PWCF News

The Newsletter of Prader-Willi California Foundation

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

October-December ~ Volume 22, Number 4

PWCF HOSTS 2011 ANNUAL GENERAL EDUCATION MEETING

Even before the General Education Meeting began on November 5 at the Renaissance L.A. Airport Hotel, attendees were connecting and enjoying each other's company.





The following day, specialists in Prader-Willi syndrome presented on various topics. PWCF's executive director **Lisa Graziano, M.A., LMFT** presented on how Prader-Willi syndrome impacts the brain and the body, and how we as parents, extended family, teachers and care providers can develop strategies to better manage the behavior of our loved one, student, or patient. She noted that the brain of most people with PWS is wired to be a bit more oppositional, inflexible, impulsive, egocentric, to experience a higher degree of anxiety, and to have a lower tolerance for frustration. While we can't change the brain in our loved one, student, or patient with Prader-Willi syndrome we *can* change our own behavior which *does* change the behavior of our loved one with PWS. We must create clear rules and routines, boundaries, a calm environment, follow the Principles of Food Security, apply these to every area of life to create what she calls the Principles of Life Security, and NEVER give in to a tantrum.

Psychiatrist **Kenneth Herrmann, M.D.** presented on psychiatric disorders that are more common to persons with PWS. These disorders include mood disorders (Bipolar disorder and Depression, which are frequently expressed as irritability), Autistic characteristics, obsessive-compulsive disorder, psychosis, and Attention Deficit Disorder. Dr. Herrmann presented information about various medications that can help reduce the symptoms associated with each of the above co-morbid disorders, highlighted the pros and cons of each, including some of the more common side effects.

Pediatric Registered Dietician **Melanie Silverman, M.S., RD, IBCL** presented on what and how to feed a child with PWS. In addition to describing the role of calories, carbohydrates, proteins and fats in a healthy diet, she reminded families about the need to maintain meal structure and routines. She presented a pictorial food plate as a tool to help families know how much food to place on the plate. She encouraged the use of "smart" supplementation, and stressed the importance of daily exercise.

PWCF Board of Director, **June-Anne Gold, M.D., FACMG, MBBS, DCH, MRCPCH, RGN, RMN** provided a comprehensive overview of various research studies. Dr. Gold's research with Drs. Virginia Kimonis, Suzanne Cassidy, and Ellen Simpson revealed an increased rate of perinatal complications in newborns with PWS. It's possible that a disturbance in the placental structure and function due to the abnormality in chromosome 15 may be the reason for a disorder in the early growth changes. Newly identified phases of growth in PWS were outlined: 1a - Difficulty feeding; 1b - No difficulty feeding/growing, not overweight; 2a - Weight increasing *without* significant increase in calories; 2b - Weight increasing *with* significant increase in calories; 3 - Hyperphagic, food-seeking, never feels full. In a study looking at the correlation between Assisted Reproductive Technologies (ART) and PWS, ART *may be* associated with increased frequencies of maternal UPD and imprinting defects, however Dr. Gold cautioned that this study was based on a very small sample size.

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PRADER-WILLI
CALIFORNIA FOUNDATION

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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
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 find a pediatrician or general practitioner who is knowledgeable about Prader-Willi syndrome?"

The mother of a newborn diagnosed with Prader-Willi syndrome recently wrote to PWCF's online share group PWCFmembers@yahoogroups.com with the following important question; "I am new to the group. My newborn son has been diagnosed with Prader-Willi. Although I have a lot of questions I could ask right now, the first thing I am looking for is a recommendation for a pediatrician…. The group we started seeing isn't very familiar with [PWS] and our insurance canceled them from the network… So I am wondering if anyone might have a recommendation for a pediatrician in [our area]."

Welcome to the group… sort of (the group I know you never wanted to join!)… I'd like to share something from our experience, take it (or not) as you will. One thing we have found to be true for us is that we won't often find medical experts/specialists with specific PWS knowledge, so we work to find people who tend to be open-minded and willing to work with us to educate themselves. This has proven to be a good strategy over time – we've been fortunate to find medical people who don't look down their noses when I show up at an appointment (or even better, email in advance) with the latest abstract from a medical journal about PWS studies, treatments, etc., or even a reprint of an article for us "lay" folk from the PWSA newsletter The Gathered View. So, my point is, even if you can't find a specific recommendation for a doc in [your area] who has PWS experience with other families, if you can find an open-minded and communicative doc through other friends' recommendations and your own interview process, that can be just as effective in getting good care for [your baby].

I'm sure you've already heard that parents are the "experts" both on their own child and PWS; I believe the best scenario is to find a doc who is willing to listen to the "expert" – you – and [read all of] the written info you will bring them from other medical experts in PWS. Best of luck to you and your family, *Michelle Donaldson, mother of Whitman, age 21.*

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Michelle makes a great point! Our pediatrician is just the one we had with our older son (2yrs at the time Oscar was born). She turned out to be fantastic. She is very knowledgeable about typical medical issues, but knew very little about PWS before we came along. She has a positive attitude, listens very well, will contact specialists if we need, reads everything we give her, and never pretends to know more than she does. I think of it as a partnership. She's not an alarmist, trusts me and my intuition about Oscar, and advocates when we need her to. It turns out that Oscar and Ruby also have an even more rare (though milder at this point) disorder and she's been great at guiding us with this as well. Above all, she never put Oscar in a box and absolutely treats him as a child first -- a child who has PWS, but is not solely defined by PWS. Best of luck, and of course, welcome to the group!! *Mary Hill, mother of Oscar, age 11*

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For the first year of my son's life, I spent a lot of time worrying about having the "right" pediatrician who was knowledgeable about PWS and could help "lead" us through this journey. I was often upset because the pediatrician did not meet my expectations - I wanted him to tell me what was coming and propose remedies. I wanted a pediatrician who thought outside the box and was ready to tackle PWS. After about a year of disappointing visits, I realized it was not the pediatrician's fault for my disappointment, MY expectations were out of line!

Pediatricians are great for colds, immunizations and answering basic developmental questions. However, I do not think it is realistic for a pediatrician to be an expert in PWS. Your pediatrician needs to listen to your concerns, address them (if possible) and quickly refer you to the appropriate specialist when needed. Our pediatrician never questions my requests for a referral. I LOVE my pediatrician because he makes getting what we need easy. And I no longer expect him to guide me: I guide my son's medical treatment and refer to our team of specialists as needed.

I do believe it is VERY important to have an endocrinologist who is knowledgeable in PWS so that growth hormone can be prescribed at the appropriate dose. Of course it doesn't hurt to be in contact with Dr. Miller, Dr Kimonis, or another PWS "specialist" either. We take part in the UC Irvine Natural History study and check in annually with Dr. Miller to make sure we aren't missing anything important. Having this "team" in place has allowed us to monitor PWS and let the pediatrician focus on what he is good at. *Susan Hedstrom, mother of Jayden, age 2.9 years*

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Maddi (now 5.5) started out with a pediatrician who knew nothing about the syndrome. When diagnosed, he handed me a google printout of the definition of the syndrome and told me I needed to contact the regional center for more help. In the days and weeks to come, the research I had done and provided him with (along with the DVD the PWSA sent me for the dr.) was never once looked at in 6 months. At that point, we looked for a different pediatrician.

We did not look for a pediatrician who KNEW the syndrome per say, we looked for a pediatrician who was interested to learn about it and open to working with me to help Maddilyn in all ways possible to give her the best care. That, I think, is the key. Within the first week we were his patient, he had watched the DVD, did all his own research and called me twice to ask me questions regarding the syndrome. We have received the best care from him that I think she could possibly receive. When he is not sure about something (because of the PWS) he is immediately on the phone with other doctors or does whatever he can to "figure it out". I believe it is a team effort. If you expect a pediatrician to know everything about the syndrome when you go into it, you will set yourself up to be disappointed. Always be open-minded and be willing to work WITH your doctor, not against them. *Shelbie Smith, mother of Maddi, age 5 years*

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Parent to Parent Continued from page 3 …

Don't give up, keep asking questions when you meet the doctor. First thing to ask: "Do you KNOW about PW?" Answer should be a definite yes, and goes on to tell about the syndrome. You don't want to hear: "Yes, I've heard about it." That is the line I heard for years, don't go for that one. To me it means the doctor knows NOTHING, just "heard" about it. Be diligent and never give up looking for the right doctor. Have gone through 3 doctors one year alone, until the right one was found. Sometimes the Regional Center can assist in finding a doctor with the experience needed. *Tina Peerson, mother of Keith Peerson*

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I don't actually worry about our pediatrician being knowledgeable about PWS. I just want a doctor who is open-minded and willing to listen to my input (information I've obtained from PWS publications, conferences, other parents, etc.) and willing to refer to appropriate specialists and/or consult with them as needed. Luckily for us the pediatrician I selected before Ryan was born is such a doctor. When he first saw Ryan upon discharge from the NICU, after acknowledging the difficult few weeks I'd been through, admitted that he only had cursory information about PWS and said that it would be important to build a team of doctors that worked together to benefit Ryan. He has always treated Ryan as a kid first, not as a kid who has PWS. By this I don't mean that he ignores the syndrome, rather he simply evaluates Ryan as he would any other child AND then factors in anything that might be different because of PWS. He reviews the reports from other specialists, always acknowledging and commenting on them when we see him. No doubt his knowledge of PWS has increased because of having Ryan as a patient, but I still don't expect him to be an expert because that's not his role. However, if we had a pediatrician who was unwilling to listen to my input or tried to act like they did know everything about PWS, I'd be shopping or a new doctor! *Julie Casey, mother of Ryan, age 7 years*

Next issue's Parent to Parent question is, *Does anyone's child or adult child with PWS experience bullying and if so, how do you help your child/adult child respond to it?"*

Food Tip

This food tip was inspired by a Family Support Meeting held this year at the Children's Hospital Orange County (CHOC) where this delicious snack was served

Fresh fruit is not always available, so whether you're in the car on your way to the next therapy or doctor's appointment, Brothers-ALL-Natural Fruit Crisps is a great new alternative to get your daily fruit allowance.

Brothers-All-Natural Fruit Crisps are a 100% freeze-dried fruit snack. Brothers starts with luscious fruits from the greatest growing regions in the world and brings them to their state-of-the-art freeze drying facility where they gently remove over 95% of the water from the fruit which transforms it into a light, flavorful, crisp fruit snack. Unlike other dried fruits, Brothers-All-Natural Fruit Crisps retain all of the nutrients of the fresh fruit with absolutely no added sugar, preservatives, or dies. Their uniquely designed bags keep Brothers-All-Natural Fruit Crisps fresh for up to 1 year. Brothers-All-Natural Fruit Crisps are peanut/tree nut free, gluten free, soy free, dairy free, vegan, and OU kosher certified. A bag of Brothers-All-natural Fuji apples contain approximately 1 ½ apples and is only 39 calories, 9 carbs, and 6 grams of sugar.

Gadget Tip

Spiffies Tooth Wipes

www.spiffies.com

Cavity causing bacteria can live in your baby's mouth before their teeth arrive. Use Spiffies to clean your baby's teeth, tongue and gums and also help keep the bacteria away. And using Spiffies Toothwipes after each feeding is not only healthy, they begin to start your baby being comfortable with having their mouth regularly cleaned.

Spiffies are individually packaged towelettes that have been soaked in a great tasting xylitol solution, a natural ingredient that prevents cavities. They can be used to clean baby's gums and first teeth without using a toothbrush. Spiffies' delicious grape, apple and mango flavors make oral hygiene a pleasure for you and your little one.

Spiffies were developed by a practicing pediatrician, Dr. Ray Wagner. Protect your child's future smile by caring for their teeth before you see them.

Spiffies products contain Xylitol, a natural food substance, that gently fights cavity-causing bacteria.

Tip for Teaching Kids to Brush When teaching children to brush, place toothbrush at a 45 degree angle; start along gum line with a soft bristled brush and brush in a gentle circular motion. Brush the outer surfaces of each tooth, upper and lower. Repeat the same method on the inside of surfaces of all the teeth. Finish by brushing the tongue to help remove the bacteria on the tongue.
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Executive Director's Column

My husband recently developed symptoms caused by a difficult to treat medical disorder. One night as we were discussing his symptoms, I tried to reassure him that he'd get through this, that we'd get through this together. To my surprise, he shared how disappointed he felt because I clearly didn't understand what he was going through. *What? How could he feel so let down when I was trying so hard to express my concern and support?*

I believe this experience is felt by many who are touched by Prader-Willi syndrome. In my work with families I frequently speak with parents who lament that their parents or in-laws "just don't get it, just don't understand." And while I don't hear these stories as often, I'm sure there are plenty of grandparents, siblings, and other extended family members who experience a lack of support or understanding from their friends and family.

While there certainly are those who appear to have absolutely no insight into how off-putting or upsetting their words or actions are, the things that parents describe as unsupportive about their in-laws' or their own parents' behavior often sound to me like well-intended expressions of support.

But support can be quite the subjective experience, with an enormous chasm between what is *meant* to be supportive and what is *experienced* as support. When it comes to communicating within the world of disabilities and particularly within the world of Prader-Willi syndrome, what others *want* to express as support or reassurance can all too often miss the mark and be perceived instead as a lack of understanding or even discounting. The result of these missed marks in communication can leave *everyone* feeling sad or alone or annoyed or even angry.

I wish I knew a magic formula to share regarding how to express care and concern in such a way that they will *always* be perceived as supportive. Unfortunately, I clearly don't know any magic formula – just ask my husband!

Maybe, as givers of support, it would be helpful if we listened more, gave less advice, learned more about Prader-Willi syndrome, and followed to the tee the directives that the well-informed parents of our loved one with PWS ask of us. Maybe it would be helpful to share that we really *want* to be supportive but feel at a loss to know exactly *how*.

Maybe, as parents in want or need of support, we could try to look beneath the stumble of not-so-helpful words that come tumbling out at us to see their kindly intent. We could gently and clearly share – again (and again and again, with as much patience as we can possibly muster) – what *would* be helpful. The support we receive may not feel "perfect" but it may just feel "good enough."

If we've gently and clearly and repeatedly shared what would be helpful *and our expectations are realistic*, but the individual from whom we're asking for support is not obliging, then we may need to come to the understanding that we must look elsewhere for the help or support or understanding we desire.

As we enter the hustle and bustle of the holidays, there will no doubt be plenty of opportunities to practice asking for and offering support. Sometimes we'll get it right, and sometimes we won't. Sometimes others will get it right, and sometimes they won't. If we're lucky, we'll get it right more times than not, and others will come through for us or come close enough more often than not.

As for me, I'll be the one continuing to stumble forward in search of different and more effective ways to express my care and concern and support to my husband.

On behalf of the Prader-Willi California Foundation, I send you my most sincere wishes for more spot-on connections with your family and friends, and all of the support you need today, tomorrow, and throughout the New Year.

Please Be A Shining Star

PWCF recently mailed our Shining Star holiday greeting cards which also give you the opportunity to make a donation in honor or in memory of your loved one, family friend, patient, or student.

Donations will fund PWCF's camp that *exclusively* serves persons with PWS ages 8-65 years; fund multidisciplinary PWS clinics, fund residential staff training programs and other educational trainings; fund advocacy services to help children receive the support they need at school; fund equipment and furniture used in group homes and vocational work sites; and so much more.

Please make your tax-deductible donation today and be a Shining Star to someone you care about. Want to use your credit card instead of sending a check? Just give us a call at 800.400.9994 or outside California call 310.372.5053 and we'll process your donation over the phone and notify the family you honor.

Top Ten Strategies to Survive and Thrive During the Holidays

From Latham Centers Blogspot http://lathamcenterspws.blogspot.com

1. **Remember how lucky you are**. Ultimately, the holiday season is a time of reflection and a time to give thanks. Families touched by Prader-Willi Syndrome have much to be thankful for and the more you can stay in touch with the spirit of the holiday the easier it will be to get over the bumps in the road. Consciously stop and list the many reasons for gratitude. This simple mental shift can alter the entire experience.

2. **Choose your landing spots carefully**. Maybe Aunt Mary's house is not a good place for you to go. Every year she disregards everything you have told her about PWS and you leave her house a frenzied mess. You can say no and you must say no to these "obligations". During the holidays especially you must surround your family with people that make your life easier not more difficult and show a level of understanding that supports and nurtures your family rather than obstructs or hurts them. If the people aren't right, the location is wrong or there are too many unknowns, opt out of those events. It is better to hurt some feelings than to be involved in a messy spectacle. The people who truly love you will understand your choices and will stick by you no matter what.

3. **Maintain regular routines**. As much as possible, you want to maintain the same consistent schedule you had pre-holidays. This consistency is relied upon by your child to create their own internal sense of security and when it is upset there is increased anxiety. With holiday parties and different people, this can be a difficult goal to achieve. Even if it is only maintaining the basic structure and important anchor points - like meal times, TV shows, nighttime routines - then do that, but the more you are able to keep things normal as usual the more success you will have in the holidays.

4. **Plan ahead**. During the holidays do "advanced scouting" and create a plan. These new experiences are exciting to many, but for individuals with PWS they can be overwhelming and debilitating. The more we can do to alleviate the unknown the better. Get menus of holiday meals, pictures of family members you will see, lists of activities and go over all of these items with your child well in advance of the outing. Create a specific game plan you will follow including, arrival/departure times, specific food plans, list of clear expectations. Stick to it through the entire event.

5. **If everyone is watching then no one is watching**. Make sure that someone is specifically assigned to be with your child at holiday parties especially around food or opportunities for food. When you assume that everyone is there and watching when at a crowded party then typically no one is and things can happen. Take turns providing individual support and oversight so that you also have time to relax and enjoy yourself.

6. **Be realistic**. Even though it doesn't always feel this way, there are no obligations in the holidays that must be met. The truth is there are some events that may not be appropriate for your child. It is better to act from this forethought rather than crossing your fingers and jumping into something that ends badly. Even if you are scheduled to be somewhere and you realize that your child isn't in the best space for handling this new situation, you can opt out. You know your child better than anyone and must act on your instincts. Don't let other's expectations determine your actions.

7. **Have an escape plan**. There is a good chance that not every party, outing and/or visit will go well. Be prepared for and understand that fully before going into each situation. Having a plan will allow you to react seamlessly if things arise during the event. Ask yourself what you will do if your child is overwhelmed or acts out at the event. For example, take two cars when you go out so that just one person must leave with your child rather than the entire family. Plan for the worst case scenario and that way you will be prepared in the event that it does.

8. **Create special moments for everyone**. Although it takes extra planning, and often comes with more stress, the holidays can be navigated very successfully by any family touched by Prader-Willi Syndrome. In order to do this, you must be thoughtful in your plans for all family members. Create special family traditions that support and nurture all family members. Although you might have to do things differently, the holiday routines you create can be even more satisfying.

9. **Take care of yourself**. Even though this is easier said than done, it must be a priority. Find ways to care for yourself and reduce your own internal stress. Even 15 minutes walking around the neighborhood can do wonders to your ability to handle stress. Whether it is exercise, hot baths, quiet reflection (outside of the house if necessary) or shopping, find little ways to stay balanced. If you don't take quality care of yourself then you are unable to help anyone else.

10. **Laugh**. Keeping a sense of humor can save your sanity and your holiday spirit. Understand that when you are stressed, your child with PWS is very sensitive to that and often feels unsafe and insecure as a result. Attempting to stay "light" and "free" in the chaos can be just enough to change that message. This is very, very difficult to do during the holidays for everyone. Keeping things in perspective and changing your focus to what is going right can be very helpful.

"I am thankful for the mess to clean after a party because it means I have been surrounded by friends." Nancie J. Carmody

Annual General Meeting Continued from page 1 …

Research on the use of Growth Hormone continues to confirm the benefits to persons with PWS, and does not work differently in patients with Deletion versus those with UPD. In exciting studies involving potential medications, Dr. Gold reported that researchers are looking at Oxytocin as a useful medication to increase trust and decrease disruptive behaviors in patients with PWS. In another study, Exenitide (marketed as Byetta) is being looked at as a potential drug to treat the hyperphagia (appetite) symptom in PWS because it appears to be a central appetite suppressant, however a serious side effect is that it also has the potential to slow stomach emptying, already a serious problem for many with PWS.

Eva Casas-Sarmiento, Esq., Client's Right Advocate with the Office of Clients' Rights Advocacy of Harbor Regional Center, outlined California's laws regarding how persons with PWS may be made eligible to receive Regional Center supports and services. Someone with PWS who doesn't also have Mental Retardation, Seizure Disorder (Epilepsy) Autism, or Cerebral Palsy may be made eligible through the "Fifth Category" which allows for eligibility if the condition is similar to or requires similar treatment to someone with Mental Retardation and if there are deficits in significant areas as outlined in the law. (Most of the areas of deficit listed in the law apply to persons diagnosed with PWS, making for a successful argument for eligibility.)

Ms. Casas-Sarmiento also presented on Medi-Cal waivers which allow California to pay for services in the family's home (vs. instead of an institution) or to help persons transition out of institutions and back to their family home. Medi-Cal is based upon income, but a Developmentally Disabled Waiver (DD Waiver) can be granted to someone with PWS if they receive at least one Regional Center service and they would qualify for services though one of the institutions listed in the waiver. The list of potential DD Waiver services includes home health aide services, nutritional consultation, supported employment, adult residential care, and crisis intervention. To get on the DD Waiver, contact your Regional Center case manager who will submit a packet to Medi-Cal on your behalf. You will be sent a packet of forms to complete regarding financial status. Medi-Cal will then determine financial eligibility, and then determine medical necessity for waivers as appropriate.

During the Business Meeting, PWCF's President, **Julie Casey**, presented a number of President's Awards. **Carl Martens** received an award in recognition and appreciation of his long-standing dedication to PWCF, his work on the Board of Directors, and his work to improve the quality of life of adults with PWS.

Mike Moore

Michael Moore and **Drew Marich** were each recognized for their work on the Board of Directors and their work to increase public awareness.

Renee Tarica

PWCF's treasurer, **Renee Tarica**, received an award in recognition and appreciation of her sustained dedication to PWCF and her work on the *Walking for PWS* events which, since 2001 have raised a staggering $600,000 to improve the quality of life of all people with PWS.

Jessica and Chris Patay were recognized for gathering 19 people who ran more than 200 miles to raise over $27,000 to support the work of PWCF.

The Patays

Linda Ryan received an award for her work to create PWCF's new camp that exclusively serves persons with PWS while providing respite for their families.

Fran Moss was awarded for her contributions to the creation of PWCF's new Prader-Willi Syndrome Residential Staff Training DVD. **Linda Hamilton** also received an award for her contributions to the DVD, as well as **Mercedes and Albert Salaz** who produced it.

Linda Ryan

Tammie Penta, an Arizona police officer and PWS parent, was appreciated for her work help a California adult with PWS successfully avoid legal prosecution.

Julia and Jeremy Rutledge were recognized and appreciated for their work to raise over $6,000 for Northern California's *Walking for PWS* event within one month of joining PWCF.

And finally, **Laura Shea** received an award for her Tea for a Cure event which raised over $8,000 for PWCF and PWSA (USA).

The Youth and Adult Program was expertly directed by **Zoe Raleigh, Kimberly Postal, Kristen Amarasekera,** and **Jennifer Yamamoto**. **Will Raleigh** joined the team in the afternoon to conduct a Sibling Share Session. The theme of this year's program was *Dance Your Socks Off!* Everyone enjoyed the day's activities, the delicious and healthy meals, and had a *great* time at the dance gig brought in by Party Creations.

Julie Casey, assisted by **Kimberlee Morgan**, recruited over 40 students from local universities to administer the day's programming and ensure the safety of all attendees. Most of the volunteers were nursing students from Marymount University who were truly amazing people!

PWCF Recognizes Special People and Organizations Who Contributed to the Success of the 2011 General Education Meeting

Prader-Willi California Foundation expresses our sincere appreciation to **Confidence Foundation** for their generous grant to support the conference, and our gratitude to **Arlo Sorenson** who nominated PWCF for a grant.

We are extremely grateful for the generous grant received from the **Joseph Drown Foundation** which helped support this year's conference, as well as support additional educational and support programming.

We are indebted to **Corporate Translations** for significantly reducing the cost of two Spanish language interpreters to help us educate our non-English speaking families. We are especially grateful to Corporate Translation's **Richard Gronbach** who went above and beyond the call of duty to ensure the success of interpretation services.

Continental Interpreting donated all of the translation equipment, including the sound-proofing box and headsets. PWCF members **Helen and John Lim and their daughter Amie** deserve special thanks for transporting the equipment to and from the meeting site.

PWCF gratefully thanks **Pat Grey, Rose Sakurai, and Paula Watney** for their donations to support the conference.

We wish to thank the following individuals for their special contributions to the success of the conference:

PWCF member **Carina Chiaj** translated the General Education Meeting brochure into Spanish so that they could be mailed to all of our Spanish-speaking families.

Cameron Graziano, age 12 with PWS, placed the stickers on all of the meeting packets.

PWCF member **Angela Lucero** and her co-worker **Karin Boresoff** filled all of the meeting packets, folded brochures, prepared meeting signs, and organized and filled the Youth & Adult Program Activity boxes.

Maureen Riley, adult sibling, assisted with Registration alongside her mom **Fran Moss**.

Board of Director **Tom McRae** created a PowerPoint highlighting the supports and services available to families and professionals from the Prader-Willi California Foundation.

Kimberly Pratto-Storr took wonderful pictures of the conference.

New Spanish-Language Resources for Families on LD.org Recursos en Español on LD.org

http://www.ncld.org/recursos-en-espanol

Today one in five schoolchildren are Hispanic, and Spanish-speaking families need access to information about learning disabilities (LD) and other resources to help their children receive the services and supports they need to succeed in school and beyond.

The National Center for Learning Disabilities (NCLD) has launched an extensive toolkit in Spanish to help families recognize potential signs of LD, work with their children to develop and enhance skills, and be an advocate for their children who are getting ready for school as well as those who are enrolled in K-12 education settings. This comprehensive toolkit includes:

- 30+ articles that provide information on
  - ~ Learning disabilities, such as dyslexia, dyscalculia, dysgraphia
  - ~ How parents can stand up for their child's rights
  - ~ Behavior challenges and LD
  - ~ Supporting a child's success in school
  - ~ Helping a child to develop "success" skills such as pro-activity, self-awareness, and perseverance
- Handy worksheets
- An interactive LD Checklist

"Early detection of barriers to learning can be life-changing for young students, and every Spanish-speaking parent and caregiver should know about these free resources," said James H. Wendorf, executive director of NCLD. "Now Hispanic families can access online tools and information in English and Spanish that will help them to be effective advocates for their children."

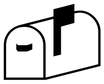
Don't forget that Prader-Willi California Foundation has a number of resources specific to Prader-Willi syndrome for Spanish speaking families.

Kids Say the Darndest Things

Submitted by PWCF member and sibling Kristen Amarasekera

Sibling **Kevin Amarasekera** commented on the dirty dancing going on at his sister, Lauren's, dance last night and said, "Lauren had better not be doing dirty dancing." Lauren, who has PWS, quickly retorted "Kevin, I HAD A SHOWER before I went!"

PWCF Gets Mail…



Dear PWCF: …I have been meaning to write you and thank you for the great PW meeting last weekend! [The *ABCs of PWS Behavior* presentation] was… meaningful to parents and caretakers. All of those suggestions we have heard before, but they NEED TO BE REPEATED OVER AND OVER and it is somehow reassuring to parents and caretakers to know that others stumble over not always responding as we should, even when we know better. The frustrations are shared by other professionals who also know better. Thanks again for reminding us of HOW WE SHOULD BE RESPONDING. I hope you will give the same presentation at every meeting; it is very inspiring as well as comforting to know that we are not alone. And I assume that even professional caretakers appreciate reminders of what challenging behavior is part of the syndrome, and not idiosyncratic to an individual…. Thank you for all you do for PW and for our children! *Peggy Smith, grandmother*

Dear PWCF: Thank you [Theresa McGrath, PWCF's Residential Training Consultant] for your informative presentation on PWS. I needed a few days to digest all the information and am now ready to move forward. As you know, it will not be an easy road but it is a necessary one. Having all of the extended family, teachers, friend and behavioral specialists on board will help to ensure that we stay on the right track.

Your stories are truly inspiring and I hope that one day we can look back and be another success story. Thank you for your dedication to the syndrome and for helping to inspire those with PWS to live their best life. Please check in every now and again to make sure I stay dedicated and focused. Many, many thanks. *Wendy Higgins*

Dear PWCF: Thank you - for all that you and your staff have done, not only for Keith but all current and future [persons with] PW. Will keep in touch. *Tina Peerson*

Dear PWCF Board of Directors: I would like to take this opportunity to thank each of you for your support and generosity in funding our first Prader-Willi Easter Seals/Camp Harmon camp. It was a huge success!

When the camp Committee and I first began investigating the possibility of a camp solely for our loved ones with PWS, I never thought we could pull it together for this summer. Amazingly, thanks to the cooperation and hard work of all of you, our executive director Lisa Graziano, Camp Harmon personnel June Stockbridge and Monica Alvarez and myself, in July we were able to provide a memorable week of camp for our children as well as much needed respite for our families.

No aspect of my work was more important to me than making sure that we had a fun and safe environment for our children. Lisa's willingness to remain at camp for the entire session ensured that we could do just that. In addition to providing a brief training to Camp Harmon's counselors, she was an invaluable help to the staff during some of the difficult moments that arose. Fortunately, there were few incidents and all were resolved well. Camp Harmon was so pleased with the outcome that they are looking ahead to provide us with another session next year!

In closing, I would like to recognize your willingness to pursue our goal of a PWS specific camp and for the financial support you granted to provide this opportunity to [all] of 50+ campers. PWCF's money was well spent! On behalf of our campers and their families, I sincerely thank you. Warmest regards, *Linda Ryan, PWCF Camp Coordinator*

Dear PWCF: I've just received your July-September 2011 newsletter. The article on Regional Center eligibility contains a major error. It states: "There are four specified diagnoses written into the law that are automatically eligible to receive services: Cerebral Palsy, Epilepsy, Autism and Mental Retardation." In fact, the definition of "developmental disability" used by California includes the definitions cited but in addition, the condition must constitute a substantial disability for the person, defined as "significant functional limitations in three or more of the following areas of major life activity…"

1. Self-Care
2. Receptive and expressive language
3. Learning
4. Mobility
5. Self-Direction
6. Capacity for independent living
7. Economic self-sufficiency

Many individuals are denied eligibility for regional center services despite having one of the above diagnoses because their condition does not rise to the level of affecting three or more life areas. This is particularly true with younger children as several of these categories are almost impossible to assess in young children.

Secondly, please note that Protection & Advocacy, Inc (PAI) changed its name to Disability Rights California several years ago.
Roberta Newton, Executive Director, Developmental Disabilities Area Board 10

Board Corner

PWCF Board of Directors Meeting of September 21, 2011

by Don Carlson

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

Awareness & Fundraising Events

Walking for Prader-Willi Syndrome Events 2012 (Drew Marich)

- Southern CA Event Location & Date - We will be using Griffith Park for the So. CA Walk in 2012. We need to meet with the park representative to determine the best walking path. As of right now we have a date of 4/29/2012.
- Central CA Event Location & Date - The support group meeting is scheduled for 10/29 and they will discuss the date and location.
- Northern CA Event Location & Date - We have put in an application to reserve the Crissy Field in Golden Gate Park for three Sundays: 4/22, 4/29, 5/6. Mike indicated that the fees for this location are $300.00-$500.00 for 200 or fewer people.

Grant Writing

Drew indicated that he feels very confident in our grant writer's skills, YES! Communications. Based on his conversation with the grant writer, the brief statement about monies held in our investment reserves that Lisa prepared is currently sufficient. As soon as the survey for PWCF's HOPE program (Helping Our People Excel), wherein PWCF will work to ensure a high quality of satisfaction for residents in group homes, vocational programs and day programs, the Board will develop the explicit long-term strategic plan for expenditures of investment monies.

Family Support Coordinator Salary - The board discussed that we should beef up the salary requirements for this position to include all related expenses.

Treasurer's Report

- Treasurer Renee Tarica reported the current operating budget.
- 2010 990 tax form are in progress.
- Drew Marich has drafted up questions for a potential new investment firm and the Board gave additional input. He will report back with the potential new firm's responses.
- Race for PWS Funds: Lisa recommended and the Board approved funding the family support coordinator position with monies raised by this fundraising and awareness event.
- Lisa recommended that the Board obtain a Financial Review due to the fact that it has been several years since the last Review. The Board agreed that a Financial Review be completed in 2012.

Long-Term Strategic Planning

- Tom McRae reported that the progress on the website design is moving forward, albeit slowly.
- Julie Casey commented that the logo captures all of the desired elements. A motion was made to approve the logo design but to possibly tweak the colors.
- Julie Casey reported that the HOPE on-line survey has been completed but has not launched yet. We are hoping to have it available for completion at the General Education Meeting. At its first meeting in 2012, the Board will review the data and determine the next direction to take toward accomplishing PWCF's long-term goal to ensure a high quality of satisfaction amongst persons with PWS in their residential and vocational lives.

Awareness Committee Report

- Facebook & Twitter updates were given by Julie.
- Oakland A's Event Report - Mike reported that 31 tickets were sold. He indicated that everyone who attended had a good time. A's mascot, Stomper, visited and PWCF was listed on the jumbotron.
- Galaxy Update - Drew reported the Galaxy event had a good turnout for the game and everyone seemed to have a good time. Participants got to meet with a player for pictures and autographs.
- Napa golf event - Paula reported that the golf course is secured and the event, spearheaded by PWCF member Sam Cropper, will take place on June 22nd 2012.
- The "About PWCF" DVD is on hold pending the completion of the new Residential Staff Training DVD.

Program Committee Report

- PWS Camp - The 2011 camp was an overall success! The camp staff was wonderful and we are looking forward to next year at Camp Harmon.
- 2011 PWCF Conference - The General Education Meeting is all set for November 5th at the Renaissance Los Angeles Airport Hotel.
- Misc. Conferences/Training Programs - Lisa is scheduled to do a presentation to marriage and family therapists and social workers at St. Francis Medical Center's Mental Health Department in Lynwood.

Continued on page 11 ...

Board Corner Continued from page 10 ...

Residential Services Liaison Committee Report

- Residential Staff Training DVD - This DVD is in its final stage of production.
- Residential Facilities
  Most homes contacted reported that they are experiencing full occupancy. The recently re-opened Griffin home has vacancies and welcomes inquiries.
- PWS needs to focus on the aging PWS community with emphasis on those people with medical needs.

Executive Director's Report

Lisa submitted her report highlighting two advocacy cases.

- PWCF should write a letter to OC Regional Center to oppose their recent written position advocating for the termination of parents' conservatorship of their adult with PWS.
- PWCF should recognize Officer Tammie Penta of Arizona for her assistance in having charges dropped regarding a PWS individual for a minor charge.

Nominating Committee Report

Drew reported that:

- Drew's and Mike's terms are up at the end of the year and they will not run for re-election.
- Renee's term is up at the end of the year and she will run for re-election.
- Nominees for the 2012 Board are: Roger Goatcher, Kim Morgan, Whitney Brass and Renee Tarica.
- The Board will contact Kim Morgan to request that she re-join the Board immediately in order to fill the seat vacated by Carl.

Adjournment

The next meeting is scheduled for January 28th or 29th 2012.

PWCF's Board of Directors expresses its heartfelt gratitude to **Carl Martens** who retired his seat on the Board of Directors after serving Prader-Willi California Foundation in excess of 20 years.

The Board appointed and welcomes back former Board President, **Kimberlee Morgan**, who will complete Carl's term.

Researchers Focus on Exenatide As Potential Weight Loss Medication in Overweight Adolescents with Prader-Willi Syndrome

Exenatide (Byetta; Amylin Pharmaceuticals, San Diego, CA) is a subcutaneous injection given twice a day which has been shown to lead to weight loss in adults. We are starting a study to see the effects of exenatide on obesity factors in overweight patients with Prader-Willi Syndrome between the ages of 13-20 over a 6 month period. The study will involve 5 visits to Children's Hospital of Los Angeles (CHLA). There will be an initial screening visit which involves blood tests and if the patient qualifies, 4 more visits will be scheduled at CHLA. All visits will include physical exams, blood draws, as well as an appetite questionnaire. In addition, two of the visits will include a mixed meal tolerance test (MMTT) and a DEXA scan. The MMTT involves placing an IV and a series of 4 blood tests over 2 hours. The DEXA scan is an x-ray that will measure body fat.

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

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

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

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

Contact: Parisa Salehi, M.D. (323) 361-8816 or psalehi@chla.usc.edu

Sensory Integration Disorder / Processing Disorder

Terri Mauro, in her definition posted on About.com Guide, writes, “Sensory Processing Disorder, also known as Sensory Integration Disorder, Dysfunction of Sensory Integration, or Sensory Integration Dysfunction is a neurological disability in which the brain is unable to accurately process the information coming in from the senses. Individuals may be *oversensitive* to some sensations, wildly overreacting to touch or movement or loss of balance; *undersensitive* to some sensations, needing crashing or banging or sharp sounds and flavors to register anything; or a combination of both. People can have mild, moderate or severe Sensory Integration deficits.

“Sensory processing problems can affect the five traditional senses -- particularly touch and hearing, but also taste, sight and smell -- as well as two additional senses: the *vestibular* sense, which tells us where our body is in space, and the *proprioceptive* sense, which tells us what position our body is in. [Persons] with Sensory Processing Disorder may appear hyperactive, oppositional, obsessive-compulsive, or attachment disordered, when in fact they are just reacting to and compensating for their unreliable and unpredictable view of the world.”

Persons with Sensory Integration Disorder can be either hyposensitive or hypersensitive to outside stimuli. For example someone who is hyposensitive to touch will constantly crash into things in attempt to experience extra stimulation, while the hypersensitive person will avoid being touched, touching things, or having things touch them when at all possible.

When someone has a visual processing deficit, it doesn’t mean they can’t see. It means they have a hard time finding the words for objects they are viewing or, even if seeing it, the brain does not process that they are seeing it. There are a number of distinct Visual Processing Disorders, and it is important to know that effective interventions are those that utilize the individual’s strengths in order to build on the specific areas in need of development. As such, interventions need to be viewed as a dynamic and ever changing process. Although this may sound overwhelming initially, it is important to remember that the process of finding successful interventions becomes easier with time and as the individuals’ learning approach, style, and abilities become more easily seen.

Auditory processing deficits are the same; the individual hears what you say but the brain does not process it in a way that the person understands, or it takes several minutes for what you have said to "click." One way to help with auditory processing deficits is to break down instructions, giving one thing at a time to do. Let the individual finish the first task before you give them another instruction. Listening therapy or music therapy can also help with auditory processing deficits.

The hypotonia (low muscle tone) associated with Prader-Willi syndrome causes most persons with PWS to have Sensory Integration deficits, particularly in the areas of touch, and the vestibular and proprioceptive senses.

Many individuals with PWS are hypersensitive to touch, disliking wearing hats, helmets, gloves, socks, or the feeling of tags, seams or ridges.

While there is currently little documented research to substantiate its efficacy, many occupational therapists have noted positive results with a variety of populations, including persons with Prader-Willi syndrome, using the Wilbarger Protocol for Sensory Defensiveness. According to the Sept-Oct 2004 issue of *Autism Asperger's Digest magazine*, “The Wilbarger Protocol (Wilbarger, 1991) is a specific, professionally guided treatment regime designed to reduce sensory defensiveness. The Wilbarger Protocol has its origins in sensory integration theory, and it has evolved through clinical use. It involves deep-touch pressure throughout the day. Patricia Wilbarger, M.Ed., OTR, FAOTA, an internationally recognized expert who specializes in the assessment and treatment of sensory defensiveness, developed this technique.

“An occupational therapist who has been trained to use the technique, and who knows sensory integration theory, needs to teach and supervise the Wilbarger Protocol. This statement cannot be emphasized enough. If the technique is carried out with-out proper instruction, it could be uncomfortable for the child and may lead to undesired results.

“The first step of the Wilbarger Protocol involves providing deep pressure to the skin on the arms, back, and legs through the use of a special surgical brush. Many people mistakenly call this technique "brushing" because a surgical brush is used. The term "brushing" does not adequately reflect the amount of pressure that is exerted against the skin with the movement of the brush. A more appropriate analogy would be that it is like giving someone a deep massage using a surgical brush. The use of the brush in a slow and methodical manner provides consistent deep-pressure input to a wide area of the skin surface on the body. Ms. Wilbarger has found and has recommended a specific surgical brush to be most effective. The face and stomach are never brushed.

“Following the “massage” stage, the child receives gentle compressions to the shoulders, elbows, wrists/fingers, hips, knees/ankles, and sternum. These compressions provide substantial proprioceptive input. Ms. Wilbarger feels that it is critical that joint compressions follow the use of the surgical brush, and if there is no time to complete both steps, then compressions should not be administered.

“The complete routine should only take about three minutes.. [and] can be incorporated into a sensory diet schedule. The procedure is initially repeated every ninety minutes. After a period of time, the frequency is reduced. Eventually the procedure can be stopped, but gains can be maintained.

Continued on page 13 ...

Sensory Integration continued from page 12 …

"Some children really like the administration of this protocol and will seek out the brush and bring it to their parents, teachers, or caregivers. Other children tolerate it with little reaction, and occasionally a child is resistive. If the child continues to resist, and you see negative changes, you must reconsider the use of the technique and contact the supervising therapist. This has rarely occurred in our practice."

Hyposensitivity to touch, on the other hand, can contribute to the skin picking associated with PWS wherein individuals with PWS continue to pick at their skin, fingernails, toenails, etc. until bleeding or serious injury results. Many families have found success using a massage technique, described by PWS specialist BJ Goff, Ed.D. at a prior PWCF General Education Meeting, to significantly reduce the picking behavior in their loved one with PWS. PWS specialists Drs. Janice Forster and Linda Gourash caution that the [massage] should not be linked verbally or temporally with the picking behavior as this could result in inadvertently rewarding the behavior. Using a simple wooden or plastic hand-held massager, gently but deeply massage the back of the person with PWS for 3-5 minutes nightly at bedtime for no less than 2 weeks. If possible, massage the back upon awakening each morning for the same 2 week period of time. If after 2 weeks the picking behavior has ceased, take a break from the massage. If/when the picking behavior returns, re-initiate the back massages for another 2 week session. Of course be sure to adhere to the "basics" of managing picking behavior by keeping the nails short, the pick area covered, keep lotion on the hands to give them less "traction" on the skin, and pursue medication intervention when necessary.

Therapy done by occupational therapists can in some cases eliminate sensory processing problems, and in other cases teach individuals how to cope with those problems in a less disruptive way. Look for a therapist who is experienced in Sensory Integration Disorders (or SIPT certified), and who can develop an appropriate sensory diet, a planned and scheduled activity program designed to meet a child's specific sensory needs, and maybe even one who is Wilbarger trained.

Upcoming 2012 Events
Save the Dates!

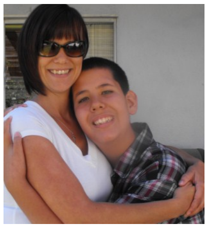
April 29	**Walking for PWS Awareness Event & Fundraiser, Griffith Park**
May 5	**Walking for PWS Awareness Event & Fundraiser, Fresno**
April 21 or May 5	**Walking for PWS Awareness Event & Fundraiser, San Francisco**
June 21 – 26	**PWS Camp at Easter Seals Camp Harmon, Boulder Creek**
June 22	**Golf Awareness Event & Fundraiser, Healdsburg**
November 3 or 10	**General Education Meeting, Northern California**

PWCF Thanks Outgoing Board of Directors

PWCF extends our heartfelt gratitude to the members of the Board of Directors who worked hard during their tenure on the Board and whose terms of service expire at the end of this year: **Drew Marich**, **Michael Moore** and **Renee Tarica**.

PWCF Welcomes Incoming Board of Directors

PWCF welcome the newly elected members of the Board of Directors **Whitney Bras, Roger Goatcher**, **Kimberlee Morgan**, and **Renee Tarica (incumbent)**. PWCF welcomes the newly elected Directors and looks forward to their enthusiasm, dedication and work to improve the quality of life of Californians affected by Prader-Willi syndrome.



Whitney Bras

Roger Goatcher

Kimberlee Morgan

Renee Tarica

PWCF'S CAMP AT
EASTER SEALS CAMP HARMON

JUNE 21-26, 2012

REGISTRATION NOW OPEN!

www.PWCF.org

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

PWCF is proud to announce the 2nd annual PWS Camp *exclusively* serving persons with Prader-Willi Syndrome ages 8-65.

Camp Harmon is located in Boulder Creek, California in the Santa Cruz Mountains. Last year's programming included swimming, arts & crafts, hiking, a dance; we'll let you know more about this year's programming. Male and female nurses are onsite to administer all medications. Staff to camper ratio is 3:1, with 1:1 available. The menu is all healthy low cal/low carb, and of course access to food is strictly secured. PWCF Camp Scholarships are available; specifics to follow asap.

Here's what some of last year's campers had to say about their experiences at PWCF's 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." Cameron Graziano, age 12***
>
> ***9 year old Emile seemed to have the time of her life, says her mom. 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***
>
> ***15 year old Chanie said this was the most fun she's ever had and she cannot wait until next summer.***
>
> ***19 year old Lauren 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.***
>
> ***Whitman, age 21, had a FANTASTIC time, the best EVER. He enjoyed his cabin-mates, counselors, and all the activities. He was happy about the daily snacks and the delicious desserts, and even lost 3 lbs during camp week – wow! He's been on the phone with new friends he made at camp.***

american CAMP association ACCREDITED

**For more information about programming, menu,
or if you need help registering online,
contact PWCF 310.372.5053**

Research Opportunities

Skin Picking Research Study: Stanford University seeks persons with Prader-Willi Syndrome ages 6-25. Does he/she engage in skin picking or other severe problem behavior? We are conducting a study to evaluate how the environment and/or brain affects the display of skin picking and related problem behaviors commonly exhibited by individuals who are diagnosed with PWS or other developmental disabilities. Our hope is that the results of this study will lead to a better understanding of how learning and neural processes influence behaviors that are characteristic of the PWS phenotype and individuals with other developmental disabilities.

Participation involves:

- Travel to Stanford University, located in the San Francisco Bay Area for 3 days, or a researcher will travel to your home (if your child is unable to travel to Stanford)
- Behavioral assessment
- Cognitive testing
- MRI scan (if traveling to Stanford)
- Behavioral treatment evaluation (if required)

Benefits of participating:

- Potential improved understanding of the variables that influence your child's display of problem behavior
- Potential improvement in your child's behavior
- You will receive an honorarium of up to $100 for your participation
- All travel-related expenses will be provided free of charge

For more information, or to enroll, contact: Dr. Scott Hall: (650) 498-4799 or hallss@stanford.edu or
Dr. Jennifer Hammond: (650) 723-7255 or hammond1@stanford.edu

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.

New Look for PWCF

Beginning in 2012, the Prader-Willi California Foundation will have a brand new look. Our new logo was fashioned by **Julie Casey, Dan Casey, Tom McRae, and Mike Moore** with input from **Lisa Graziano** and **Drew Marich** and designed by graphic artist **Craig Jann** of Eye-Con Design (www.eye-condesign.com). Tom is working hard with our webmaster and a brand new website will be revealed in 2012. These exciting changes reflect the commitment and dedication of PWCF's Board of Directors to ensuring the highest quality of life for persons with Prader-Willi syndrome and their families.

PWCF Member and Researcher Daniela Rubin, PhD Tackles PWS Obesity and Increasing Physical Activity

by Mimi Ko Cruz

Reprinted with permission from CSUF Public Affairs

It was difficult to keep his balance on a sensory-testing machine and he stepped off the platform twice, but the sixth-grade boy got through it, and Debra J. Rose meticulously recorded the results.

The professor of kinesiology and director of the Center for Successful Aging, is part of a team of professors, staff and graduate students working on Prader-Willi Syndrome and childhood obesity research. The syndrome is a genetic disorder that causes one in 12,000 to 15,000 people to develop an insatiable appetite, often resulting in life-threatening obesity.

“We're testing sensory perception, motor skills and activity levels, checking bone density and taking other related measurements today," Rose said on a recent Saturday as children with Prader-Willi Syndrome began participation in a 24-week study, with the goal of increasing physical activity levels.


Kinesiology grad student Lindsay Schroeder high fives a Prader-Willi patient after he completed a physical agility test. Photo by Greg Andersen

The project, which began in 2008, has been funded by U.S. Army Medical Research Agency grants. More than $6 million (including a $1.4 million grant awarded this month) has been awarded to date to complete several projects at Cal State Fullerton (CSUF) and at the University of Florida (UF) at Gainsville, under the helm of lead researcher **Daniela A. Rubin**, assistant professor of kinesiology.

Rubin and the research teams at Fullerton and Gainsville have been studying Prader-Willi Syndrome to gain insights into the role of exercise and nutritional phases of the condition. They are comparing data with that of those who are obese but don't have the disorder. Their conclusions, they said, will most likely result in effective interventions for obesity prevention or treatment.

During the first years of research, Rubin and Daniel Judelson, assistant professor of kinesiology, evaluated how children with and without Prader-Willi Syndrome respond to different types of exercise. From their results so far, Rubin said, "with a few exceptions, it appears that during exercise metabolic responses of children with the syndrome are similar to those without the syndrome."

She said that at Gainsville, **Daniel J. Driscoll**, professor of pediatrics and genetics [and Chair of PWSA (USA)’s Clinical Advisory Committee], and his colleagues have identified the different nutritional stages of Prader-Willi Syndrome, delineating a hormonal profile for each phase. Preliminary findings from the ongoing studies have been reported in journal articles and the research team has made presentations at conferences nationwide.

Now, Rubin and her colleagues are administering a home-based intervention that involves 36 families so far. The intervention consists of a six-month physical activity curriculum called Active Play At Home. It includes a combination of playground games and interactive console-based games. Parents are involved as key mediators for the completion of the program, Rubin said.

Some of the parents in the Active Play At Home project also are involved in a decision-making intervention being directed by **Jie Weiss**, associate professor of health science.

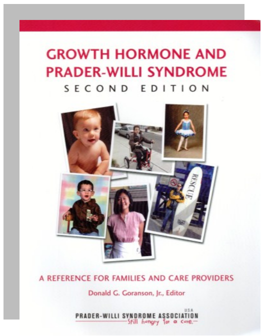
The intervention involves obese children, ages 8-11, and youths with Prader-Willi Syndrome who are 8-15, plus their parents or guardians. The materials are being provided to families at no cost and instruction is being given in English and/or Spanish. The curriculum was developed by Rubin; Rose; Lenny Wiersma, professor of kinesiology; and kinesiology graduate students Matt Junior and Lindsay Schroeder. The study subjects are taking part in different types of games at least three times a week. **Additional subjects and their parents are being sought for the Active Play At Home study. To sign up, call Diobel Mendoza Castner, project manager, at 657-278-8737.** “We are recruiting 65 families total at CSUF and 35 at the UF until August,” Mendoza Castner said.


Diobel Mendoza Castner, left, uses a DXA (dual X-ray absorptiometry) machine to measure the body fat and bone density of a research subject. Photo by Greg Andersen

Excerpted from her research statement, Dr. Rubin states, “My research interests lie in understanding the relationship between obesity in childhood and type 2 diabetes and cardiovascular disease. Specifically, I want to demonstrate the key role of physical activity or exercise in modifying these associations. My professional drive is fueled by the development of practical, feasible, and creative physical activity interventions for children and adolescents with the aim to ameliorate obesity and its accompanying comorbidities. People with disability, unfortunately, present not only a higher incidence of childhood obesity but also less participation in organized physical activity. Therefore, development of alternative programs is vital for this sector of the population to contribute to normal growth and development and ultimately a better quality of life.”

Continued on page 17 ...

Growth Hormone and Prader-Willi Syndrome 2nd Edition: A Reference for Families and Care Providers Now Available



PWSA (USA) has completed the second edition of its valuable book *Growth Hormone and Prader-Willi Syndrome*. Everything you – and your child's or adult child's physicians – need to know about how Prader-Willi syndrome and growth hormone treatment can be found within this easy-to-read and information-packed publication.

Each book is $12 plus shipping and handling. To order from PWCF call 310-372-5053 (or within California call 800-400-9994). To order from PWSA (USA) call 800-926-4797.

Attention PWS Scientific Researchers

Barbara McManus, PWSA (USA)'s Director of Family Support, announced that Prader-Willi Syndrome Association USA is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with Prader-Willi syndrome. PWSA (USA) is seeking to fund 2-4 projects competitively awarded and up to $50,000 per year for two years aimed at discovering and developing treatments, cures, and technologies benefiting those with Prader-Willi syndrome. To apply, please go to http://www.pwsausa.org/research/letter_of_intent.htm

Tackling Obesity continued from page 16 …

Daniela A. Rubin *is an Assistant Professor of Kinesiology at CSUF where she joined the faculty in 2006. She received her PhD. in human movement science and M.A. in exercise science, from the University of North Carolina at Chapel Hill; Teaching B.A. from the Higher Institute of Physical Education Professorate, Mar del Plata, Argentina. Dr. Rubin is a member of the American College of Sports Medicine, the Prader-Willi Syndrome California Foundation, and the Prader-Willi Syndrome Association USA. She has authored one book chapter, 17 scientific journal articles, nine scientific journal abstracts and 15 abstracts in annals of scientific meetings.*

About the Research Funding

The U.S. Medical Research Agency grants awarded to Cal State Fullerton's Prader-Willi Syndrome and childhood obesity research, were originally sponsored by U.S. Rep. Ed Royce (R-Fullerton) in 2008.

"This research will help with a growing national health problem," Royce, a 1977 Cal State Fullerton alumnus (B.A. business administration-accounting) said when he successfully advocated for the funding. "Obesity plagues all branches of the military, with an estimated 58.4 percent of America's soldiers, 22 and older classified as overweight. Prader-Willi Syndrome is a complex and potentially devastating condition that, if studied, may help control obesity and reduce healthcare costs over the long run."

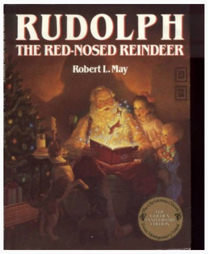
Why Study Prader-Willi Syndrome?

Prader-Willi Syndrome is part of a growing national health challenge, according to researchers at Cal State Fullerton and the University of Florida at Gainsville. Faculty members at both institutions are exploring the disorder's links with obesity.

"In our first study, in collaboration with Children's Hospital of Orange County, we evaluated children with this genetic disorder and contrasted their physiologic responses to exercise with those of other children, overweight and normal weight. We wanted to determine if having excess fat lowers the benefits we obtain from exercise," said Daniela A. Rubin, assistant professor of kinesiology and the study's lead researcher.

"We also wanted to understand the factors that will increase a physical activity program feasibility, from a caregiver's point of view, so we could design more tailored interventions," she added. "With the information that we collected in our first study, we came about the concept of designing a physical activity program to be conducted at home. We know that children must have fun to be physically active, thus playing games is key to a successful program. This is how Active Play at Home was born. We are excited to have developed this physical activity program. The feedback from participating families has been very enthusiastic and positive. We look forward to begin analyzing our data to see, scientifically, if the program has a positive impact in the lives of the participants."

The True Story of Rudolph



A man named Bob May, depressed and brokenhearted, stared out his drafty apartment window into the chilling December night.

His 4-year-old daughter Barbara sat on his lap quietly sobbing. Bob's wife, Evelyn, was dying of cancer Little Barbara couldn't understand why her mommy could never come home. Barbara looked up into her dad's eyes and asked, "Why isn't Mommy just like everybody else's Mommy?" Bob's jaw tightened and his eyes welled with tears. Her question brought waves of grief, but also of anger. It had been the story of Bob's life. Life always had to be different for Bob.

Small when he was a kid, Bob was often bullied by other boys. He was too little at the time to compete in sports. He was often called names he'd rather not remember. From childhood, Bob was different and never seemed to fit in. Bob did complete college, married his loving wife and was grateful to get his job as a copywriter at Montgomery Ward during the Great Depression. Then he was blessed with his little girl. But it was all short-lived. Evelyn's bout with cancer stripped them of all their savings and now Bob and his daughter were forced to live in a two-room apartment in the Chicago slums. Evelyn died just days before Christmas in 1938.

Bob struggled to give hope to his child, for whom he couldn't even afford to buy a Christmas gift. But if he couldn't buy a gift, he was determined to make one - a storybook! Bob had created an animal character in his own mind and told the animal's story to little Barbara to give her comfort and hope. Again and again Bob told the story, embellishing it more with each telling. Who was the character? What was the story all about? The story Bob May created was his own autobiography in fable form. The character he created was a misfit outcast like he was. The name of the character? A little reindeer named Rudolph, with a big shiny nose. Bob finished the book just in time to give it to his little girl on Christmas Day. But the story doesn't end there.

The general manager of Montgomery Ward caught wind of the little storybook and offered Bob May a nominal fee to purchase the rights to print the book. Wards went on to print *Rudolph, the Red-Nosed Reindeer* and distribute it to children visiting Santa Claus in their stores. By 1946 Wards had printed and distributed more than six million copies of *Rudolph*. That same year, a major publisher wanted to purchase the rights from Wards to print an updated version of the book.

In an unprecedented gesture of kindness, the CEO of Wards returned all rights back to Bob May. The book became a best seller. Many toy and marketing deals followed and Bob May, now remarried with a growing family, became wealthy from the story he created to comfort his grieving daughter. But the story doesn't end there either.

Bob's brother-in-law, Johnny Marks, made a song adaptation to Rudolph. Though the song was turned down by such popular vocalists as Bing Crosby and Dinah Shore, it was recorded by the singing cowboy, Gene Autry. "Rudolph, the Red-Nosed Reindeer" was released in 1949 and became a phenomenal success, selling more records than any other Christmas song, with the exception of "White Christmas."

The gift of love that Bob May created for his daughter so long ago kept on returning back to bless him again and again. And Bob May learned the lesson, just like his dear friend Rudolph, that being different isn't so bad. In fact, being different can be a blessing.

Merry Christmas 2011

Utah PWSA Develops PWS Software for Families

Lisa Thornton, President of the Utah PWSA, reports that "Through money raised from the Vivint Gives Back Project contest, Utah PWSA is developing a CarefulSteps internet-based software that will allow families to access a checklist or best practices (steps) that they should be implementing for their child in such areas as medical care, education, therapies, and legal issues. The software will also include many resources that will correspond with the steps, everything from sample IEPs, special needs trusts, to medical abstracts and articles by PWS experts on a variety of topics. We are in the development stages and hope to have the first phase out to families in the next six months or so."

PWCF thanks Lisa Thornton and the Utah PWSA for using their $100,000 Vivint contest winnings to benefit families in California as well as throughout the United States!

Vivint Offers PWCF Members Discount on Security Systems

Vivint recently wrote to PWCF's President, Julie Casey, thanking PWCF for our participation in the 2011 Vivint Gives Back Project. Below is a copy of their letter in which they extend to PWCF members a generous discount on security systems.

Dear Julie: We admire your resolve to help families in need and would like to acknowledge your dedication by offering your charity recipients a special discount on Vivint products.

There are many ways that the parents of children with Prader-Willi Syndrome can use home automation to monitor their child's safety. Because Prader-Willi causes developmental delays, parents can use Vivint door locks and door sensors to prevent their children from going outside without a chaperone. Sensors can also notify parents when children open the fridge or the pantry, helping parents reduce obesity and monitor their child's eating more easily. Parents can also use our security cameras to see their children during the day and know where they are and what they're doing. These are just a few of the ways that your families could use Vivint technology.

Because we know the families you serve could benefit from this technology, we would like to offer your charity recipients a special discount: $50 off the activation fee for a Vivint Home Automation package or $50 off the upgrade fee to home automation. This discount applies to all families that are affiliated with your charity and have a child with Prader-Willi.

We understand that treating this condition can be a financial burden on the families that you serve, so we'd also like to offer your organization two "Scholarship Accounts." These accounts include the $50 discount off an upgrade or activation fee, as well as the Family and Friends monitoring fee discount. Vivint customers typically pay $68.99 per month for monitoring, but your scholarship account holders will pay only $48.99 each month. We encourage you to use these scholarships for families that can benefit from the features we offer but are not able to afford the full monthly monitoring price.

Please have the families who you deem eligible for the "scholarship accounts" contact me via email, hmero@vivint.com to get their accounts activated.

This is a fantastic opportunity, and we hope that it will help you help families in need. This is a special offer only available to families and individuals affiliated with the Prader-Willi California Foundation, so please pass this message along to the families you serve. Thank you for making a difference.

Sincerely,

Holly Mero, Vivint Gives Back Coordinator
hmero@vivint.com • C: 720.620.0151 • P: 801.705.6264

MEMBERSHIP ACTIVITY

October-December, 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
Margarita Gutierrez
Norma Rosas

New Family Members
Jeannine & Jerry Kowal
Lisa & Nathan Miller
Julie & Harry Perkins

New Professional Members
Rick Ingraham, DDS, Quality Mgmt & Dev.
Dawn Morley, Area Board I

Renewed Individual Members
Ester Del Rea

Renewed Family Members
Patricia & Jose Ramirez

Renewed Extended Family Members
Karen & Russell Benedikt
Terri Canales
Sally & Chet Collom
Peggy Smith

Renewed Professional Members
Mary Archibald, CPA, Frith-Smith & Archibald, LLP
Lynne Bird, M.D., Children's Hospital at San Diego
Mary Lane Carlson, EdD, MPH, RD, CDE
Vicki Cox, M.S., Univ of California at San Francisco
David Crump, Interim Executive Director, PWSA (USA)
Lynn W. DeFreece, North Valley Services
Jaime Fisher, MS, Genetic Medicine Central CA
Ken Krieger, San Diego Regional Center
Phillip D.K. Lee, M.D., Univ of Texas Medical Branch
Dan Moore, Inland Regional Center
Zylnna Andaya Oliva, New Life Homes
Roberta Newton, Executive Director, Area Board X
Mary Ellen Stives, Area Board XIII State Council
Julie Tauscher, PRIDE Industries
Joe Tontodonato, Arc of Dan Diego
Nancy Varni, R.N., Children's Hospital Orange County

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

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 ~ October-December 2011

SHINING STAR DONATIONS

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Mark & Susan Lewis

Arcturus ($100 - $249)
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Kathleen A. Dignan in honor of Timothy P. Dignan
Laura & Ray Esau in honor of Rebecca Loewen
Lisa & TJ Graziano in honor of Cameron Graziano, and in memory of Grandpa Pete, Max, Mel & Olive
Mary & Bill Graziano in honor of Cameron Graziano
Jean & Lowell Hobrock
Margot & Gerry Lawrence in honor of Lisa Lawrence
Elias & Miriam Liberman in honor of Yvette Tarica
Linda M. McGee
Ana Ozawa in honor of Laura Sanchez

Vega ($1 - $99)
Araceli Cobos in honor of Vega
Kelly & Kurt Jaeger in honor of Brooke Marich
Gail Morgan
Kathryn Naegeli in honor of Kath (Kathryn) Morine
Judy Schlafer in honor of Timothy A. Schlafer
Margaret Sharpan
Margaret & Bill Spinelli in honor of Cameron Graziano

Magnanimous General Donations
The Joseph Drown Foundation
Vivint Gives Back Foundation

Donations in Honor of Samantha Morgan
Suzanne Privette

PWS Camp Scholarship Donations
Thomas & Patti McRae's donation matched by Adobe Matching Gift Program

Donations to Support the General Education Meeting
The Confidence Foundation
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PWCF Thanks All Of You For Your 2011 Gifts

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.

Prader-Willi Syndrome

Residential Staff Training DVD

NEW!

Created by Prader-Willi California Foundation
with support from Prader-Willi Syndrome Association (USA)

Produced by Albert Salaz, Jr. Productions

The Prader-Willi California Foundation and the Prader-Willi Syndrome Association (USA) created this DVD to provide Residential Service Providers with critical information about how Prader-Willi Syndrome impacts their residents. Viewed consecutively or independently, each of the ten sections addresses key areas, providing an overview of the subject matter and specific tools and strategies to improve the quality of life for residents and providers alike: Physiology, Home Set-Up, Psychosocial Management, Behavioral Management, Crisis Intervention, Communication Management, Weight Management, Family Involvement, Community Involvement, and Behavior Management Programs. Vocational Work Site providers, Day Program providers, and other care providers will find the information contained within this DVD most helpful.

This concise production is a user-friendly tool for care providers, designed to be used as a training tool for professional care providers. Working together, we will help individuals born with Prader-Willi Syndrome live a meaningful and productive life and pursue their hopes and dreams to the full extent of their talents and capabilities.

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

PWS Residential Staff Training DVD

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