Hill

Oscar sits perched on a concrete wall in the shady courtyard of the windowed hospital building. He checks his watch and then leans over into the landscaped border, his lanky limbs splaying at odd angles, and scratches designs onto a gray rock with a stray piece of red bark. I'm hunched over my phone trying to access some conference notes on scoliosis research in people with Prader-Willi syndrome. Our appointment with Oscar's spine specialist is in eleven minutes but my "smart" phone is having trouble accessing the internet.

I've charged Oscar with keeping track of time for me. His watch is his security blanket, helping him bring order to the chaotic world of shifting schedules and revised plans. He's obsessed with time so I call on him to use the watch in appropriate ways whenever I can. Now, when we need to make sure we get to the appointment on time is a good use of his excessive checking. (Later, when he's supposed to be napping, not so much.)

"Mom, eh, eh, we have ten minutes eh eh", he says, flicking his wrist up to within inches of his nose to consult his watch for the fifth time in the three minutes we've been out here.

"Ok, Oscar, thanks." I reply distractedly. The signal is in and out and I'm starting to wave my phone above my head in desperation. I know it won't help, but it makes me feel better.

"What are you doing, eh, eh?" I can tell he's worried we'll be late. His extra "ehs" are some verbal tic that increases with anxiety. The tic and the stuttering cycles that wreak havoc on his ability to get his words out are the two main reasons we're considering returning to private speech therapy.

"Oh, sweetie, I'm just looking for this research I saw about scoliosis and Prader-Willi syndrome to show Dr. Gray."
"Oh", he replies, his brow furrowing with confusion.

"*I* have Prader-Willi syndrome, right eh eh?" he says half to me, half to himself.

His brain does not allow that he might have both. And yet he knows we are here in this hospital every four to six months to check on the twenty-some odd degree S-curve we detected when he was two. He remembers squeezing into a hard plastic back brace for an entire year, until he outgrew it last April and the orthopedist we were seeing for his unrelated bone disorder said he didn't need it anyway. (*That* doctor didn't believe in bracing until thirty degrees or worse. Another one, at a third hospital, thought surgery was the way to go.)

Oscar stops work on his design and looks up past the shimmering windows toward the narrow slice of blue sky to ponder the possibility of having both -- scoliosis *and* Prader-Willi. I can feel his anxiety level creeping higher, but I feign distraction with my phone. Sometimes talking only fuels his anxiety so I'm hoping he'll drop this topic until after the appointment when we're buckled into the car for the hour-long ride home. We can talk then. If he gets too anxious now I won't be able to sneak in that twelve-tube blood draw that we need for his endocrinology appointment next week.

My feigned distraction is no deterrence however. He perseveres.

"So, mom, is Prader-Willi syndrome a *disabled eh eh*?" he asks, sitting up straight now. His voice stumbles awkwardly over the word "disabled". He's not sure it's the right word and I can see in his eyes that he's afraid of the answer.

"Yeah, Prader-Willi syndrome is a *disability*", I respond, looking up to smile reassuringly into his deep brown eyes. I know something about fearing disability. Fear of disability haunted me before I had children. And then, when Oscar was born, I feared him – the floppy baby who couldn't move his head or latch onto my breast. I don't fear Oscar now and I'm sad that he might be starting to grieve his diagnosis.

I'm not prepared for Oscar's next question. "But what do *I* have that's disabled?"

I'm not sure how to answer. My mind races with all the ways in which Oscar already knows he needs extra help. He has a 1:1 aide in school to assist with transitions and sensory breaks and staying on task. His schoolwork is modified for length and difficulty. His food intake is strictly monitored. He works with a learning specialist, two OTs and a speech therapist every week. He still naps for two hours every afternoon. And just a few minutes ago, as we walked into this sun-dappled courtyard, he was talking excitedly about how much he loves math and how his teacher is so good at giving him the right level math for *him*. "It's not the same level as the other kids but it's the right level for me, mom, and it's so fun eh eh."

I realize now that while I use the word disability to describe our circumstances to other people, I've apparently never told Oscar that Prader-Willi syndrome is a disability. I've never referred to Oscar as disabled, not to him or to others. We've always just focused on what he can do. *Dis*ability implies "cannot" to Oscar. No wonder he's confused – we've only ever talked about "can".

I've given up on finding that scoliosis research and am struggling to form an answer to Oscar's question. What does he have that's disabled? What do I tell him now, at age nine? He's probing for the first time and I don't want to gloss over his question.

So I decide to start with, "Remember how I told you that when you were a baby your muscles were really weak?"
"Oh yeah, I remember that," he replies, smiling with relief, assuming there's nothing more to add.

He scoots his bottom off the wall and claps the red dust from his hands. He checks his watch. It's time to go.

Mary Hill is an active member of the Prader-Willi California Foundation. Mary writes about life with PWS on her blog Finding Joy in Simple Things (*www.findingjoyinsimplethings.blogspot.com) and posts on the 27th of every month at Hopeful Parents (www.hopefulparents.org).*

RACE for PRADER-WILLI SYNDROME
April 15-16, 2011
raceforpws2011.com

PWCF members **Chris and Jessica Patay** are raising money for the Prader-Willi California Foundation by participating in the Ragnar Relay Series (www.ragnarrelay.com*)* Southern California race. They are the only team in the race, out of 400 teams, raising money to benefit children and families struggling with Prader-Willi syndrome. Their goal is to raise $50,000!

This race isn't for the faint of heart. It is a 202.2 mile running relay that begins in Huntington Beach and ends on Coronado Island in San Diego. It is an overnight, 24-hour long race consisting of 36 legs split among 12 runners. Each runner will take on 3 legs in that 24 hour period. The shortest leg is 2.4 miles (labeled "easy"!) and the longest leg is 9.6 miles. Each runner will run between 13 and 21 miles. Who is on the Team? These amazingly dedicated and generous people:

Christopher Brown
Paul Hill
Drew Marich
Kimberlee Morgan
Jason Ng (Pacer)
Christine Onufrak
Brad Patay (Driver)
Chris and Jessica Patay (Team Captains)
Andrew Purdy
Jennifer Rinkenberger
Mercedes Rivera
Christian Rollino
Daniela Rubin
Linda Ryan (Driver)

Say the Patays, "This is the first relay race for most or all of our team. It's an invigorating and exciting physical and mental challenge to take on! This is all for the benefit of children and families struggling with Prader-Willi syndrome [who are aided by the] Prader-Willi California Foundation."

For more information, to read the bio of each Team member, and to donate go to www.raceforpws2011.com

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Prader-Willi Syndrome Association (USA) ALERT!

Risk of Stomach Necrosis and Rupture Possibly Related to Chronic Gastroparesis
A Cause of Death from Sepsis, Gastric Necrosis or Blood Loss

Signs and symptoms of stomach necrosis and rupture:

- **Vomiting**
  - Any vomiting is very unusual in Prader-Willi syndrome
- **Loss of appetite** (ominous sign)
- **Lethargy**
- **Complaints of pain, usually non-specific**
  - Pain sensation is abnormal in Prader-Willi syndrome due to high pain threshold; rarely complain of pain
  - Pain is often poorly localized
  - Peritoneal signs may be absent
- **Abdominal/stomach bloating and dilatation**
- **Fever may or may not be present**
  - Temperature regulation is altered in Prader-Willi syndrome
- **Guaiac positive stools** (chronic gastritis)

THESE SIGNS SHOULD RAISE SUSPICION OF STOMACH NECROSIS/RUPTURE AS A POSSIBLE DIAGNOSIS WHICH CAN BE LIFE THREATENING!

History may include:

- **History of binge eating within the week**
  - Hyperphagia and binge eating are characteristic of Prader-Willi syndrome, regardless of whether obese or slim
  - Frequently occurs after holiday or social occasion with less supervision of intake
- **History of gastroparesis**
  - Common in Prader-Willi syndrome, though often undiagnosed
- **Often slim or history of significant obesity followed by weight loss**
  - May leave the stomach wall thinned

For more information call PWSA (USA) at 800-926-4797
or PWSA (USA) Medical Crisis Hotline 941-312-0400

The Individualized Educational Plan

From the National Dissemination Center for Children with Disabilities website www.nichcy.org

When a child receives special education services under the Individuals with Disabilities Education Act (IDEA), he or she must have an Individualized Education Program (IEP). This is a written document listing, among other things, the special educational services that the child will receive. The IEP is an extremely important document in the educational lives of students with disabilities receiving special education under IDEA. The resources listed below will help you learn more about IEPs—what the law requires, what information a typical IEP contains, how IEPs are developed, and so on.

What's the IEP's purpose?
An Individualized Education Program (IEP) is a written statement of the educational program designed to meet a child's individual needs. Every child who receives special education services must have an IEP. That's why the process of developing this vital document is of great interest and importance to educators, administrators, and families alike.

The IEP has two general purposes: to set reasonable learning goals for a child and to state the services that the school district will provide for the child. The IEP is developed jointly by the school system, the parents of the child, and the student (when appropriate).

Who develops the IEP?
The IEP is developed by a team of individuals that includes key school staff and the child's parents. The team meets, reviews the assessment information available about the child, and designs an educational program to address the child's educational needs that result from his or her disability.

To write an effective IEP for a child with a disability, parents, teachers, other school staff — and often the child — must come together at a meeting to look closely at the child's unique needs. These individuals combine their knowledge, experience, and commitment to design an educational program that must help the child to be involved in, and progress in, the general education curriculum — that is, the same curriculum as for children without disabilities. The IEP guides the delivery of special education and related services and supplementary aids and supports for the child with a disability. Without a doubt, writing and implementing an effective IEP requires teamwork.

So…who's on the team? Here's a list, as specified in IDEA, our nation's special education law. Note that the order in which the IEP team members are going to be listed and discussed has nothing to do with their priority on the team, that every member has an equal say and important expertise to contribute.

IDEA (at §300.321) describes the IEP team as including the following members:

The parents of the child*;
Not less than one regular education teacher of the child (if the child is, or may be, participating in the regular education environment);
Not less than one special education teacher of the child, or where appropriate, not less than one special education provider of the child;
A representative of the public agency who is qualified to provide, or supervise the provision of, specially designed instruction to meet the unique needs of children with disabilities; is knowledgeable about the general education curriculum; and is knowledgeable about the availability of resources of the public agency;
An individual who can interpret the instructional implications of evaluation results;
Other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate (invited at the discretion of the parent or the agency); and
The child with a disability (when appropriate).

**** Parents on the IEP Team***
Since the passage of Public Law 94-142 in 1975, parents have been recognized as vital members of the IEP Team. Everyone agrees that parents have an enduring and passionate interest in the well-being and education of their child, so it makes perfect sense that Congress would ensure that parents are represented on the IEP Team, front and center. The school must invite the parents to the IEP meeting early enough to ensure that one or both parents have the opportunity to attend and participate. The notice must include the purpose of the meeting, its time, and location, and who will attend.

Typically, parents know their child very well—not just the child's strengths and weaknesses, but all the little qualities that make their child unique. Parents' knowledge can keep the team focused on the "big picture" of the child; they can help the team to create an IEP that will work appropriately for the child. Parents can describe what goals are most important to them and to their child, share their concerns and suggestions for enhancing their child's education, and give insights into their son or daughter's interests, likes and dislikes, and learning styles. By being an active IEP team member, parents can also infuse the IEP planning process with thought about long-term needs for the child's successful adult life.

Being actively involved in developing their child's IEP is a parent's *right* and a parent's *choice*. This means that the public agency must: notify parents of the meeting early enough to ensure that one or both of the parents have an opportunity to attend [§300.322 (a)(1)]; schedule the meeting at a mutually agreed on time and place [§300.322(a)(2)]; and take whatever action is necessary to ensure that the parent understands the proceedings of the meeting, including arranging for an interpreter for parents with deafness or whose native language is other than English [§300.322(e)].

Continued on page 11 ...

PWS Research

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.

Inpatient Hospitalization & Weight Gain/Loss in Patients with PWS

Laurie Ziliak, a Doctoral Candidate in the School of Education at Oakland City University, is conducting a study of weight gain in people with Prader-Willi syndrome. The objective of this research project is to compare circumstances of inpatient hospitalizations, including admissions into psychiatric units, that could have impacted weight gain/loss in patients with PWS. With your participation, she hopes to document how best to meet the needs of a person with Prader-Willi syndrome while hospitalized. This research project is unfunded. This study was approved by the Oakland City University Institutional Review Board on December 2, 2010.

A questionnaire has been created that asks a variety of questions about the hospitalization(s) of the person with Prader-Willi syndrome for whom you care. You are asked to please complete it to promote the health and safety of individuals with Prader-Willi syndrome. The questionnaire link is: http://www.surveymonkey.com/s/K5FKYZX

For more information contact Ms. Ziliak at (812)499-7230 or lsziliak@hotmail.com. If you have any questions about this study or would like it verified, you may contact her chairperson, Dr. Bart McCandless, by mail at 138 N. Lucretia, Oakland City, IN 47660, by phone at (812) 749-1378, or by e-mail at bmccandless@oak.edu

Steps to Manifesting

by Jennifer Pastiloff

1) Give voice to your dreams. Set your intentions.

2) Write down your goals. Affirm in advance that you already have them. Yes!

3) Thank the universe, in advance, for what you are manifesting.

4) Expect to be delighted! Be in the feeling of what you want to receive.

5) Speak your goals with excitement and joy as if they are already in motion. Keep them fresh in your consciousness daily.

6) Take action on your dreams. Step out of your comfort zone.

7) Trust. Trust is the bridge between your asking and its manifestation.

8) Surrender and let go. Release what is no longer right for you.

9) Say YES! YES! YES! to your dreams and to who you are.

Jennifer Pastiloff, a yoga instructor who practices in Santa Monica and Los Angeles, is the creator of *"Manifestation Yoga": Causing Breakthroughs in Your Life Through Your Asana Practice.* Jennifer is also the number of fan of and aunt to Blaise, a little boy with Prader-Willi syndrome. Jennifer recently expressed to PWCF that in honor of her nephew she is starting a non-profit to provide free yoga to children with special needs.

Yoga helped Jennifer transform her life and she invites you to do the same –and have fun whilst doing so! Her classes are strong and filled with arm balances, inversions and music. She leads workshops and retreats worldwide, including Yoga + Wine
Retreats to Ojai and Tuscany, Italy. She hosts fund raisers and writes for LA Yoga and Elephant Journal. In her classes, she combines her love of words and poetry, music, and the healing arts. Classes are challenging, yet completely personal. Says Jennifer, the *most* important part of her class is having a sense of humor. Her rule of "if you fall you must laugh" is strongly enforced!

To learn more, call Jennifer Pastiloff at 310-926-0172 or visit www.jenniferpastiloff.com.

PWCF 2011 Officers Elected

At its January meeting, PWCF's Board of Directors elected the following persons to serve as this year's Officers and Executive Committee members:

Julie Casey – President
Christopher Patay – Vice President
Julie Tauscher – Secretary
Renee Tarica – Treasurer

Board Corner

Summary of the Board of Directors Meeting on January 29, 2011
submitted by Michael Moore

Board Members Present: Julie Casey, Don Carlson, Tom McRae, Chris Patay, Paula Watney, Michael Moore, Julie Tauscher, Renee Tarica, Drew Marich, June-Anne Gold, MD, and Lisa Graziano, Executive Director. Board members absent: Carl Martens.

President **Julie Casey** called the January meeting to order. The first order of business was to welcome our newly-appointed Board member, **Don Carlson**, who is fulfilling the remainder of **Ken Knox's** term, and newly elected members **June-Anne Gold, MD** and **Paula Watney**. The Board elected the 2011 officers: **Julie Casey** as President, **Chris Patay** as Vice President, **Renee Tarica** as Treasurer, and **Julie Tauscher** as Secretary.

The inaugural *RACE for PWS* to be held on April 15th through 16th, was discussed by **Chris Patay**, with the Board authorizing PWCF as the beneficiary of the proceeds. Details regarding the RACE have been emailed to PWCF members, with a link to Chris and **Jessica Patay's** dedicated-PWS fundraising and awareness website for this terrific event– check it out today at www.RaceForPWS2011.com !

In light of the on-going California state budget challenges, the recent CA Regional Center budget cuts were discussed, with the Executive Committee authorizing **Lisa Graziano,** Executive Director, to fly to Sacramento to attend one or both protest rallies if the opportunity to speak and represent the PWCF membership was determined to be worthwhile. The Board discussed a letter drafted by Lisa to petition our State Legislators not to cut funding to support badly needed state services our constituents currently receive.

Lisa Graziano presented the annual Board Orientation and reviewed for new and existing Board members, PWCF's history, mission statement, policies, procedures, overview of products and services available to members, etc.

Drew Marich led a discussion around long-term PWCF Strategic Planning, including the critical assessment of our 2010 Board goal accomplishments: to create a Residential Staff DVD (currently in editing phase), to re-design an improved website, and to achieve the $100,000+ fundraising goal, which was accomplished in large part with help from the $30,000 winnings from the APX Alarms event! The Board also discussed a phased long-term strategy to make steady progress towards realizing PWCF's BHAG ("Big, Hairy, Audacious Goal).

Regarding public awareness events, **Mike Moore** discussed that while we have had Northern California's Golden State Warriors basketball events the past three years, this year we are exploring the opportunity of having a larger group attend an Oakland A's Baseball game, which would provide a weekend afternoon of family fun on a much more economical basis to families. Another benefit of this venue would be the opportunity for PWCF to place a PWS awareness-raising message on the Oakland Coliseum Jumbo Tron. We are looking at Saturday, August 13th at the 1:00 pm game versus the Texas Rangers as our 2011 PWCF Northern California game date – more details coming shortly!

Julie Casey noted that new PWCF Board communication tools implemented last year are working well, including our dedicated Wiggio Board site, and email voting and polling procedures.

2011 Board Goal Setting and Strategizing was discussed at length, including creating a "PWS Story" DVD and brochure for out-reach, fundraising and public awareness; to apply for and obtain more grants; to scheduling a 2011 Board retreat to achieve an even more cohesive governing Board; to increase outreach to our Spanish-speaking population, including providing the General Education Meeting brochures in Spanish and hiring a translator for the conference; and progress on the BHAG.

Lisa reported on the status of the PWCF Residential Staff training DVD which continues to move forward, but is still some months away from completion. Julie led a discussion around the vision and strategy behind our BHAG with a working draft title of "California Partnership," with all Board members tasked with coming up with three alternative name options by February 28th. The Fundraising Committee reported on the dates for the 2011 *Walking for PWS* events; in Southern California (Van Nuys) on Saturday, May 1st; in Central California (Fresno) on Saturday, May 1st; and in Northern California (Berkeley) on Saturday, May 14th. A *Walk* site in San Diego is still in the planning stages. Mike reported on potential new locations for the 2012 Northern California *Walk*: West Bluff Amphitheatre, Western Triangle, and Crissy Field in the Golden Gate National Park directly adjacent to the Golden Gate Bridge! This location was not available for our 2011 Walk date of May 14th.

Lisa gave a brief update on the new PWS Camp and proposed camper scholarship options for the Board's consideration. A motion was made to authorize $15,000 for camp scholarships and subsidies for PWCF members (up to $227 scholarship per PWCF member -in-good-standing), with the scholarship approval policy guidelines to be determined.

The 2011 PWSA(USA) Scientific Conference will be held on November 11th followed by the General Conference from November 12th -13th, both in Orlando, FL. PWCF's General Education Meeting is scheduled for Saturday, November 5th and will be held in Southern California.

Continued on page 11 …

Board Corner continued from page 10 …

Tom McRae reported on the PWCF Website re-design, with Ryan Delane owner and consultant of Website Maintenance and Design, making a brief capabilities presentation to the Board. A motion was made to authorize up to $5,000 for Ryan to re-design our website.

A Residential Facilities update was submitted by **Fran Moss** in a report in absentia.

Renee Tarica, Treasurer, reviewed all 2010 Smith Barney Financial and Investment statements, as well as the draft 2011 Operating Budget.

PWCF's PWS Camp at Easter Seals' Camp Harmon!

July 27 – August 2, 2011

Boulder Creek, California located in the Santa Cruz Mountains
Serving persons with Prader-Willi syndrome ages 8-65 years

http://centralcal.easterseals.com/site/PageServer pagename=CACN_PS_campharmon

Cost: $726; Camp Scholarship available to PWCF Members in Good Standing to reduce costs to $500.

Applications will be mailed and posted online soon. If you haven't already informed PWCF that you are interested in attending the new PWCF Camp, please let us know. For more detailed information, please contact the PWCF office.

Can you sponsor a camper who cannot afford to attend camp? Please let PWCF know!

*PWCF thanks **Linda Ryan**, Chair of the camp project, and **Patricia** and **Don Carlson** for their continued hard work on this important project.*

IEP Continued from page 8 ...

When is the IEP developed?
An IEP meeting must be held within 30 calendar days after it is determined, through a full and individual evaluation, that a child has one of the disabilities listed in IDEA and needs special education and related services. A child's IEP must also be reviewed at least annually thereafter to determine whether the annual goals are being achieved and must be revised as appropriate.

What Information Should Be in Your Child's Individual Education Plan?

Your child's IEP should contain the following statements:
Present levels of academic achievement and functional performance. This statement describes how your child is currently achieving in school. This includes how your child's disability affects his or her participation and progress in the general education curriculum.

Annual goals. The IEP must state annual goals for your child, what you and the school team think he or she can reasonably accomplish in a year. The goals must relate to meeting the needs that result from your child's disability. They must also help your son or daughter participate in and progress in the general education curriculum.

Special education and related services to be provided. The IEP must list the special education and related services to be provided to your child. This includes supplementary aids and services (e.g., preferential seating, a communication device, one-on-one tutor) that can increase your child's access to learning and his or her participation in school activities. It also includes changes to the program or supports for school personnel that will be provided for your child.

Participation with children without disabilities. The IEP must include an explanation that answers this question: How much of the school day will your child be educated separately from children without disabilities or not participate in extracurricular or other non-academic activities such as lunch or clubs?

Dates and location. The IEP must state (a) when special education and related and supplementary aids and services will begin; (b) how often they will be provided; (c) where they will be provided; and (d) how long they will last.

Participation in state and district-wide assessments. The state and district give tests of student achievement to children in certain grades or age groups. In order to participate in these tests, your child may need individual accommodations or changes in how the tests are administered. The IEP team must decide what accommodations your child needs and list them in the IEP. If your child will not be taking these tests, the IEP must include a statement as to why the tests are not appropriate for your child, how your child will be tested instead, and why the alternate assessment selected is appropriate for your child.

Transition services. By the time your child is 16 (or younger, if the IEP team finds it appropriate for your child), the IEP must include measurable postsecondary goals related to your child's training, education, employment, and (if appropriate) independent living skills. The IEP must also include the transition services needed to help your child reach those goals, including what your child should study.

Measuring progress. The IEP must state how school personnel will measure your child's progress toward the annual goals. It must also state when it will give you periodic reports on your child's progress.

To learn more about these and other components of the IEP visit www.nichcy.org/EducateChildren

Prader-Willi Syndrome Association (USA)
Growth Hormone Treatment and Prader-Willi Syndrome

- Clinical Advisory Board Consensus Statement, June 15, 2009 -

Growth Hormone Treatment and Prader-Willi Syndrome

Since the commercial release of recombinant human growth hormone (GH) in 1985, therapeutic use of this medication has been studied in a variety of medical conditions and genetic syndromes. Based on current medical knowledge, the Clinical Advisory Board of the Prader-Willi Syndrome Association (USA) has drafted and approved this policy statement to guide health care providers in the use of GH treatment in individuals with Prader-Willi syndrome (PWS). Currently, 60% of the individuals in the PWSA (USA) database are receiving GH therapy.

Current considerations regarding the use of GH treatment in PWS can be divided into the following categories:

1. GH treatment of infants/children with PWS to improve body composition abnormalities and improve linear growth
2. GH treatment of adults with PWS to improve body composition abnormalities and improve bone mineral density

Numerous studies indicate that GH deficiency occurs frequently in children with PWS and that treatment with GH is efficacious in improving the growth and body composition of these children[1-4]. GH should not be a substitute for appropriate nutritional intake and physical activity.

GH treatment is FDA-approved for individuals with PWS. It is well-recognized that GH deficiency is a part of PWS and that provocative testing for GH deficiency is **not** indicated for children with PWS because: 1) the results can be influenced by obesity; 2) different testing protocols give widely discrepant results; 3) the diagnostic boundary for normal/abnormal GH result in response to testing is still debated; and 4) there is no ideal testing protocol.

GH Treatment of Infants and Children with PWS

Multiple studies have documented the benefits of GH therapy in individuals with PWS, including, but not limited to, improvements in lean body mass, decreased body fat, increased bone mineral density, and normalization of adult height[1-5]. Further, GH treatment in infants and children with PWS has been shown to improve strength, agility, and motor development. Treatment with GH has also been shown to positively affect nitrogen balance and increase energy expenditure in individuals with PWS. Moreover, GH treatment may help preserve lean body mass during caloric restriction. There is evidence that beginning GH therapy prior to two years of age is beneficial because of the positive effects of this treatment on mental and motor development[6-8].

The risks and benefits of GH treatment should be thoroughly discussed with the child's parents or guardians before making a decision to treat. At the same time, it should be stressed that GH therapy is only one treatment tool for their child and should be used in conjunction with appropriate nutritional intake and physical activity. GH treatment should not be viewed as a substitute for diet and exercise.

Treatment should commence using standard dose guidelines (0.18 – 0.3 mg/kg/week) given as a daily subcutaneous injection with careful monitoring of clinical status at regular intervals. Standard GH treatment includes dose initiation and adjustment based on weight. However, there is some evidence that lean mass is a better indicator of GH requirements and, therefore, monitoring clinical growth and IGF-1 levels is helpful in determining dose adjustments. The Clinical Advisory Board recommends that the GH dose in children with PWS be adjusted on an individual basis rather than by specific criteria. Clinical monitoring should include nutritional status, height, weight, and head circumference measurements; calculation of growth velocity; bone age; physical examination; and measurement of IGF-1, glucose, insulin, and thyroid hormone levels, as well as ensuring adequate nutrition for growth and brain development. If feasible, assessment of body composition is also helpful.

Children with PWS have an increased risk for spinal curvature abnormalities, including scoliosis and kyphosis. In general, these findings may first become apparent or more rapidly progress during periods of rapid growth. There is no evidence that GH itself causes these abnormalities[9]. *Children with PWS, whether or not they are treated with GH, should receive a careful back examination at least annually.* The decision to initiate or continue GH treatment in a child with spinal curvature abnormalities should be made in consultation with an endocrinologist and an orthopedic surgeon experienced in PWS, and after full discussion with the child's parents or guardians.

Children with PWS are prone to developing obesity and its associated complications, including glucose intolerance and type 2 diabetes mellitus. GH may induce insulin insensitivity. Therefore, children with PWS and GH deficiency should be carefully monitored for signs and symptoms of glucose intolerance during GH treatment, particularly if they are massively obese (e.g., >200% of ideal body weight) or have a family history of diabetes mellitus. Routine biochemical screening tests may include fasting blood glucose, urine glucose dipstick or HbA1c. If diabetes mellitus occurs as a result of GH therapy, the GH treatment should be stopped. If treatment is restarted, the dose of GH should be substantially reduced. If glucose intolerance occurs with GH therapy it can typically be treated with an oral hypoglycemic agent, such as metformin.

Continued on page 13 ...

Growth Hormone continued from page 12 ...

Children with PWS have an increased prevalence of respiratory dysfunction, which may be related to obesity, hypotonia, or central respiratory drive abnormalities[3,10]. Careful history and assessment of respiratory abnormalities should be evaluated prior to and during GH therapy. Individuals with sleep apnea, either before or after beginning GH therapy, should be evaluated by a pulmonologist, otolaryngologist, and gastroenterologist to determine if:

1) The apnea is mild or central in origin (in which case GH is not contraindicated).
2) If the apnea is severe and obstructive in origin, this needs to be addressed before GH is initiated.
3) There are confounding pre-existing conditions, such as morbid obesity, upper respiratory tract infection, adenoid/tonsillar hypertrophy, or gastroesophageal reflux that may exacerbate sleep-disordered breathing. In addition, some groups recommend that individuals with PWS have overnight polysomnography before and ~ 6-12 weeks after beginning GH treatment[10] and if there is any worsening of clinical symptoms while on GH therapy.

GH Treatment of Persons who have Achieved Final Height and Adults with PWS

Recent studies indicate that adults with PWS also benefit from GH replacement therapy, with improvements in body composition, bone mineral density, and exercise capacity[11,12]. Treatment doses are typically started at 0.2 mg/day and increased by 0.2 mg increments as necessary to maintain IGF-1 levels within the normal range for age and sex. The prevalence of GH deficiency in adults with PWS is not well-documented, but the problems surrounding provocative testing for GH deficiency are the same as described above for children. However, at this time in the U.S. insurance companies still require documentation of GH deficiency by provocative testing in adults with PWS.

For the list of References, please contact the PWCF office 310-372-5053

Arc of San Diego Creates Turtle Park at Corte Maria Group Home

The Arc of San Diego empowers individuals with disabilities by creating opportunities to achieve their individual goals, thus providing them the opportunity to live a full and gratifying life. The Arc has a dozen 24-hour residential care homes, two of which serve people with Prader-Willi syndrome.

Recently, inspired by house manager Lance Spellman's vision, Arc created a Preservation for Education at their home in Chula Vista that serves adults with PWS, becoming the host location for all of their agency's participants to learn about life preservation and actively participate in physical education. In the home's backyard, they created a Turtle Park, fulfilling their vision to rescue two to three California Desert Turtles from the San Diego Turtle and Tortoise Society to create a proper preservative environment for them. The Turtle Park is a place where all of their residents will experience the joy and personal fulfillment of caring for something that is alive and maintaining on-going care for this living being. Many residents have a difficult time with their own daily care, and Arc believes that caring for a rescued turtle on a daily basis will help them better understand the fundamental concept of regular personal care. In addition, studies suggest that caring for and interacting with animals has a therapeutic impact and reduces loneliness in residents of long-term care facilities. Taking care of the turtles will give these Chula Vista residents a great sense of purpose as turtle care will be incorporated into the daily chores and duties of the residents. In addition, residents from the Arc's other 11 group homes will visit the Turtle Park and become educated about how to care for the turtles, preserve their lives and maintain their physical environment – all skills that are directly transferrable to the independent living skills and skills of daily living that Arc impresses upon their group home residents on a daily basis.

The Chula Vista home is also working to create a garden consisting of local flora and fauna such as dandelions, rose and grape leaves. They also planted and will cultivate their own home grown vegetables such as zucchini and summer squash which are essential to the desert turtles' nutritional wellbeing. Beyond the obvious purpose of providing a source of food for the turtles, the garden also serves as a vehicle through which the group home residents will learn the fundamental of horticulture. A secondary purpose of the garden is to create the opportunity for the group home residents to be involved in the tangible aspects of creating something that is alive and nurturing it as it grows and thrives.

Unfortunately, most people who live in a group home do not have the opportunity to have children of their own and Arc believes that their group home residents will be given the chance to generate a bond with a creation of their own, develop the garden over the course of time, and enjoy a sense of accomplishment as it matures.

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

Our Healthy Siblings – The Neglected Population

by Janalee Heinemann, M.S., Director of Research and Medical Affairs, PWSA(USA)

Author's Note: The following was written [more than] sixteen years ago, but sibling issues have remained the same. Recently, the following article was read by a couple of young mothers who did not know we had this information on siblings. They requested we reprint this article and also inform our readers of the sibling booklet Sarah and I wrote for younger siblings, *Sometimes I'm Mad – Sometimes I'm Glad*. It is primarily for ages 4-14.

Last week, while going through old mementos, I came across a Christmas card from our daughter, Sarah, written when she was in third grade. She is now 12 years old and a sibling to 13-year-old Matt, who has Prader-Willi syndrome. Included in the card was a list of jobs she would perform as a gift to us. Between the usual (1) I will clean my room and (4) I will take Lambi for a walk daily, was (2) I will help when Matt has a tantrum and (3) I will help keep food away from Matt. What seemed like a normal life to Sarah at age 8, was *far* from normal for the average 8-year-old. Now that Sarah is 12, she is much more aware and sensitive to what her peers view as OK and not-OK, plus there is nothing more important to a 12-year-old than to be just like the other kids. When your cupboards and refrigerator are locked, and your brother's behavior is "weird" and embarrassing at times, it is hard to be comfortable in these situations with your peers. Sarah recently told me of an incident on the bus where a Special-Ed school bus went past theirs. The boys on her bus began making fun of the children on the Special-Ed bus and mocking them. Sarah said, *"I was mad at them and wanted to say, 'Stop it! How would you feel if someone did that to you?' But, I didn't because I was afraid they would turn on me and make fun of me because of Matt."*

As a professional, I worked with families of children with cancer. Their sibling dilemmas and problems are very similar to our PWS siblings and most siblings of children with developmental disabilities. The unique issues to our PWS siblings are the weight and behavior issues. Since Sarah and I wrote the PWS sibling book, *Sometimes I'm Mad and Sometimes I'm Glad* [more than] five years ago and geared it as reading for younger siblings, I would like to focus here on the commonalties of siblings of all ages in situations of disabilities.

I find that there are a myriad of feelings for siblings: resentment, guilt, love, jealousy, anger, a desire to protect, being left out and isolated, a fear of the disability being contagious or inherited, embarrassment, compassion, and loneliness. Other issues I hear from siblings are that the parents love the disabled sibling more, seeing the sibling's disability as a stigma on themselves, and a desire to be "sick" themselves to get attention. I asked Sarah if I missed any feelings and she said, "Sometimes you just feel downright miserable." There is frequently a mixture of all of these feelings, with some surfacing stronger at times. The strength of the feelings and how your child will overtly act or react is often age related.

YOUNGER CHILDREN may be at risk because:
(1) They have a limited understanding of what is wrong.
(2) They are egocentric and wonder "*Will I catch it?"; "What will happen to me?"*
(3) They believe in 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?"*
(4) Their parents are the most important people in their world, and their parent's attention is often diverted to the disable child.
(5) 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:
(1) 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.
(2) 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.
(3) They feel isolated i.e. "*My parents don't understand me."; "My friends don't understand what I have to go through*."
(4) They are acutely aware of their parent's double standard for their sibling on discipline, chores, achievements, and tolerated behavior.
(5) They now may resent having to "take care" of their disabled sibling. I find that during this age period, they are the least sympathetic and understanding of their disabled sibling – but that's true in "normal" family situations also.
This is an all-too-long phase when you pray your kids will grow out of it before they kill each other! Even at this "worst of ages" though, siblings have a strong bond. The same 12-year-old brother who, over a minor issue such as which TV program to watch, will shout, "I hate him. I wish he were dead!" will also be the first to hotly defend his brother if a group of peers pick a fight or make fun of him.

Continued on page 19 ...

In the Trenches

Vol. 4

by Jessica Patay

"I am your mother, the first mile of your road." ~Kelly Corrigan

Ryan & Jessica

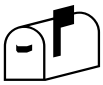
I run a marathon every week. Actually, my life is an ongoing marathon. And so is yours. As parents or caregivers of a child or adult child with Prader-Willi syndrome, we put in miles upon miles as we expend so much of our physical, emotional, and mental energy weekly, sometimes daily. The tenacious spirit, perseverance, and endurance that is required to train for and run a 26.2 mile marathon is what is required of you and me.

We crossed the "starting line" of our marathons when we first "knew something was wrong" with our baby, toddler, or teenager. Although our marathons don't quite have a finish line, we do have mile markers. Our children have mile markers and so do we, and sometimes the difference between the two are completely blurred. Some of Ryan's past mile markers were when his G-tube was removed and I could give him a bottle only. No more carrying around the IV pole, tubes, and syringes, along with formula and bottled water. His lips, tongue, mouth and jaw were finally strong enough to take in the milk and baby food his low-tone body needed. Another famous mile marker was Christmas Eve, 2005, when Ryan, at age 2 ½, was able to stand up, take my husband Chris' and my hands, and walk from the family room to the dining room. Five seconds of pure bliss. The crowd (my family) hooted and hollered from the sidelines with tears falling out of their eyes. Since then there have been other mile markers like Ryan recognizing his printed name, and subsequently learning to write his name. Despite how terribly he grasps a pencil, we celebrate he can write his name. Finally. And someday he will be able to actually read the books he obsessively looks through for hours at a time.

As Ryan accomplishes his mile markers, they feel like my own. Because I was the one who was watching and waiting, teaching and coaching, hoping and praying, that with each baby step of progress, he would reach his finish line. One of a thousand finish lines to be crossed. As a mother of a child with PWS, I have my own personal mile markers: 1) Getting through a day without losing my patience over Ryan's incessant questions; 2) Establishing a strong behavior program at school; 3) Resolving marital issues to maintain a close, unified relationship with Chris, despite our stress levels; 4) A proud moment when I've chosen to remain quiet and composed when I want to scream at Ryan (or any of my kids…). And for me, I too, have many finish lines yet to be crossed.

Runners feel like they are in a special universal club of runners. When we pass each other on the street during a run, we nod our heads, make eye contact, smile, say hello, wave, or any other friendly gesture. "We know in our know-ers" how incredible it feels to run, to hit the pavement, to sweat and hurt, and to accomplish mile after mile. Well, parents of children with special needs are also in a universal club. Together. We know the heartache and the blessing. We know the triumphs and challenges. We know the sweat and hurt and sore muscles of our ongoing marathons. When I pass another parent with a disabled child, I always try to make eye contact and smile. They have their unique marathon and I have mine.

PWCF Gets Mail…



Dear PWCF: It is with great sadness that I relay the news my brother Mike (Hi-tops the clown) died December 6th in his sleep from a seizure. He was a great clown and brother! He will be missed deeply. I plan to continue on the Swan Bros Circus name performing as a tribute to him-- the show must go on. *Andy [Andy and his brother Mike provided entertainment at the Youth and Adult Program at the 2010 conference in San Jose]*

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Dear PWCF: THANK YOU so very much for your continued support of the PWS clinic. It seems like it keeps getting harder and harder to make ends meet in a private clinic practice. I feel very honored to be able to offer such a quality clinic to our patients and we couldn't do it without your support. I'll look for the grant check in the mail. Again thank you! Sincerely, *Jamie Fisher, M.S., Certified Genetic Counselor, Genetic Medicine Central California*

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Dear PWCF: We allotted a small sum of money to each of our three children to distribute among charities of their choosing. Your organization was chosen by one of them. We hope this small donation will be helpful to you! *All the best, The Hill Family*
This note was accompanied by a handwritten note that read, "I chose this foundation because I have a brother with Prader-Willi syndrome and it can be hard for me sometimes even though I understand why he acts certain ways." *Abraham Hill age 12*

Understand the Motivations Behind Misbehavior

by Lisa Peters of Massachusetts

My son Nicholas had always been an adorable boy, calm, passive and always friendly. When he turned 5 he entered an adapted kindergarten program, complete with a teacher trained in handling children with special needs. I was thrilled that we seemed to find the perfect environment for Nick and looked forward to his participation.

Suddenly, without warning it seemed, my adorable little boy turned into a monster. He was hitting the teacher and other students. He was tantruming in the classroom and refusing to be compliant in any way. He was in trouble and I had no idea what to do. Even the teacher, skilled in special needs teaching was somehow stumped.

Thankfully, we had a Special Needs Director who wouldn't give up. She was determined to get Nicholas, the teachers and us the help we all needed. She found a Behavior Specialist familiar with PWS (a miracle, I know). He very quickly came to the school and did nothing but observe Nicholas and his interactions at school. He watched, he listened and he recorded all that he saw throughout the day.

After his observations, he recorded all his information into a Functional Behavioral Analysis (FBA) and met with all of us to review his results.

What he discovered was eye opening and somewhat sad since I believed that there was something seriously wrong with my son. What I discovered was there was something seriously wrong with the way we all were treating him. Since children diagnosed with PWS have many physical, emotional and intellectual difficulties it is necessary for us as caregivers to create a learning environment that addresses these limitations.

For instance, let me share what we discovered:

1. Nicholas always tantrumed around transition times.

Since there were so many of them throughout the day we needed to find a way to reduce the number and find tools for him to use that would help him to transition more easily. Simple things like giving him something to hold while he transitioned made a huge difference for Nick. We created a transition backpack filled with lots of his favorite things. For some reason, this seemed to give him some extra security and helped make moving from class to class easier. He was also given advance notice of when a transition was coming up to help him better prepare for it. Visual charts were also created to help him know what was coming next. The aide would show him the chart and remind him what was coming next.

2. Fatigue/Tiredness

This was HUGE. Nicholas was often tired throughout the day. Since his stamina was not as advanced as the other kids he was getting tired and often, especially toward the end of the day. We provided him with a safe spot in the classroom.... complete with a mat, pillow and bean bag hair so that if he got tired, he could rest. I thought he would misuse this modification but what I found was the opposite. Nicholas wanted to be with the other kids but seemed comforted to know that it was there if he needed it. Some days he needed it, other days he did not.

3. Communication

Nicholas had trouble communicating quickly because of some poor motor planning issues. So when a teacher or child did something to upset him, he could not communicate quickly or clearly enough for them to understand. Teachers were trained to take extra time with Nicholas and allow him to speak. They instructed other child in how to better communicate with Nick.

4. Token system

Nicholas was NOT being rewarded for all the small things he WAS doing correctly. The only time he was addressed was during poor behavior episodes thus rewarding and reinforcing this type of behavior. He quickly realized that this was how he could gain attention. A token system was initiated were he would earn small plastic coins for good behavior that he could Velcro onto a board and see how he was progressing through the day. At the end of the day if he earned all of his coins, he would get to bring home another special backpack just for him, filled with books and other learning activities. He would bring the backpack back to school every day and start again. This a form of ABA therapy and for Nicholas, it worked!

5. Sensory input

Nicholas is calmed by sensory input, particularly swinging. The physical therapist provided a "special needs" swing in the gym area where she performed PT on other children. This swing was used for Nicholas when he was having an episode, or if teachers found he needed more relaxation. It honestly worked like a charm.

These are just a few of the accommodations that were made for Nicholas and were documented in a behavior plan agreed upon by the Behavioral Specialist, the teachers, therapists and, of course, us parents. We constantly revisited this plan and fine-tuned it,

replacing what didn't work, with programs that did. It's a lot of work, but it was worth it to see my son come home from school happy.

If your child is starting to exhibit behavior that is unusual, it may be his way of telling you (and the school) that he is feeling overwhelmed. Professional help may be needed. You are within your rights to ask the school to perform a Functional Behavioral Analysis performed by a trained professional, and request that a Behavior Support Plan be developed. Find out what is triggering these outbursts and address them. This takes a lot of work and a commitment from the school and parents, but by working together you may be able to make some necessary modifications that ensure your son's success at school.

PWCF is grateful to
Albert Salaz, Jr.
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for his hard work to produce the new DVD
The Brain & Behavior in Prader-Willi Syndrome

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Presented by Janice Forster, M.D. of The Pittsburgh Partnership
Produced by Prader-Willi California Foundation

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PWCF Testifies at Senate Hearing on Proposed Cuts to Regional Centers

by Lisa Graziano, M.A., Executive Director

On Thursday, February 10th I flew to Sacramento to represent PWCF at the Senate Budget Subcommittee Hearing on Health and Human Service. Thousands of people with developmental disabilities, families, advocates, community-based providers, regional center employees, and others packed the hearing room, overflow rooms, and hallways at the State Capitol. Senator Mark DeSaulnier chaired the Hearing, alongside Senators Elaine Alquist and Bill Emmerson, and for six hours heard testimony on Governor Brown's proposed $750 million reduction in State funding of Regional Centers and other services overseen by the Department of Developmental Services. The turnout for the February 3 and February 10 budget subcommittee hearings were the largest in several years, according to State Capitol police and other security.

As reported by Marty Omoto of the California Disability Community Action Network (CDCAN), "The Governor's proposed cuts to developmental services – the bulk [of which are] focused on the growth in spending and caseload of the 21 non-profit regional centers – are largely unspecified at this point. The Governor is proposing that.. the Department of Developmental Services develop a plan with details on how to achieve the bulk of the reduction (or savings to the State) in a process that includes stakeholder input. The Brown Administration intends to present these details and its recommendations to the Legislature probably in May or early June. Those recommendations will likely include statewide purchase of services standards that could place significant limits on the use of services and narrowing of eligibility impacting people with developmental disabilities, their families, regional centers, community based organizations, facilities and individual workers."

These proposed cuts are a big deal – a *really* big deal – because they in essence threaten the very *existence* of the current Regional Center system which carries out the Lanterman Act. Passed in 1977, the Lanterman Act established the right of Californians with developmental disabilities to receive "treatment and habilitation services and supports in the least restrictive environment" and make choices in their own lives, including "program planning and implementation." PWCF's Board of Directors authorized me to fly to Sacramento to add our voice to those protesting the cuts. I arrived at the State Capitol early enough to be assured entry into the Hearing Room. As we waited to testify, many of us introduced ourselves and shared our "story." I sat next to a man who said his four year old son has received such good early intervention services from his Regional Center that the autistic symptoms are all but gone. When I shared that my son has Prader-Willi syndrome, the woman sitting in front of me leaned back and shared that she has a friend whose daughter has Prader-Willi syndrome. In the first of what would be a series of "it's a small world" experiences, that friend is PWCF member **Carolyn Anderson** with whom I have had the pleasure to connect over the last couple of years.

At the commencement of the Hearing, the Department of Developmental Services provided an overview of their proposed yet still-vague plan to cut spending on Regional Centers and Developmental Centers. Much of what I heard proposed sounded a great deal like eliminating the funding that supports actual services, as opposed to cutting overhead and administrative line items. Fortunately, Senator DeSaulnier appeared to hear the same thing and, in short, advised the Department to continue to look at cutting expenses other than in the areas of actual face-to-face-service provisions.

Many people, including parents, former and current Regional Center employees and vendors, and persons with all types of developmental disabilities, provided brief statements – and I mean brief, being limited to one minute each! – about how the proposed cuts would impact them. Very knowledgeable professionals testified that the proposed cuts are just too deep, too wide, and too devastating. After I testified and sat back down, the man next to me indicated that his daughter was diagnosed with Autism but another doctor just recently told him that he suspects she has PWS. I gave him my card and a PWS brochure. In but a moment later I was stunned to hear "Prader-Willi syndrome" again when a parent testified that her youngest son has PWS and needs the State's help on a daily basis. Later in the day, amongst the throngs of people in the hallways, I just happened to share the elevator with that same parent. She and her husband said they've meant to contact PWCF but have been just too overwhelmed with the day-to-day stressors to make the call. Once again, my card came in handy. And on my way out of the Capitol, I ran into PWCF Professional Member **Paul Wurst** who had also made the journey to add his voice to the protests.

What will happen next? The Legislature's full budget committees will meet and begin taking final action on the Governor's budget proposals. What will ultimately happen I don't think anyone knows at this point, but what I do know is that the State's debt is massive and the budget shortfall is immense and will only be made worse by the certain lack of Federal funding dollars that California has received in years' past. What will the Subcommittee do with all of the testimony they received? I *hope* they will weigh heavily the often heart-felt testimony presented to them. I *hope* they will direct the Department of Developmental Services to work harder to find less painful areas to reduce expenditures. I *hope* they will not reduce funding in the areas where I and other parents raising a child or an adult child with Prader-Willi syndrome – or any other developmental disability – are reliant. While we hope, however, we must simultaneously work.

If you are interested in becoming more informed on legislative matters that affect our PWS community, probably one of the best ways to do so is to sign up to receive email updates from the California Disability Community Action Network at www.cdcan.us .

Laughter Through Tears continued from page 14 ...

OLDER TEENS often begin to feel more comfortable with themselves and their situation but a parent needs to be aware that:
(1) 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.
(2) Or it's an age when parents themselves see a way to "escape" and expect the teen to become overly responsible.
(3) Sometimes they feel need to "make up" for their disabled sibling by being an overachiever.
(4) They may question more the justice of why God let this happen.
(5) They feel a need to protect their sibling from the world.
(6) They begin to become concerned about who will take care of their disabled sibling if something happens to their parents.

I don't list all of the above issues to add *more* guilt to a population of parents who are already over burdened and guilt ridden. I only mention these potential problems to let parents know they are not alone and to remind parents of the impact on siblings. As parents, we do the best we can, but often look back and feel that it wasn't good enough – that we made mistakes. Some of the pitfalls we parents fall into are that we:

- abdicate some of the parenting role to our healthy sibling. This may not be all bad as long as the burden is not on just one person. Spread the responsibility out. We don't have to apologize to our children for helping them turn into responsible, caring people. The problem comes when one sibling is taken advantage of. As overwhelmed parents, it is tempting to use the siblings to ease our own burdens.
- say things we wish later we hadn't said because we knew they weren't helpful. What parent can honestly say they haven't made one of the following remarks: "*You should be thankful you don't have...!"; "How would you feel if you had..."; "Why can't you be more understanding of...?"; "You shouldn't feel that way about...."*
- give in frequently to our disabled child to avoid problems or to appease your guilt over the situation - and expect the siblings to give in also.

Besides forgiving ourselves for being human and our siblings also, other steps we parents can take after realizing we have done orsaid something inappropriate are:
(1) Acknowledge to your child that you made a mistake
(2) Let your child vent his/her feelings and admit you also have some of the same feelings regarding your disabled child – or to the situation the disability creates i.e., "We don't hate Matt for the problems of living with locked cupboards and refrigerator, but we do hate the syndrome at times."
(3) 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 Sarah to eat in front of him, the compromise is to allow her to snack after he is in bed.
(4) Find some special time away from *all* your children so you can come back feeling more refreshed and less sorry for yourself. Kids do not look kindly on parents who are martyrs.

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. Although Sarah is still struggling with the ethical dilemmas of all 12 year-olds, I trust the day will come when she has the personal integrity and sensitivity that her grown brothers and sisters have. Our healthy siblings' lives will be partly enriched and partly damaged by their situation. We can nurture the enriched part and minimize the damaged part by accepting them and ourselves with all of the normal faults and feelings that accompany the family of any child with a disability.

Social Security and Disability Resource Center

by Tracy Curtis

The Social Security and Disability Resource Center website (SSDRC.com) provides a detailed overview of how the Federal disability system works (social security disability and SSI) and also provides answers to many questions that applicants typically have but often have trouble finding answers to. For the most part, the site is based on the author's personal experience as a former disability-Medicaid caseworker, and also as a former disability examiner for the Social Security Administration. The link to the site is www.ssdrc.com

MEMBERSHIP ACTIVITY

January ~ March, 2011

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
Richard Rust & Mary Jane Morris

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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