PWCF News

The Newsletter of Prader-Willi California Foundation

An Affiliate of

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

July-September ~ Volume 22, Number 3

New Friends and Memories to Last a Lifetime Made at PWCF's New PWS Camp at Easter Seals Camp Harmon

Heather & Lauren

In July, PWCF held its first PWS Camp at Easter Seals Camp Harmon. What an extraordinary experience for all! Six days of fun… swimming, hiking, tie-dying, arts & crafts, costume party, singing, dancing, campfire, horse-drawn wagon rides, all dispersed between the tastiest, healthiest, and most plentiful low-cal, low-carb, low-fat diet you've ever seen, prepared by one of the universe's most extraordinary people, Camp Harmon's master chef **Mama Deb**.

PWCF's new PWS Camp wouldn't have materialized were it not for the efforts of two more of the universe's most amazing women – past PWCF Board member and Camp Coordinator **Linda Ryan** and Camp Harmon's Camp Director **June Stockbridge**.

All of the 56 campers received a scholarship from PWCF to help them attend camp, and each and every camper left camp with exciting memories that will last a lifetime. For some, PWCF's new PWS Camp was a life-changing experience. For one newly-diagnosed 19 year old who has been struggling to come to terms with the diagnosis, attending camp and meeting other wonderful young women with PWS for the very first time was described by her parents as life-altering; "She's a whole different girl! She talked the whole way home about camp. She now knows she isn't the only person on Earth with PWS, and she has a whole new and improved perspective on having the disorder. She's now enthusiastic about her life… and she has a new best friend." Read below more first-hand accounts of camp from the campers and families themselves. Be sure to take a look at all of the smiling faces posted on the website (PWCF.org), and stay tuned to mark your calendar for next year's PWS Camp!

Linda, June & Lisa

Writes 12 year old camper, **Cameron Graziano** about his first time ever at a camp: As I was walking to my cabin my heart was bouncing with excitement. I thought, "What will I do? What will I eat? Anyway, my cabin mates were good and the cook was awesome. The dance, campfire, movies, and sleepovers were the best. When I left, I felt like I was crying inside. Leaving the best camp was sure a disappointment. Overall, I would like to go back.

Shandra Beer, mom of 9 year old **Emile**, writes: Miss Emile seemed to have the time of her life. We are hearing new stories everyday and she has written three different people letters to tell them all about her time at Camp Harmon. She is already asking for me to sign her up for next year :) I was equally impressed with the kindness of the counselors and how they so easily accepted our children into their hearts. Emile especially loved someone named Kelly…Thanks so much.

Savati James wrote that her 15 year old daughter, **Chanie** says this was the most fun she ever had. She cannot wait until next summer. Thank you again.

Michelle Donaldson describes her 21 year old son **Whitman** as having had: a FANTASTIC time – even given that he's been to two other camps besides Camp Harmon, and many other Camp Harmon sessions over the years, he said this one was "the best EVER." He really enjoyed his cabin-mates, counselors, and all the activities. He said he thought there were more exercise-related activities as opposed to the arts-and-crafts type, but that was fine with him – and he also was happy about the new addition of daily snacks and the delicious desserts. He even lost 3 lbs during camp week – wow! And he's already been on the phone with new friends he made at camp. Thank you both, Linda [Ryan] and Lisa [Graziano] and the PWCF Board for creating this fantastic opportunity. I am already thinking of several kids I know with PWS who did not get to go to this session, and hoping I can help them to be aware of it in advance next year…If I have one complaint, it's my complaint with all the Camp Harmon sessions – too short! Between the drop-off and pick-up, there are only four actual days off – and four full days of camp for the campers, who I know would enjoy more …Anyway, you all did a wonderful thing for our families, and I am very appreciative.

Emma, Haley & Alicia

In This Issue:

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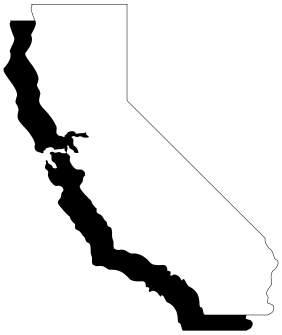

"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families."

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Wendy Young	415-380-0721	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
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Jennifer Rinkenberger (Infants & Children with PWS)	559-930-7834	jenrink@mac.com

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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

"What supplements do you find most helpful and how do you determine the correct dosage?"

For "tummy troubles" I found peppermint extract/oil capsules extremely helpful. One capsule fits all. Follow bottle directions. Available at health food stores. *Dale Morris, parent of 22 year old daughter*

Back in 2003 when my son was about 4 years old, he started taking 200 mg Coenzyme Q-10 to help improve his articulation. Q-10 was not widely used back then so we didn't know what to expect. We asked other parents about their use Q-10 and learned that Coenzyme Q-10 should only be taken in a gel or liquid form, as the powder/pill form is not absorbed by the body. We settled on a gel-cap (we now use Jarrow brand) and two weeks later, his Grandpa, who didn't know about the start of the supplement, commented that he was beginning to "catch on to Cameron's lingo" because he could understand everything Cameron was saying. At the same time, his physical therapist (also blind to the start of the Q-10) also commented that Cameron's overall motor planning skills were greatly improved. Five years later we took Cameron off the Coenzyme Q-10 to rule out whether it was causing his then-recurrent migraine headaches. We learned that the Q-10 was not the culprit, and we also learned that without Coenzyme Q-10, Cameron becomes sluggish, sleepy, more irritable, and his food drive kicks up about 17 notches. Even my husband commented, "We will NEVER take Cameron off this stuff again!" We've got Cameron's Coenzyme Q-10 in our earthquake kit, alongside the rest of the essentials. Cameron also takes 1,000 mg of L-Carnitine Fumarate (for cellular energy) and Pro EFAs (essential fatty acids). We purchase both at Whole Foods. *Lisa Graziano, parent of a 12 year old son.*

Next issue's Parent to Parent question is, "*How do you find a good pediatrician or general practitioner who is knowledgeable about Prader-Willi syndrome?"*

"Trust Hormone" May Help Curb Symptoms of Devastating Disease

by Elizabeth Norton as printed in Orphanet Journal of Rare Diseases
http://www.ojrd.com/content/pdf/1750-1172-6-47.pdf

Life for those with a genetic disease called Prader-Willi syndrome, which affects an estimated one out of 15,000 people, can be challenging both for the patient and his or her family. Sufferers have an insatiable hunger that can lead to life-threatening obesity if access to food is not restricted. And worse, they have behavioral problems akin to autism. Tantrums and tears are common because these patients have difficulty understanding the motives of others and controlling their own emotions. But treatment with the brain hormone oxytocin may help bring both emotions and eating into balance, according to a new study.

Several clues pointed to the potential of oxytocin, often thought of as the "trust hormone." Research conducted on the brain tissue donated after death from Prader-Willi patients showed that the hypothalamus (the body's thermostat) has abnormalities in the nerve cells that produce this hormone. Moreover, the hypothalamus releases oxytocin in response to touching, social interactions, relaxation, and trust—all the things people with Prader-Willi syndrome have trouble with. And oxytocin treatments have improved the social skills of autistic patients. Finally, the hormone is thought to contribute to feelings of fullness after eating, "satiety" in scientific parlance.

To see whether oxytocin could benefit individuals with Prader-Willi syndrome, endocrinologist Maïthé Tauber of the Children's Hospital in Toulouse, France, and colleagues injected oxytocin or a placebo into the noses of 24 adult patients. The researchers monitored the patients' behavior; they also used cartoon stories to test patients' grasp of social interactions and pictures of faces to see how well they could recognize emotions.

For the two days that patients were studied after treatment, those who were given oxytocin were significantly more trusting and less sad. They were less disruptive and had fewer conflicts with others. They also had higher scores on the tests evaluating social understanding, compared with the placebo-treated group.

The study, appearing online in the Orphanet Journal of Rare Diseases, focused on behavior issues, which Tauber says "are harder to control than food intake." However, the patients did eat less after the oxytocin treatment, and five did not finish everything on their plates, which Tauber says is unusual in Prader-Willi syndrome.

"The research of Tauber and colleagues is meticulous and very exciting," says Daniel Driscoll, M.D., a geneticist at the University of Florida in Gainesville. There is currently no treatment for the disorder except behavior modification and diet control. Driscoll says a better understanding of the role of brain chemicals, such as oxytocin, may lead to better treatments at the various stages of this complex disorder.

The authors write that although longer-term, larger studies will be needed, the present work opens new perspectives for patients with Prader-Willi syndrome. "Because previous research shows abnormal oxytocin secretion, we hope that the treatment may not only improve the patient's mood and behavior but also help correct the underlying problem," Tauber says.

Professor Maithé Tauber (Hôpital des Enfants and Paul Sabatier Université, Toulouse, France) accepted PWSA's invitation to present at PWSA's Scientific Day Conference on November 11. Professor Tauber will speak on the topic of The French Reference Centre for PWS and Pertinent Endocrine Issues in PWS . Daniel Driscoll, M.D. chairs PWSA's Clinical Advisory Board.

Gadget Tip

Jitterbug Cell Phone

Touts Jitterbug about their phone, "It's bigger, has a comfortable keypad to make dialing easy, has a familiar dial tone to confirm service (that no other cell phone has), and has a brighter LCD screen which makes it easier to see even in daylight." The phone comes pre-programmed and ready to use right out of the box. No contract is required, and there's live, 24-hour Jitterbug Operators to greet you by name, connect calls, and update your Phone Book. The Jitterbug® Cell Phone is only $99 and service plans start as low as $14.99 per month. A purchase price of $144 includes $99 for the phone, a one-time activation fee of $35, and $10 for shipping and handling. Contact Jitterbug at 888-824-1895 or order online at www.jitterbugdirect.com

Food Tip

This food tip was submitted by Lesley deLone of Mill Valley

Sugar-Free Jam Preserves
Nature's Hollow takes fresh juicy ripe fruits and adds just the right amount of fresh ingredients for the most amazing sugar free diet jam you will ever taste. Sweetened with Xylitol, you will never know the difference from preserves sweetened with regular sugar. The most flavorful sugar free diet product ever comes in Apricot, Strawberry, Raspberry, Peach, Mountain Berry, and Wild Blueberry. Each flavor contains about 20 calories per tablespoon, with 7 grams of carbohydrates.

Other sugar-free products available from Nature's Hollow include:

Sugar-Free Honey
Nature's Hollow sugar free diet Taste Like Honey, is made with a great tasting healthful natural sweetener called Xylitol. Xylitol is a 5-carbon sugar alcohol that is ideal for diabetics and those concerned about sugar intake. Unlike sugar, Xylitol has a very low glycemic index, has fewer calories, and is good for your teeth. Enjoy this sugar free honey product on muffins, oatmeal, yogurt, or use it to sweeten your favorite beverage.

Sugar Free Hickory Maple BBQ Sauce
Nature's Hollow unique barbeque sauces add a hearty flavor to red meats, chicken and fish. Unlike most barbeque sauces that are filled with corn syrups and sugars, Hickory Maple Barbeque Sauce is sugar-free and gluten-free. You'll savor the smokey taste of maple on all meats and find it especially mouth-watering when cooking on the grill.

Sugar-Free Ketchup
Nature's Hollow sugar free diet ketchup is the best tasting low carb ketchup you have ever tasted. It is made with a great tasting healthful natural sweetener called Xylitol.

Black Bean and Olive Salsa
Ripe olives combined with black beans make this delicious southwest style home made salsa dip. Just the right amount of spices and the freshest ingredients make this salsa a family favorite. Don't just make chips and salsa, try this fine salsa on beef, chicken and fish.

Products are available at Whole Foods or online *http://natureshollow.com*

Executive Director's Column

Lisa Graziano, M.A.

September 11, 2001. Ten years ago. The fear; the loss; the inescapable trauma that each of us experienced no matter how direct or distant our connection to the Twin Towers in New York City, the Pentagon in Virginia, or the crash site in Pennsylvania. September 11 is an anniversary that will exist forever in infamy. To those of you who lost a loved one, PWCF expresses our heartfelt sympathy.

Anniversaries of prior traumas or losses tend to reawaken strong emotions, no matter how long ago they occurred. A decade has elapsed but I can vividly remember watching the television and listening to the radio as the horrific events unfolded throughout the day, wondering what on *earth* was happening and then, upon learning these were terrorist attacks, fearing strikes would soon hit close to *our* home.

Like most of you, the shocking images seared into my memory on 9/11 are intertwined with my own personal goings-on of the day. I had just left my young son in the care of someone else for the first time in his life on this, his first day of preschool. My worries about my son's safety out on the preschool play yard were now dwarfed by the crushing fear that Los Angeles would be the next terrorist target. I drove straight back to the school, sat in my car in the parking lot, and counted down the seconds until I could hold my beautiful little boy in my arms again and keep him safe.

Keeping my son safe is a never-ending challenge.

Keeping *all* persons with Prader-Willi syndrome safe is a never-ending challenge.

I have the extraordinary privilege to speak with parents every day, and the overarching theme of our conversations almost always boils down in some way, shape or form to, "Please help me keep my loved one safe." Whether it's safety at school, safety at home, safety at the work site, safe from emotional upset, or safe from going to jail for committing a crime they were driven to commit, safety is *always* an all encompassing concern.

The world does not yet understand Prader-Willi syndrome. Even the name of the disorder is often mispronounced (it's Prah-der) by the very professionals on whom we are supposed to rely for help. While it is true that public awareness of the syndrome is increasing, there are still not many and certainly not enough situations where parents and care providers experience the luxury of connecting with a professional who is already knowledgeable – and I mean *really* knowledgeable, not just "fake" knowledgeable – about the syndrome. Rarely do we meet a professional who can actually show *us*, teach *us*, guide *us* in what we need to know and how we need to do it for our child *right now,* in *this* moment. It is almost always we parents who must provide critical information to the professionals in our child's or adult's life about how to reduce or manage the impact of PWS: what medications and supplements can help reduce symptoms; what assessments should be made and why; what early intervention therapies are absolutely mandatory; that praise and positive motivation strategies work well and the use of punishment does not; that a low carb/higher protein diet with food cut into small pieces and spread around on a smaller sized plate can fool the brain of someone with PWS; that implementing structure and routine and the "Principles of Food Security" are absolutely crucial to behavior management; that environmental calmness and composure must prevail at all times; that tone of voice means more than the words being used; and every other "PWS basic" known to improve quality of life.

But if *we* haven't learned these PWS basics, how will the rest of the players in our loved one's world ever know to use them?

If we're really lucky or smart or both, we may figure out *some* of the basics on our own. But too often this doesn't happen, and we certainly won't figure out *everything* we need to know about PWS, especially when new discoveries are being made every day. If we can't rely upon the medical / therapeutic / educational / residential / vocational experts to know or teach us everything we need to know about PWS, where and how, then, are we to learn it so that we may provide our loved one with the highest quality of life to which they're entitled?

There are only two ways that I know of: through professional PWS organizations such as Prader-Willi California Foundation, and from other parents who are raising or have raised a child with PWS. Only from these sources will we receive the most accurate information and the greatest insight, advice, guidance, and support.

And so, I am, in all honesty, utterly baffled and have been for many years by how few families attend conferences, trainings, and special events and take advantage of the information, guidance and support that is available. Fatigue. Apathy. Exhaustion. Embarrassment. Fear. Disillusionment. Hopelessness. I've no doubt these are among the factors that keep families from availing themselves to resources or from connecting with other families. If we're going to change how the world understands people who have Prader-Willi syndrome, though, we must increase our own understanding and then share this information with each and every one of the professionals in our loved one's life so that they are more knowledgeable when they work / live / educate / represent not only our child but the next child or adult with PWS as well.

This educational process started back in 1956 when doctors Andrea Prader, Alex Labhart, and Heinrich Willi first identified this constellation of symptoms we now call Prader-Willi syndrome. Since then there have been many advances in our understanding of PWS and its treatment strategies and, yes, too many stalls in progress as well. Science is currently on another exciting roll of discoveries, however, and it is up to each of us to seek out this new information, incorporate and implement it wherever we can, and teach others about what we learn. Attend PWCF's conference this November 5. Attend PWSA (USA)'s conference November 11-13. Attend FPWR's conference on October 15. Read a PWS book or view a DVD you've not yet seen. Attend the next Family Day event nearest you. Attend a support group or, if there isn't one near you, work together with PWCF and other families to start one. In so doing any of these you'll not only benefit yourself and your family, you'll be helping the next generation of people born with Prader-Willi syndrome.

Angel Flight Can Help Patients Travel

An Interview with Marita Eddy by Edward Becker, Director, PAN Support Network

Marita Eddy is the travel coordinator for Angel Flight, a non-profit organization that helps to ensure that needy patients can travel to long distance medical appointments. Flights are arranged either through pilots using their own planes, or on a commercial aircraft. Questions about Angel Flight should be directed to Marita Eddy at meddy@mail.nih.gov

Angel Flight's Mission and Services Born on a wing and a prayer more than 30 years ago, a group of general aviation pilots in the DC area bought a Beechcraft Bonanza 36, a six-seat, single-engine plane. The Washington Aviation Ministry (WAM), as it was called, was primarily an air taxi for prominent religious and humanitarian figures with an occasional patient mission. Over the years, the group grew and expanded into an air ambulance service transporting patients needing immediate care. In 1987, WAM became Mercy Medical Airlift (MMA). The name *Angel Flight* was used to describe the fast-growing number of patient missions flown using volunteer pilots in their airplanes for distances under 1,000 miles.

MMA created other services to ensure that no needy patient would be denied access to medical care for lack of air transportation. Programs included a call-referral service matching patient requests with resources and "Special Lift" programs for patients involved in clinical trials. MMA formed partnerships with commercial airline companies to donate tickets and frequent flyer miles for patients needing to travel more than 1,000 miles.

MMA joined with other volunteer pilot associations across the country to form Air Charity Network (ACN), which provides 90 percent of charitable air transportation in the United States. Every 24 minutes a child or adult in need is being flown through the generous volunteer and donor resources of these grass roots organizations.

Angel Flight Brief Stats In 2010, Angel Flight Mid-Atlantic flew 1,166 missions and MMA Commercial Airline Programs provided more than 5,000 flights. MMA provided service for more than 22,000 clients.

During the previous 12 months - 1,539 missions have been completed for patients diagnosed with a rare disease. 926 of these missions were for patients participating in Clinical Trials. These missions were completed utilizing charitable airline resources through programs operated by Angel Flight at NIH and Mercy Medical Airlift. Public benefit of these missions exceeded $460,000.

One of our pilots is the man who created MapQuest. When he sold MapQuest, he used some of the proceeds to buy a plane and learn how to fly. He donates some of his time as an Angel Flight pilot among his many other endeavors. Another pilot learned how to fly when he was 16. That was in 1945. Some of our pilots are retired. Many are former military. Some are executives who fly frequently on business. A few are doctors. We have women pilots too. They all love to fly.

Once on the ground at the airport, patients may need to have transportation to the hospital. [A program called] Earth Angels provides transportation for patients who are coming to the NIH Clinical Center in Bethesda, Maryland… One of my fabulous "Earth Angels" will volunteer to drive to the airport, greet the patient and take him/her to NIH. These volunteers are people from the community who take time out of their day help out. It's a way of donating that doesn't take much of their time, but means a lot to the patients. Having someone smile and say, "I'm your Earth Angel" is a comforting thing to hear when you've been flying all day.

General Eligibility Information For specific information, go to www.angelflightatnih.org . Patients need to be ambulatory, capable of walking and sitting upright during the flight. **They require medical treatment, evaluation, rehabilitation or testing that is only available at a long-distance facility or be in a clinical research study.** Their physician must complete a medical approval form so that we know the patient is medical stable to fly. They must have a financial need and no other way of reaching their destination.

We assume that families that can afford the cost of air transportation will use their own resources. However, we understand that when a family member has a chronic illness, the family may incur major medical expenses and may have to travel frequently and long distances for specialized medical evaluation and care. We also want to encourage patients to participate in clinical research studies, especially patients with rare diseases. Scientists know so little about most rare conditions and the number of patients affected is so small that there is a great need for every patient to participate if possible. We want to help drive that research forward.

For commercial tickets each patient may bring one escort. For general aviation flights, if the patient is a child, we may be able to include both parents depending on total weight and distance.

The decision as to whether to fly in small planes or on commercial flights is based on a number of factors. Short flights are usually quicker by general aviation. Also, patients who live in remote or rural areas have easier access to local and regional airfields. These patients often prefer flying with our private pilots. For patients who live farther than about 600-700 miles, I recommend commercial flights. However, these guidelines are flexible. We can consider other factors as well. We offer travel for a patient and one escort.

The biggest issue with commercial flights is the availability of resources. We work with airlines, foundations, other air transportation organizations. We match patients with the best resource. Different programs have different rules.

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Some programs are specifically for children. Others, just for cancer patients. Sometimes the need outweighs the available resource and we have to turn people down. That is hard for us to do. Fortunately, we continue to expand the number of programs and services we can offer.

MMA exchanges donated frequent flyer miles for commercial airline tickets. MMA has a two-year relationship with the American Cancer Society (ACSA). Flyers can donate frequent flyer miles from United Airlines and Delta Airlines to the ACS. MMA can then exchange the donated miles for commercial airline tickets for cancer patients. MMA hopes to expand its relationship with Southwest Airlines. Southwest donates a limited number of tickets every January. Other programs help different categories of patients and a generous benefactor allows MMA to purchase tickets outright for patients who don't fall into any of the other categories.

How is Angel Flight funded/supported? Angel Flight is supported by donations of services and money from individuals, corporations, foundations and trusts. Donors may contribute through workplace giving programs, such as the Combined Federal Campaign and the United Way. Angel Flight Mid-Atlantic has earned Best in America seal for non-profit management. MMA has earned the top four-star rating from Charity Navigator.

Unused airline miles can be donated via www.donatefrequentflyermiles.org/. For US Airways, donate to Mercy Medical Airlift. For United Airlines and Delta Airlines, donate to the American Cancer Society.

How can someone volunteer? We love volunteers. They help in a variety of ways. Folks who are interested can go to Air Charity Network's Member Organizations (www.aircharitynetwork.org) page and contact one of the volunteer pilot organizations in their area.

Important links for Angel Flight:
www.angelflightatnih.org – referrals come directly to me
http://mercymedical.org – information about all Mercy Medical Airlift programs
http://patienttravel.org – information about air transportation resources for patients
www.donatefrequentflyermiles.org – learn how to donate frequent flyer miles

Exercise: Good for the Body *and* the Brain

Article summarized by Elizabeth Greskovics
of Manhattan Beach
Source: realage.com

In a study at the University of Campinas, heart-pumping activity was found to decrease appetite by upping protein levels in the hypothalamus; tricking your brain into thinking you're full. It appeared to make brains more sensitive to key chemicals that play a role in appetite communication.

Researchers witnessed some key chemical changes in the brains of overweight animals that began getting regular exercise. The levels of two types of proteins, interleukin-6 and interleukin-10, increased in the hypothalamus. These proteins served as a type of appetite control within the part of the brain that receives signals from important hunger hormones like leptin and insulin. As a consequence of these protein increases, researchers found that the animals' brain cells became more sensitive and receptive to hunger signals. End result? The animals started to eat less.

This is not the first study to support the theory that turning up your physical activity level can dial down your appetite, but this is one of the first studies to highlight a possible underlying mechanism for the effect. More research will need to be done to determine whether exercise has exactly the same effect on humans. But for now, we already know lots of other great health reasons to crank up our physical activity levels.

Does it all work the same way in persons with Prader-Willi syndrome? We don't know, but regular and fun exercise sure can't hurt!

The woods would be very silent
if no birds sang there except
those who sang best. ♫

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2011
SUPPORT

November 12-13, 2011
General Conference
Infant & Youth Program
Youth & Adult Program **(Registration Now Closed)**
Siblings Program

November 11, 2011
Professional Day
Scientific Day & Observers
Chapter Leaders Day

31st PWSA (USA) National Conference
November 11-13, 2011
The Buena Vista Palace Hotel, Disneyworld, Florida
http://www.pwsausa.org/conference/2011/

Back to School

What You Need to Know About IDEA 2004: IEPs for Children with Behavior Problems

by Pat Howey, Paralegal and Advocate

www.wrightslaw.com

Question: *Help! The school had my child with autism arrested. The charges were dismissed but I am afraid this will happen again. What can I do?*

Answer: You are wise to think this may happen again. You need to write a letter and request that the IEP team meet to review and revise your child's IEP, in light of the behavior issues that led them to have him arrested. Your letter should include relevant information about your child's history and your concerns. (For more about this, read Preparing for IEP Meetings: Providing Information & Sharing Concerns at www.wrightslaw.com)

But first, **you** need to learn what the law requires IEP teams to do when when children with disabilities have behavior problems.

The IDEA 2004 regulations and commentary to the regulations were published in August 2006. The law, federal regulations and commentary describe what IEP teams must do when a child's behavior "impedes the child's learning or the learning of other children."

Do not assume that your child's IEP team is knowledgeable about these requirements.

The questions and answers about the requirements for meeting the needs of children with behavior problems (below) are taken from IDEA 2004, the special education regulations, and the Commentary.
Note: Wrightslaw: Special Education Law, 2nd Edition includes IDEA 2004 and the special education regulations. You can download the special education regulations and commentary and other resources from IDEA 2004 at Wrightslaw.

If a child’s behavior impedes the child’s learning or that of others, must IEP Teams base positive behavioral interventions and support on a functional behavioral assessment?

Yes. Conducting functional behavioral assessments typically precedes developing positive behavioral intervention strategies.

Does “consideration of special factors” address the behavioral needs of children with disabilities in the IEP process?

Yes. The IEP Team determines whether a child needs positive behavioral interventions and supports. If the behavior of a child impedes the child’s learning or the learning of other children, the IEP Team must consider the use of positive behavioral supports, supports, and other strategies to address that behavior. (20 U.S.C. § 1414(d)(3)(B)(i), 34 C.F.R. § 300.324(a)(2)(i))

If the child's behavior impedes the child's learning or that of others, must the IEP Team develop a plan to address these problem behaviors?

Yes. If the child's behavior impedes his learning or the learning of others, the IEP team must include strategies, including positive behavioral interventions, supports, and other strategies to address that behavior. If the child's behavior that impedes learning is not addressed in the IEP, the IEP Team must review and revise the IEP to ensure that the child receives appropriate positive behavioral interventions and supports and other strategies. (34 C.F.R. § 300.324(a)(2)(i) and 34 C.F.R. § 300.324(a)(3)(i).

Must school districts train teachers regarding the use of positive behavioral interventions and support?

Yes. School districts must provide teachers with high-quality professional development, including the use of scientifically based instructional practices. School districts must ensure that personnel have the skills and knowledge necessary to improve the academic achievement and functional performance of children with disabilities. Each district must ensure that all personnel necessary are appropriately and adequately prepared. (20 U.S.C. § 1412(a)(14), 34 C.F.R. § 300.156)

Each State must establish and maintain qualifications to ensure that personnel are appropriately and adequately prepared and trained, and have the content knowledge and skills to serve children with disabilities. (20 U.S.C. § 1412(a)(14), 34 C.F.R. § 300.156(a))

Must school districts use research-based positive behavioral supports and systematic and individual research-based interventions when addressing the behavioral needs of children with disabilities in their IEPs?

Yes. School districts must ensure that scientifically based research drives their professional development activities and services. (34 C.F.R. § 300.226(b)(1))

The implementation of early intervening services specifically focuses on professional development for teachers and other school staff to enable such personnel to deliver scientifically based academic and behavioral interventions, and providing educational and behavioral evaluations, services, and supports. (20 U.S.C. § 1413(f)(2), 34 C.F.R. § 300.226(b)(1))

The definition of "scientifically based research" is included in the regulations (34 C.F.R. § 300.35). Scientifically based research is referenced in IDEA 2004 (20 U.S.C. § 1411(e)(2)(C)(xi)). The full definition of the term “scientifically based research” includes that a peer-reviewed journal published the research, or that a panel of independent experts through a comparably rigorous, objective, and scientific review approved it.

Must public agencies provide positive behavioral interventions and supports for all children identified as having an emotional disturbance?

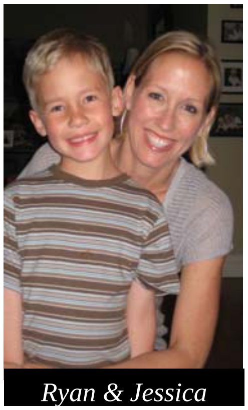
No. IEP Teams make decisions on an individual basis for each child. IEP Teams need not consider such interventions, supports, and strategies for a particular group of children, or for all children with a particular disability. IEP Teams **must** consider the use of positive behavioral interventions and supports, and other strategies to address the behavior of a child whose behavior impedes the child’s learning or that of others. (20 U.S.C. 1414(d)(3)(B)(i)), 34 C.F.R. § 300.324(a)(2)(i))

Pat Howey is an advocate who has helped parents obtain special education services and resolve special education disputes. Pat is an active member of the Council of Parent Attorneys and Advocates (COPAA) and other organizations. As a member of the Wrightslaw Speakers Bureau (www.wrightslaw.com), Pat provides training for parents, educators, and others who want to ensure that children receive quality special education services.

In the Trenches

Vol. 6

By Jessica Patay



Ryan & Jessica

A dear friend of mine says to her “special” daughter every morning as she looks into her chocolate eyes, “You are a gift.” It’s her daily mantra. Before the cares of the world set in, before the grind begins, before any reminders of the challenging journey she is on, *before*. She has chosen to remind herself, despite the hardships of having a disabled child, that her daughter is a gift. Everyday. To her. To her family. To the world.

My friend’s beautiful way of facing every day of her daughter’s disability has had a profound impact on me. That I need to adopt an “attitude of gratitude” about Ryan before my day begins. Armed with my morning coffee, I should clear my head of concerns and worries and to-do lists (so many of them!). As my earliest riser Ryan comes down the hallway, I need to hug him, look into his watery blue eyes and say, “You are a gift to me. You are a gift to our family.”

It sounds so sweet and syrupy and cliché sometimes. It’s very hip and chic these days to throw around phrases of thanks and take on a no-complaining-no-whining rule. We “say” we are grateful. We keep gratitude journals. We say having a disabled child is a “blessing in disguise.” We say it in our head. It’s true in theory. Yet when our hearts ache with the reality, and the on and off grieving we parents undergo, we quickly forget. We can so easily get swallowed up in just how *darn hard* our journeys are. And they are.

Therefore, in an effort to be proactively adopting a theme of gratitude in my head AND heart, I have compiled a list of things about Ryan that I am thankful for. Here are some examples:

1. Ryan is very polite and appreciative.
2. Ryan never complains about any meal or snack I make for him.
3. Ryan never complains about chore time.
4. When I say it’s time for a bath, he says, “Can I play in there?” versus “But I am not dirty” and “Do I *have* to?”
5. Ryan is very enthusiastic about family outings.
6. Ryan has language and uses it. (Yes, despite the 873 questions per day or per hour, I am thankful.)
7. Ryan loves to go to school.
8. Ryan never pops out of bed once tucked in. He’s asleep in 60 seconds.
9. Ryan is fearless. (which leads to #10)
10. Ryan loves roller-coasters, all sizes and speeds!
11. Ryan is a go-getter at times and surprises us with great tenacity in physical tasks.
12. Ryan is extremely thankful, for everything, even stickers from the Trader Joes clerk.
13. Ryan hugs me and says, “I love you Mama” completely unprompted. He says it often.

Have you ever NOT OPENED a package or present? Just left it in the closet? By not listing, thinking about, and meditating on qualities and traits in Ryan I am thankful for, I am basically choosing to not unwrap a gift. That would be foolish at best and detrimental at worst. I owe it to Ryan. I owe it to myself. I am one of those people who, when receiving a birthday present in the mail, open it immediately. My husband will tease, “Can’t you wait till your actual birthday?” And I quickly and sheepishly say “No!” I’m like a kid again on Christmas morning voraciously ripping through gifts with parents pleading me to slow down. So how can I NOT unwrap Ryan? He’s my sweet beautiful ocean-eyes blondie who is social, affectionate, and very complimentary. Who, despite his many limitations and anxieties, has a true zest for life, and family, and holidays, and of course, food. Ryan Bradley Patay is a gift, a gift I get to unwrap every single day.

PWCF Gets Mail…

Dear PWCF: I just want to tell you the good news. Christine was accept[ed] into the Regional Center. Thank you for your letter and for your support. Thanks again, *Maritza Chan*

Dear PWCF: Thanks so much for passing this [article on the potential role of oxytocin medication to reduce some of the symptoms of PWS] on!   With all the very incredible people working to perform studies/research for the folks inflicted with PWS, our hats are off to you. They give all our families hope. This latest article that's being forwarded is just another example of the strides that are being made. *Neil and Janice Hubberth, parents to Joseph 14 yrs. old with PWS, Windsor*

Dear PWCF: Thanks…for all your help with my Regional Center. Kelsey is at her new group home. She seems very happy. We couldn't have done this without your help.   *Laurie McGinnis*

Board Corner

PWCF Board of Directors Meeting Meeting of June 4, 2011
Submitted by Tom McRae

The Board of Directors meeting was held at Redondo Beach, CA.
Board members present: Julie Casey, Drew Marich, Tom McRae, Chris Patay, Renee Tarica, Julie Tauscher, and Paula Watney. Others present: Lisa Graziano (Executive Director) and Fran Moss (Consultant)
Board members absent: Don Carlson, June-Anne Gold, Carl Martens, Michael Moore

Fundraising

- **Race For PWS** – **Chris Patay** reported that the April race raised over $25,000 after expenses. To learn more about the entire team that **Jessica and Chris Patay** put together for this fantastic event visit www.raceforpws2011.com.
- **London Marathon for PWS** – **Jon Gold**, husband of Board member **Dr. June-Anne Gold**, completed the London Marathon (26.2 miles!) in April and raised over $700 for PWCF.
- **Walking for Prader-Willi Syndrome** – Our Northern, Central, and Southern California May 1st and 14th *Walks* have netted over $25,000 to date [$41,000 has been raised as of 8/31]. The Board discussed ideas to invigorate and improve these annual *Walks* going forward. We'll be looking at new sites, better ways to connect with new parents of PWS kids at the walk, and reaching out to our PWCF community to get broader participation in the planning and staging of the events.
- **Grant Writing** –
  - ◊ **Maureen Spindt**, PWCF's new grant writer from YES! Communications, has been busy (and keeping **Lisa Graziano** busy too!). There is a good deal of planning and strategy involved in grant writing and Maureen has been busy setting up shop for PWCF grants with Lisa providing her the raw data on PWCF's needs. To date, Maureen:
    - ∗ Submitted a $5,000 grant request for General Operating Support to the Carl Wynn Foundation
    - ∗ Submitted an $18,000 Letter of Intent for group home exercise equipment to The Ahmanson Foundation. This one was turned down, but we'll try elsewhere.
    - ∗ Currently working on a $5,000 grant request to the Ronald McDonald House of Charities Southern California for educational games, therapeutic art supplies, and PWS educational materials.
  - ◊ **Lisa Graziano** submitted a grant to Southern California Edison for a laptop and desktop computer.
- **Fore! Golf Anyone? – Sam Cropper** is looking into the idea of a golfing fundraiser. **Paula Watney** and **Drew Marich** like the idea and agreed to look into it too.

Awareness, Education, and Support

- **PWCF Camp** – **Lisa Graziano** reported that programming, planning and registration for the new PWS Camp at Camp Harmon is going well. Lisa is working with **Lynda Ryan** to finalize the menus. As of 6/1/2011, 48 registered participants. Lisa will be sending a mailing to each eligible but not yet registered family next week.
- **Corporate Outreach** – **Jon Gold** worked with **Lisa Graziano** to revise our corporate outreach letter. The revised letter along with a copy of our new PWCF Walk DVD was mailed to a sampling of Fortune 500 companies in California. Although we did not get a corporate sponsorship for this year, we did raise awareness. We plan to continue this effort.
- **Press Releases** – **Lisa Graziano** issued a press release to publicize the PWCF walks, runs, and races (www.prnewswire.com/news-releases/california-walks-runs-and-races-for-prader-willi-syndrome-120723199.html).
- **Family Support Coordinator – Lisa Graziano** requested that the Board pursue hiring a part time Family Support Coordinator. As PWCF takes on additional responsibilities, Lisa's workload has increased. The Board ran out of time to sufficiently discuss this request and so we will follow up with Lisa at the next Board meeting.
- **Social Media** – **Julia Casey** gave the Board an update on how the social media work she has spearheaded is progressing.
  - ◊ There are now over 700 people who "Like" our PWCF page. I love it! If you haven't visited PWCF's Facebook page (www.facebook.com/pwcf1), please do!
  - ◊ **Vivint Gives Back** – Last year PWCF won $30,000 dollars by participating in this contest. But this year PWCF has dropped to a distant #4 position. Given that each person can only vote for 1 organization, we want to throw our support behind the Utah PWS Association. Check out PWCF's Facebook page (again, that's www.facebook.com/pwcf1). It is kept up-to-date with the latest info on how you can help.
- **General Education Meeting (GEM)** – Planning continues for the annual GEM (Saturday, November 5). The following speakers have been confirmed:
  - ◊ **June-Anne Gold,** M.D. : "The Changing Face of PWS With Early Intervention"
  - ◊ **Melanie Silverman**, MS, RD, IBCLC : "Nutritional aspects of PWS"

  The Program Committee is pursuing:
  - ◊ A psychiatrist to address psychiatric aspects of PWS.
  - ◊ Experts to address Regional Center eligibility and Medi-Cal access.

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PWCF Public Awareness Activities

Julie Casey, President

Levitt Pavilion Concert Series summarized by Julie Casey

Prader-Willi California Foundation had the privilege of partnering with The Levitt Pavilion Pasadena (www.levitpavilionpasadena.org) for their summer concert series this year. Levitt Pavilion is a non-profit entity whose commitment is to "contribute to the well being of families through the arts in a learning and entertainment environment outdoors." As part of their free summer concert series, they partner with other local non-profit agencies to mutually raise awareness.

PWCF had an awareness booth at the July 20th children's concert, *Putumayo Kids Presents: Kids World Party with Asheba*. I had the honor of manning the booth with fellow parent **Kimberly Storr**. Long-time PWCF member **Mercedes Gutierrez** stopped by and stayed most of the evening, and one of the founding members of PWCF, **Bob Scott**, stopped by to say hi as well. Both he and Mercedes were very pleased to see PWCF having a public presence in the community. PWCF was introduced at the start of the concert as a community partner and several people stopped by to speak with us. A nurse from a local hospital came and gave us a donation check noting that she has seen a few babies born with PWS over the years and knows how difficult it can be. A physical therapist who recently started working with a young child with PWS eagerly spoke with us.

My belief is that the more PWCF is out in the community and the more the public hears *Prader-Willi Syndrome* and *Prader-Willi California Foundation,* the greater awareness we build. Well over 500 people heard these words on July 20th and saw our booth. These and our various other public awareness events held throughout California are building recognition of the syndrome which will help *all* of our children.

Kimberly Storr, Mercedes Gutierrez

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Board Corner continued from page 10 …

- **Outreach to Spanish-speaking Population** – Board members reaffirmed the importance of continuing to improve our efforts to outreach to the Spanish-speaking PWS population. For this year's GEM, we will accommodate our Spanish-speaking community with both a translator(s) and brochures printed in Spanish.
- **New Website** – The Board's website committee continues to work with **Ryan Delane** of WSMad on getting our new website designed and built. Progress, although slow, is encouraging. As part of the redesign we are developing a new logo for the PWCF brand. **Julie Casey** has done a stellar job at driving the sometimes contentious task of arriving at a consensus for the new logo. We're not there yet, but we're close.
- **Baseball and the Oakland A's –** The board discussed opportunities for "awareness" at the upcoming PWCF event, "Take me out to the ball game!", Oakland A's baseball on Saturday, August 13th. I'm a SF Giants fan (please, I cannot hear your boos), but I'll be there. The Board's **Michael Moore**, who continues to open doors for PWS awareness, is working hard to make something happen.
- **Is There a Doctor in the House? –** To generate interest in PWS research **June-Anne Gold** is researching the idea of sponsoring a young doctor for the National PWS conference.

Residential Services

- **Residential Trainings**
  - ◊ **Theresa McGrath** continues to receive high marks for her onsite residential trainings. At her June 4 training at Alta Regional Center in Sacramento over 70 participants received training. **Patti Diamond**, the Training Officer at Alta Regional Center, plans to notify other regional centers about the availability of this training.
  - ◊ **Lisa Graziano** recommended to the Board to pursue hiring an additional PWS Residential Service Training Consultant.
- **Residential Staff Training DVD** – **Fran Moss** and **Lisa Graziano** continue to work on the new Residential Staff Training DVD that will provide "generic" training that could be used nationwide.
- **"Guidelines for Home Visits" Document** - **Lisa Graziano** proposed the creation of a "Guidelines for Home Visits" document that group homes would provide to families.

Closing – It is an honor for me to work with the dedicated folks on our PWCF team. I know that for myself, I am often challenged, at times overwhelmed, with the demands of home and work. I suspect most all of you are too, but… we could always use your help!

Life should not be a journey to the grave
with the intention of arriving safely
in an attractive and well preserved body,
But rather to skid in sideways,
chocolate in one hand,
wine in the other,
body thoroughly used up,
totally worn out and screaming
"WOO HOO what a ride!"

Be Disaster Prepared

PWCF member **June Leitheim** called the office recently to suggest that families be reminded about how important it is to have an out-of-state contact number for emergency purposes. Experts say it's simply a matter of time when the next disaster will strike, so it's important to be prepared now.

In addition to the emergency kit "staples," care providers of children and adults with PWS are encouraged to add a few extra items to your kit, such as supplements, vitamins, medications, band-aids, and activity items such as arts & crafts and Word Searches.

Borrowed from AAA's *Westways*, September 2011 edition, the following is a checklist of disaster items you may need when the next disaster strikes.

☐ Water: one gallon per person per day for at least three days
☐ Food: at least a three-day supply of nonperishable food, plus a can opener
☐ Extra water and food for your pets, plus extra leashes, treats, and toys
☐ Warm blanket, extra set of clothes, and sturdy shoes for each family member
☐ Baby items, such as extra formula and diapers
☐ Prescription medications
☐ Supplements and vitamins
☐ List of allergies to any drug (especially antibiotics) or food
☐ Small hygiene kits, including a toothbrush, toothpaste (including Biotene for dry mouth symptoms)
☐ Personal sanitation items, including moist towelettes and garbage bags with plastic ties
☐ Mess kits, paper cups, plates, plastic utensils, and paper towels
☐ Battery-powered or hand-crank radio
☐ Flashlights and extra batteries
☐ First-aid kit with plenty of band aids
☐ A whistle to signal for help
☐ Dust mask
☐ Wrench or pliers to turn off utilities
☐ Local map or GPS device
☐ Cell phone with chargers
☐ Pocket knife
☐ Extra keys to your house and vehicles
☐ Emergency cash in small denominations; quarters for public pay phones
☐ Copies of important documents – such as birth certificates, insurance policies, and passports, in a waterproof container
☐ Permanent marker, paper, and tape
☐ Photos of family members and pets for identification purposes
☐ List of emergency point-of-contact phone number
☐ Out-of-State contacts

Volunteer Recognition Corner

PWCF is grateful to the following persons for raising public awareness of PWS:

Julie Casey and **Kimberly Pratto-Storr** at Levitt Pavilion
Mike and **Kirsta Moore** at the Oakland A's baseball game

Thank you to **Cameron Graziano** for helping to affix labels and stamps for awareness event mailings

Thank you to **Carolyn Meyer** for making it possible for a family and their child's IEP Team and school staff to receive a PWS Inservice Training

Police Officer and Past President of the Prader-Willi Syndrome Arizona Association **Tammie Penta** successfully helped a PWCF family avoid prosecution after the arrest of their child for shoplifting.

Principles for Improving Executive Skills

By Peg Dawson, Ed.D.

Executive skills are skills that [people] need to function independently. They include planning, organization, task initiation and sustained attention, goal-setting, decision-making, and problem solving.

For [persons] with learning disabilities or attention disorders, developing these skills often does not come naturally. Instead, they must be expressly taught through direct instruction and nurtured through close supervision. Following are some key principles to guide you and your child's teacher [or your adult child's residential and vocational work staff] as you work to improve the important skills listed below. [Please know that the principles outlined in this article apply to both the developing child and the grown adult with PWS.]

In all kinds of ways, parents organize and structure their child's environment to compensate for the executive skills their child has not yet developed.

Consider your child's developmental level
Understand what's normal for his age. If his skills are delayed or deficient you will need to intervene with tasks that match his actual developmental level. If you're not sure what's normal for his age, talk to his teacher and other parents.

Move from the external to the internal
Begin by changing things in her environment before trying to change her. For example, start with changing her physical or social environment, altering the tasks you expect her to perform, or changing the way you interact with her by providing cues, supervision, and encouragement.

Use—rather than fight—your child's innate drive for mastery and control
From an early age children work hard to control their own lives. Support this agenda by creating routines and schedules so he'll know what to expect. Build in choices to give him some control. Practice difficult tasks in small steps, increasing demands gradually, and using negotiation rather than authority.

Modify tasks to match work capacity
The goal is to teach your child to engage in work by getting her to override her desire to quit or to do something preferable. This is done by making the first step of a task easy and immediately following with a reward. Gradually increase the effort she must expend to achieve the reward; either increase the task demands or increase the amount of time you expect her to work before earning the reward.

Teach deficient skills
Rather than expecting your child to acquire skills through observation or osmosis, intentionally teach the skills he lacks. Define a skill and select a task with which to teach it. Outline the steps required to complete the task, and provide ongoing modeling, cueing, support, and supervision until he is able to perform the task on his own.

Provide the minimum support necessary for success
Adults often provide too much or too little support. In either case, the child does not develop the ability to perform the task independently. Determine how far your child can get in a task without help and then intervene. Do not do the task for her; offer enough support (physical or verbal, depending on the task) to get her over the hump and moving toward success.

Use incentives to augment instruction
Incentives can be simple (praise) or elaborate (a point system that lets him earn rewards daily, weekly, or monthly). For some tasks—and some children—mastery of the task is incentive enough. Other tasks, however, do not have built-in incentives. Rewards make the effort of learning a skill and performing a task less burdensome. Furthermore, placing an incentive after the task teaches the child to delay gratification—a valuable skill in its own right.

Provide supports and supervision until success is achieved
Parents often set up a procedure, see that it's working, then drop what they're doing yet still expect their child to be successful. For example, a parent may walk her child through the process of organizing his desk, then leave him to maintain the organization scheme before he's had a chance to practice and master it. Mastery does not come all at once; it's a process that requires your feedback all along the way.

Gradually cut back support, supervision, and incentives
While some parents fail to keep interventions in place long enough for their child to achieve success, others keep the same level of support and supervision in place long after their child is capable of acting independently. Remove supports gradually as your child achieves mastery of new skills. Remember principle No. 6: Don't cue or prompt your child when she doesn't need it. Likewise, don't go from all to nothing too abruptly. That's the equivalent of going from training wheels to pushing your child off on a two-wheeler and expecting her to ride without falling.

The long-term goal is to be able to send your child [or adult] out into the world armed with a set of skills he can use to tackle problems on his own.

For more information, see *Smart But Scattered: The Revolutionary "Executive Skills" Approach to Helping Kids Reach Their Potential,* by Peg Dawson, EdD and Richard Guare, PhD, Guilford Press, 2008.

Regional Center Eligibility: Pursue and Maintain

We hear it all too often: “My caseworker told me my child is doing so well he no longer qualifies for Regional Center and so they closed our case.” Or, “My child graduated from the Regional Center when she turned 3.” This article will provide a brief overview of Regional Center eligibility and why parents should pursue and maintain it.

A Regional Center is a private, nonprofit agency that is contracted by the state of California to provide services to people who have developmental disabilities. Regional centers receive their funding from the state of California and from private donations. There are 21 Regional Centers that serve approximately 220,000 developmentally disabled children and adults in California. The Lanterman Developmental Disabilities Services Act of 1969 is the law that spells out the rules and regulations that all Regional Centers must follow. Governed by their own board of directors, each Regional Center must abide by the Lanterman Act as well as adhere to their specific contract with the California Department of Developmental Services (DDS).

By definition *every child age birth to three years who has received a diagnosis of Prader-Willi syndrome is eligible to receive Early Start early intervention services provided by their Regional Center.* Additionally, it continues to be successfully argued that *all individuals with PWS should be made eligible to receive Regional Center services for the remainder of their lives.*

Shortly before your child turns 3 years old, your Regional Center caseworker will coordinate an assessment of your child in order to make a determination as to whether your child meets the criteria, as established in the Lanterman Act, to be eligible to continue to receive services provided by the state of California through the Regional Center system.

There are four specified diagnoses written into the law that are automatically eligible to receive services: Cerebral Palsy, Epilepsy (seizure disorder), Autism, and Mental Retardation. A “Fifth Category” for eligibility includes “disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature.” Many children with PWS will meet the criteria for Mental Retardation, a few will meet the criteria for Epilepsy, and the remainder of individuals with PWS can successfully be argued to meet the Fifth Category of eligibility. (Many years ago PWCF advocated California legislature to include PWS as an automatic eligible condition, but the then-Governor vetoed the bill. When the “climate” is right, we will once again pursue amendments to the law to include PWS.)

What kinds of services may be available from the Regional Center system? The following is a partial list:

- Early intervention services for at risk infants and their families
- Genetic counseling
- Family support and counseling
- Childcare, day care, diapers
- Lifelong individualized planning and service coordination
- Training and educational opportunities for individuals and families
- Resource development
- Social skills training
- Assistance in finding and using community and other resources
- Advocacy for the protection of legal, civil and service rights
- Work services programs
- Affordable housing

Many Regional Centers mistakenly inform parents that Regional Center eligibility terminates when the child turns three years old because the school district “takes over” or that the child has “graduated” out of the Regional Center system. While it is true that *Early Start* early intervention services end at age three years when the school district takes over responsibility for providing services that relate to the child’s *educational* needs, individuals with PWS may absolutely be made eligible to continue to receive Regional Center services.

Prader-Willi California Foundation strongly advises all families to maintain Regional Center eligibility no matter how well your child is currently doing because you never know what services your child or adult with PWS may one day need or want and it is far easier to maintain eligibility than to pursue it later. For families whose child is older than 3 years, it is *never* too late to apply for eligibility.

All families are encouraged to get a copy of the easy-to-read book *Rights Under the Lanterman Act*, written by Protection and Advocacy, Inc., and the Department of Developmental Services publication titled, *A Consumer’s Guide to the Lanterman Act.* The links and contact information for these books and organizations are listed at the end of this article. Stay informed of the laws; don’t let your child or your family be denied services you’re entitled to. You are your child’s best advocate!

If your Regional Center determines that your child does qualify for eligibility, you will be notified and your case will be transferred from Early Start and you will be assigned to a new case manager. Your current services should continue uninterrupted *unless* they can be provided by your child’s school district.

If your Regional Center determines that your child does *not* qualify for eligibility, you should be notified in writing and given the opportunity to appeal the decision by completing an appeal form that should be included with the letter. You have ten (10) days from

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Continued from page 15...

the date you receive your Regional Center's letter to submit your written appeal of this decision. You must submit your appeal form with your written request that you receive "Aid Paid Pending" within the ten (10) day time limit so that your appeal is properly served and so that services continue uninterrupted throughout the eligibility appeal process. Be sure to send your appeal letter Return Receipt After Mailing so that you have proof the Regional Center received your appeal. If you fail to submit your letter of appeal within the ten (10) day time limit, all of the services your Regional Center has been providing will be terminated. **Prader-Willi California Foundation strongly advises all families to appeal a Regional Center decision to deny eligibility to a child with Prader-Willi syndrome because it can be successfully argued that *all individuals with PWS qualify for Regional Center eligibility under current law.***

DDS currently contracts with Protection and Advocacy, Inc. (PAI) to help consumers and family members resolve disputes with their Regional Center. PAI services are offered free of charge, though the agency is often so overwhelmed with work it can be difficult to get assistance. If you have any questions about the services you are receiving or wish to receive, if you have been denied a service or the continuation of a service you believe is of benefit to your child and/or your family, and/or if your child has been denied eligibility, contact your PAI office. If PAI is not able to assist you, or if they can't help in a timely manner, you may wish to contact an attorney who has experience aiding families who have disputes with a Regional Center (and, if you have a school-age child, preferably one who is knowledgeable about the educational legal system as well), or contact the Prader-Willi California Foundation.

If you never utilize the services available through the Regional Center system, terrific! But if you or your child ever do need a service that is provided by the Regional Center, it is far easier to receive a service if you have maintained eligibility than to initiate the eligibility process and try to re-enter the Regional Center system.

Resources

- Directory of Regional Centers www.dds.ca.gov/RC/RCList.cfm
- Department of Developmental Services (DDS) www.dds.ca.gov
- *A Consumer's Guide to the Lanterman Act*, available from the Department of Developmental Services
- English Version www.dds.ca.gov/ConsumerCorner/docs/LA_Guide.pdf
- Spanish Version www.dds.ca.gov/ConsumerCorner/docs/la_guide_SpanishVersion.pdf
- Or call 916-654-1888 or write to Department of Developmental Services, Office of Human Rights and Advocacy Services, Attn: Consumer's Guide, 1600 Ninth Street, Room 240, MS 2-15, Sacramento, CA 95814
- *Rights Under the Lanterman Act*, (Book #5063.01), Protection and Advocacy, Inc.
- www.disabilityrightsca.org/pubs/506301coverpages.pdf
- Protection and Advocacy, Inc. 800-776-5746 www.pai-ca.org
- Association of Regional Center Agencies www.arcanet.org
- State Council on Developmental Disabilities

Research Opportunities

Parental Coping Strategies Qualitative Research Study: University of Phoenix education doctoral student Carol McLurkin, M.A., SpEd is conducting a study entitled, *How Parents Cope with Raising Children with Developmental Disorders: A Case Study.* The purpose of the study is to explore parental coping strategies. Ms. McLurkin is interested in conducting telephone or face-to-face interviews (in the Antelope Valley) with seven parents of a school-age child (age 5-21) with PWS. For more information or to schedule your interview, contact Ms. McLurkin at (661) 718-3699 or carol@mclurkin.com .

Home-Based Physical Activity Program for Children with PWS: Interested in having your family be more physically active? We are looking for children with PWS 8-15 years and one parent or guardian to participate in a 24-week home-based program using interactive console and playground games provided to them at no cost. Participation also requires four to five visits (3.5 hours long) to the California State University Fullerton campus. During the visits, the child will complete a health assessment, a very easy and accurate body fat measurement, and movement-related assessments. Children and parents will also complete questionnaires. Incentives include 1) $30 gift cards for visits; 2) keeping the provided sports and media equipment; 3) $60 gift cards during the program. Parents/guardians will be reimbursed for mileage for visits to CSUF. For more information or to participate in the study, contact the research office at 657-278-8737, 657-278-3671 or pwstudy@fullerton.edu or contact Dr. Daniela Rubin at 657-278-4704 drubin@fullerton.edu. Hablamos español.

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

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

PWS and Early-onset Morbid Obesity Natural History Study – All Persons with PWS: Conducted by Virginia Kimonis, M.D., Chief, Division of Genetics and Metabolism, UCI Med Ctr. The purpose of this study is to collect natural history information on PWS and early onset morbid (severe) obesity.
WHO: Persons with a confirmed diagnosis of Prader-Willi syndrome ages birth-60 years, receiving and not receiving growth hormone.
WHERE: UCI Med Ctr and General Research Centers at UCI Med Ctr. and Children's Hospital, Orange County in Orange, CA.
CONTACT: Virginia Kimonis, M.D. at 714-456-5791 or email at vkimonis@uci.edu or Sandra Donkervoort, MS, CGC research coordinator at 949-824-0521 or email at sdonkerv@uci.edu.

The Bumpy Bridge and the Big Man on the Beach

by Lisa Peters, Massachusetts

Eager to enjoy the last few sunny days of summer vacation, the boys and I drive to our local playground. I am surprised to see the parking lot jammed with SUV's and mini vans. It appears that I am not the only one saddened to see the warm, lazy days of summer come to an end.

The park has a playground area nestled under the shade of several large pine trees. There are many wooden climbing structures, a collection of slides, and a large truck tire swing that sits in the middle of the park. A thick covering of wood chips and fragrant pine needles soften the ground. There is also a small beach area that overlooks Pentucket Pond where Mallard Ducks and Cormorants frolic on the sandy shore.

My vehicle no sooner comes to a stop and Weston is out the door, one hand clutching a beach towel, the other hand holding his sneakers.

"Later Mom!" he shouts as he runs toward the beach.

"Stay where I can see you," I shout.

"OK Mummmm," he answers, annoyed with my motherly concerns and completely oblivious to what I have said. Like a flash he is gone.

Nicholas and I climb slowly out of the vehicle.

"Where do you want to go first?" I ask Nicholas, knowing exactly what he is going to say.

"The bumpy bridge!" He answers with a wide smile. He reaches for my hand.

The bumpy bridge is a miniature version of the rickety wooden bridge in Indiana Jones and the Temple of Doom. It has been built on chains so it sways precariously back and forth. It hangs only a few inches off the ground but climbs over large truck tires from one side of the playground to the other. There are ropes on each side of the bridge for children to use to help steady them, as they cross the creaky wooden structure. Few children need to use these railings as they run easily over the swaying planks, maintaining their balance thoughtlessly as they advance full-speed-ahead to the awaiting wooden castle.

For my son Nicholas, the bumpy bridge is not just a crossing device to get to the pretty castle. To him, it is like a gym, a place for him to exercise his muscles. It is an obstacle course. Like Project Adventure for kids, where he is free to practice his climbing skills and develop the confidence that most children instinctively posses. The bumpy bridge has steep hills. Every step causes the bridge to sway. This disrupts Nicholas's under-developed sense of balance and although he is nine years old, his low muscle tone and lack of coordination make it difficult for him to stay centered. He crosses the bridge like he is crossing a thin sheet of ice, he chooses his steps carefully. He must stop often, using the rope handles to steady himself.

The bumpy bridge is, by far, Nicholas's favorite activity in the park.

Nicholas is noticeably taller than the other children on the playground. They swarm past him like bumble bees flying quickly and confidently over the bridge to the painted castle. I take a seat on one of the wooden benches. Nicholas looks over to me for reassurance. I give him the mandatory secret thumbs-up sign. He winks and smiles, ready to begin his perilous journey across the bumpy bridge.

Holding my breath, I watch my son climb slowly and carefully. After several minutes, he finally reaches the castle and stops for a moment to rest, wiping the sweat that has started to roll down his face. He looks at me again and waits for our secret sign. While the other children wiggle their way into the castle, Nicholas stops, and turns around. He is not interested in joining the other kids in the coveted castle. He is more interested in crossing the bridge again. Only this time, I notice, that like the other more nimble children, he is trying very hard not to use the rope handles for support. He moves even slower now desperately trying to cross the bridge without touching the ropes, the sweat now pouring from his face.

Soon, another band of giggling preschoolers comes charging toward him. I take a deep breath praying they don't knock him down. He grabs the handles and stops. The mob of children passes all around him. I am ready to hear him scream, but instead, he smiles at them. He is not jealous of their ability to cross swiftly and easily. I, unfortunately, am having trouble suppressing this unhealthy emotion and feel saddened that my son must work so hard simply to cross a bridge.

As I continue to observe Nicholas, I notice that he is happy. He is enjoying every one of his careful steps. When he starts to wobble, he smiles and grabs the handles. And when more droves of children almost knock him over, he smiles again, enjoying every second of his tiring adventure. He is exhilarated and anxious to continue practicing the art of crossing with no hands. He is uninhibited by his differences. Instead, he embraces them. He does not obsess about the meaning of the word "normal". To him, he is the normal one, finding pleasure in the simple act of crossing a rickety bridge.

Continued on page 17 ...

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After several crossings, Nicholas starts to tire and tells me he is ready to go home. We head over to the beach area where Weston is playing. As usual, in the beach environment, Weston has found the perfect place to expel some of his restless energy. A group of small children has assembled around him. Like the Pied Piper of Hamlin, he is leading the tiny tanned tots in a game of skip the stones. Weston's gang of miniature beach combers search the sandy shore for flattened artillery.

"I found one," the boy in the green shorts shouts. He runs over to Weston and hands him the precious rock.

"Dude," Weston says coolly, "That's a good one, why don't you throw it?" He encourages the timid boy to throw the stone. He winds up and throws. The rock bounces off to the left and plunks hard into the water.

"Nice try guy," Weston says, encouraging the boy to try again.

After a difficult year at the middle school, Weston has found himself this summer. He has discovered that in a new environment like the beach, his boundless energy and keen senses are just the helpful skills he needs to make plenty of new friends and find interesting treasures. The same traits that got him in so much trouble at school now help him to navigate and flourish in the beach environment. The damage to his self-esteem is finally repaired as Weston learns that there is a lot to like about himself.

"Weston, it's time to go," I shout.

"Awwwww Mummmmm," he answers, "See ya latter guys," he shouts to his gaggle of giggling groupies.

As Weston, Nicholas and I drive away from the playground, I reflect on our summer vacation adventures. Each of my children has faced difficult aspects of their diagnosis, and yet each has found a way to overcome. Nicholas found his courage while crossing the bumpy bridge. Weston found it leading a group of small children on the beach. Perhaps each of them crossed their own bumpy bridge this summer, both boys concentrating carefully and choosing his own pathway across the difficult terrain.

I am sad our summer adventures are over, but for the first time in a long while I am looking forward to fall. I know the rope handles will be there if I need them.

The Importance of Conservatorship

by Tina, Cliff, and Deanne Peerson

Keith Peerson
2 weeks prior to death

Keith was so enjoying life. He actually started losing weight. Our biggest mistake was not getting guardianship before he was 18. Please let your parents know how important it is to apply for and receive conservatorship before their child turns 18.

We didn't have a very good understanding of the law. And unfortunately, our Regional Center didn't help in that matter. When we moved and changed Regional Centers, I knew we would have a struggle because they really emphasized having the "clients" get out on their own. Even though Keith lived away from home, he was in a non-PWS group home and that bothered me. As soon as he was placed, his counselor didn't see him for two months! Guess her job was done with him and it was on to the next "client." She had worked with Keith since we moved here and always made the comment about him getting out on his own! We fought it until this past October when he went to his Day Program and called to say he wouldn't be coming home. We didn't know where he was! We received a letter from his counselor stating basically if we didn't approve of his moving out, we couldn't have any contact with him! Keith did call after two weeks. He came to visit for Thanksgiving and told me that he didn't say those things, his counselor did. Not realizing that we only had a couple more months with Keith, I let it go.

I know that the job of a Regional Center caseworker is a tough one, but while we were trying to support Keith to be "independent" as much as possible, we also knew that he could *never* live on his own. Even when he moved out and I finally talked with his counselor, I asked her (it had been two weeks since he'd left our home) if she knew he needed his CPAP machine to breathe at night; she was just going to ask about that. Hmm, that information was in his file. Then she asked me if he snuck food. Hmm, shouldn't you have asked that *before* he moved out? Of *course* he snuck food… he was a 385 pound stealth!

I appreciate everything that PWCF and PWSA (USA) have taught us throughout the years. I am still continuing our membership as I think Keith would want this. And there still needs to be a cure.

Public Awareness Continued from page 11 ...

PWS Family Day at the Oakland A's

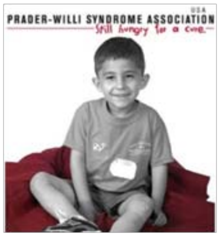
Though it was a smaller than expected crowd, those who did attend the Oakland A's baseball event on August 13 had a great time! The event was organized by PWCF Board Member **Michael Moore** who chairs the Public Awareness Committee.

Families gathered for some good 'ol fashioned fun on a beautiful, sunny afternoon. Before the game our group was treated to a visit from the A's mascot Stomper; great fun for the kids! Mike arranged for an awareness-raising message to be displayed on the A's Jumbotron where thousands of fans were exposed to Prader-Willi syndrome via the Prader-Willi California Foundation.

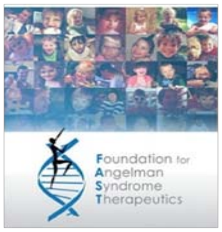
It's events like these where we reach "the masses" to increase awareness of PWS. Thank you to Julie and Mike, and thank you to every single person who attended one of these events. By your very participation, you are helping to increase awareness of Prader-Willi syndrome.

Stay tuned for next quarter's newsletter to read an overview of the September 17 event, PWS Family Day at the Galaxy Soccer Game, organized by PWCF Board member and Fundraising Committee chairperson **Drew Marich!**

Utah PWSA Wins Vivint Gives Back Contest



With PWCF's members' help, Utah PWSA won $100,000 in the Vivint Gives Back Contest with over 45,500 votes! Utah's president **Lisa Thornton** expressed her "thanks to all of you for all the work you have done voting and getting others to vote!" PWCF thanks all of our wonderful members for casting your daily votes for Utah PWSA. Without your help, Utah very well would not have won. Utah's winnings will help benefit all persons with PWS and their families throughout the country. Please view the wonderful video made by Vivint: http://www.youtube.com/watch?v=C-xytXwoPkw



It should be noted that the grand prize winner, with over 217,000 votes, was the Foundation for Angelman Syndrome Therapeutics who won $250,000! Angelman syndrome is the flip-side of Prader-Willi syndrome, where the deletion of genes occurs on the maternal 15th chromosome instead of the paternal chromosome.

Congratulations to Utah PWSA and all of the contest winners! PWCF expresses a *huge* thank you to Vivint who helped increase awareness of Prader-Willi syndrome all over the world. Winning this contest is a shining example of the great we can do when we work together.

For more information about Vivint security systems visit www.vivint.com

* * *

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

Prader-Willi California Foundation
2011 General Education Meeting

Friday, November 4, 2011
Meet & Greet Mixer 7:00 p.m.

General Conference
Saturday, November 5, 2011
8:00 a.m.— 5:15 p.m.

Renaissance
Los Angeles Airport Hotel
9620 Airport Boulevard
Los Angeles, CA 90045
310.645.5252

The ABCs of Managing PWS Behavior

Is There a Role for Psychopharmacology in Treating People with PWS?

WHAT and HOW to Feed a Child with Prader-Willi Syndrome

Update on PWS Research Including the Newly-Identified Nutritional Phases

Entitlements: Overview of Regional Center Eligibility and Medi-Cal Waivers

Share Sessions and Business Meeting

PWCF 2011 General Education Meeting Registration Form

Register online at www.PWCF.org or by check with this form

Early Bird Discount: Register by 10/12 and deduct $10 per person/couple!

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

Fees May Be Reduced or Waived Upon Request

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

Please Print:

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

____
Mailing Address *City* *State/Zip*

____
Telephone *Email*

Number of Vegetarian Lunches Requested: _______________

Youth & Adult Program "YAP" Registration

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

Fees May Be Reduced or Waived Upon Request

Names & Ages of Persons Enrolling in YAP Program:

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

Fee Calculation

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

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

○ Please charge my: ○Visa ○MasterCard ○AmExpress

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

Mail Registration Form with payment to:

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

PWCF is grateful *to the following supporters for helping us continue to provide quality supports and services to individuals with Prader-Willi syndrome and their families. Thank You!*

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

DONATIONS ~ July-September, 2011

Magnanimous General Donations
Susan & Mark Lewis

Donations in Honor of Samantha Morgan
Suzanne Privette

PWS Camp Scholarship Donations
Michelle & Kevin Donaldson
Patti & Tom McRae

Donations in Memory of Jean Lowe and in Honor of Alexandria Lowe
Kavita Reddy

Donations in Memory of Will Williams and in Honor of Lexi Higgins
Mary & Ronald Higgins

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Avery Barth & Andrew Barth, Trustees, Barth Family Trust
Victor Coleman
Lisa, TJ, Cameron and Daisy Graziano
Claire & D. Michael Van Konynenburg

General Donations
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Deutche Bank Americas Foundation – matched Tona Cota's donation
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Nan & Paul Freed
Judith Hein
Marion & Philip Hodges
Millennium - Matched Steven Vickers donation
Greg Hulbert
Ross Smith
Visa Givingstation – Matched donation from Brian Huff

MEMBERSHIP ACTIVITY
July-September, 2011

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

New Individual Members
Maria Carrillo
Kristin Keidl

New Family Members
Cindy & Mike Buchanan
Kim Cain & Keenan Morris
Eileen & Drew Higgins
Sandra & Dan Levine

New Extended Family Members
Penny Batt

New Auxiliary Members
Diana Karina Airles
Don Daughtry
Andres Ochoa Ozawa
Francisco Sanchez Perez
Angela Stage

Renewed Auxiliary Members
Jen Saliba, Grandview Elementary School

Renewed Extended Family Members
Dolores & Gene Albaugh
Tod Holdorf & Cassie Wilcox
Lianne & David Noddle
Mary & Pat Williams

Renewed Family Friend Members
Nancy & John Jenkins

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.