

October-December 2012
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In this issue:

SSI vs. SSDI6

LRE & The Right to Eat ...7

Food & Behavior Management9

PWS Thank You Note Cards11

Research Opportunities ..13

When my Daughter Was Born15

In the Trenches16

PWCF Camp.....21

PWCF's 2012 General Education Meeting *Putting the Pieces Together*

This year's General Education Meeting, *Putting the Pieces Together*, took place on the first weekend of November at Downtown San Jose's Hilton and Hyatt hotels. As dusk fell Friday evening, the conference began with a social Meet & Greet. Attendees came from throughout California to mingle over a few drinks by the outdoor fire pit. The atmosphere was convivial as families enjoyed the company of old friends, new friends, and had inspiring conversations about everything from daily life and school to long-term planning.



Conference day started early in the morning. Parents and caregivers checked in their child or adult into one of five Youth & Adult Program rooms, assigned by age group. Each room featured lots of fun arts and crafts activities, and outside entertainers including "tattoo" artists, music and rhythm entertainment, and a comic magic show. PWCF is extraordinarily grateful to **Kimberly Martinez, Jowella Chico, and Julie Tauscher**, each a professional provider for a PWS residential or vocational work site, for skillfully directing this year's Youth & Adult Program. We are also extremely grateful to each of the volunteers from West Medical College, San Jose State University and San Jose City College who made sure participants in the Youth Program enjoyed a fun and safe day, and learned a great deal about the syndrome.



Because the Hilton discovered just two weeks before our conference that it had goofed, conference planners needed to put on their "Flexible Brains," to borrow terminology from Social Thinking expert Michelle Garcia Winner, to find a site for the General Conference. We linked our conference to the Hyatt just across the street and kept our fingers crossed for good weather. Fortunately, the plan worked well with conference registrants even expressing it was nice to go outside between sessions and get a breath of fresh air.



The first presenter was **Michelle Garcia Winner, M.A., CCC-SLP** who gave an enlightening and thought-provoking overview of **Social Thinking** which is the ability to "consider your own and others thoughts, emotions, beliefs, intentions, knowledge, etc. to help interpret and respond to the information in your mind..." She shared that one can't produce social skills if one can't observe well, that we must understand our own emotions (often difficult for persons with PWS) in order to understand others' emotions, and that the only reason we even care about social skills is to influence how "you" feel about "me." Key factors in teaching thinking and related social skills are to teach how to 'think with your eyes', communicate well which consists of thinking about the person you are near or talking to, establishing

a physical presence, and perspective taking which consists of thinking about the other person such that, "I monitor you and modify my behavior to keep you thinking about me the way I want you to think about me."

Ms. Garcia Winner shared that there are many people, with and without developmental disabilities, who are bright but don't understand that the reason they lack deeper friendships is that they lack good social skills. She finds it helpful to increase their self-awareness by sharing with them there are different types of smart: "computer smarts" and "social smarts." Interestingly, Ms. Garcia Winner doesn't place much stock in school-based "social skills groups" because she believes they generally don't teach the "subtleties" of social thinking, are contrived and give kids the false idea that they should like everyone, be liked by everyone, and be able to belong to *any* social group. She advises that children (and adults) should be guided or taught how to identify the "right" group to join, and that one can get into a lot of trouble trying to join the "wrong group." What could potentially be a "wrong" group? One in which the individual has no chance of being accepted as a valued member. Strategies Ms. Garcia Winner suggested that parents and care providers can use to help develop their child's/adult's social smarts include encouraging the individual to "think about with whom you'd want to be friends when you walk into a room."

Continued on page on 20...



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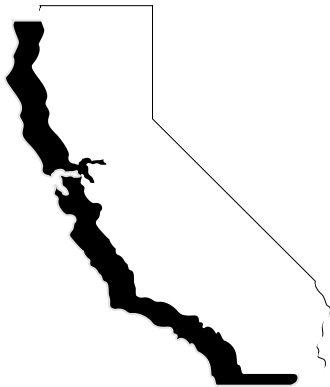
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"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families."

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Patti McRae	408-920-8003	pattimcrae@sbcglobal.net
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	310-372-5053	pwcf1@aol.com
	Julie Casey	818-843-7321	julie.casey@att.net
Orange County - Contact	Jenn Paige Casteel	949-735-0472	marchroses@hotmail.com

Inland Region Area

San Bernardino/ Riverside County	Maria & Ken Knox	909-421-9821	teachknox@aol.com
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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.yahogroups.com. In the search box under the heading "Join a Group" enter *PWCFmembers*. When the *PWCFmembers* group name appears, click and follow instructions to join.

PWCF Online Information Sharing Group for Professionals. This online information sharing group is for professionals working with individuals with Prader-Willi syndrome e.g., Regional Center caseworkers, residential staff persons, etc. To join the group, go to www.yahogroups.com. In the search box under the heading "Join a Group" enter *PWSProfessionalsExchange*. Click and follow instructions to join the *PWSProfessionalsExchange* group.

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

In what at-home income-earning business does your adult with PWS successfully engage?

We have a home office and Trevor cleans it weekly. Toilets, vacuuming, dusting, trash emptying, etc. Once he completes the job, he is very proud of himself and so are we! Some weeks, it takes an entire evening, other times he gets it done in an hour, depending on his level of energy, so I suggest paying for a completed job and not hourly! We also have a family friend that has a dog sitting business and Trevor will often help her with walking, feeding or exercising the dogs.

Submitted by Linda Ryan, mother of Trevor, age 22.

Next issue's Parent to Parent question is "Today I lost my temper with my son. I didn't just yell at him, I screamed at him! I feel ashamed and sorry for how he must feel. How do you express regret or apologize after an event like this?"

Two Easy Ways to Support PWCF Without Spending Any Extra Money!

Ralphs will support PWCF when you register your Ralph's Reward Card online in the Community Contribution Program. Once you register, every time you shop for groceries with our Ralph's Reward Card, a donation will automatically be made to PWCF at no additional cost to you!



- 1) Go to www.ralphs.com
- 2) Click on "services" along the top red bar then select "Community Contributions"
- 3) At the bottom of the page click on "enroll"
- 4) Follow the directions to establish your online account or sign-in to your existing account
- 5) Designate Prader-Willi California Foundation – Organization #93694 – then whenever you use your Rewards Card a portion of your purchases will be donated to PWCF



Sign up for eScrip which encompasses three ways to support PWCF

- 1) Sign-up and register your reward cards, credit cards and debit cards then whenever you shop at participating merchants a portion of your purchase amount will be given to PWCF
 - Visit www.escrip.com to sign up
 - Click on "about the program" along the top then click on "sign-up"
 - Search for Prader-Willi California Foundation or enter group ID# 500042750
 - Once our name appears you can select it and then continue your enrollment
 - Once your cards are registered a portion of purchases made at participating merchants will automatically be donated to PWCF
- 2) Shop at the eScrip online mall
 - Once you set up your eScrip account you can shop lots of merchants including Amazon right from your personal eScrip page or install the AutoEarn program to make sure participating online merchants are redirected to your eScrip page to ensure a portion of your purchase is donated to PWCF
 - Alternatively you can shop through this link:
<https://secure.escrip.com/jsp/group/onlinemall/groupmallredir.jsp?gid=500042750>
- 3) Participate in the eScrip Dining by Rewards Network
 - Once you enroll in the eScrip program and register your cards, a portion of purchases made at participating restaurants will automatically be donated to PWCF

Note: Safeway/Vons limit their contributions to K-12 schools therefore PWCF is not eligible to receive donations for purchases made at their stores; however purchases at all other participating merchants are eligible.

Food Tip



Skinny Pop Popcorn. A single serving bag is only 100 calories and 9 carbs. All natural, cholesterol free, zero trans fat, preservative free, dairy free, peanut free, gluten free, a good source of fiber, and absolutely delicious!

Contact skinnypop.com or 847-982-9800 to find where you may purchase Skinny Pop Popcorn.

Gadget Tip

Letter-based Combo Locks



Are you tired of remembering a number combination or losing the key for a padlock? You might consider trying one of the many new styles of padlock that use letters to spell a password. The style on the left enables you to create a specific password that opens the lock, which you can see in front of you. Be careful if there are eyes around you though, since the entire password is visible at once with this style. The style on the right is useful since it can be opened with both a master key or with the letter-based code. You can't peek at the password with a single glance, since you have to maintain watch on the code letter-by-letter. Both kinds of padlock are available in both hardware stores and stores that supply back-to-school items.



DSM-5 and PWS

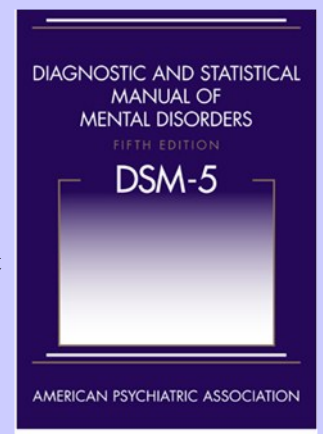
by Katherine Crawford, Family Support Coordinator

"DSM" is short for the Diagnostic and Statistical Manual of Mental Disorders. The DSM is *the* manual for diagnosing mental health disorders. Doctors use it. Psychiatrists use it. Insurance companies use it when determining whether or not to reimburse for services. While Prader-Willi syndrome itself is not a mental health disorder, some of its symptoms can be diagnosed and treated from a mental health standpoint. In December, the American Psychiatric Association (APA) released the changes for the latest edition of this manual. Though the DSM-5 is not yet finalized, there are a number of important changes that may impact parents and individuals impacted by Prader-Willi syndrome. These changes may help you receive both Regional Center eligibility and insurance company reimbursement of therapies and medications.

Three new proposed categories and changes that may impact individuals with Prader-Willi syndrome are:

- A new diagnosis for youth tantrums called "*Disruptive Mood Dysregulation Disorder*". This diagnosis is being considered to help reduce the misdiagnosis of Bipolar Disorder (and subsequent psychiatric drug treatment) for children who have severe recurrent temper tantrums. With that in mind, DMDD covers an age range of 6-10.
- There is also a new diagnosis for people who hoard but do *not* otherwise show symptoms of Obsessive-Compulsive Disorder. This is commonly seen in individuals with PWS, and may help with reimbursement of treatments for them.
- Finally, Asperger syndrome has been merged into the autistic spectrum on the mildest end, which will likely help individuals dually diagnosed with PWS and Asperger syndrome from being denied therapeutic interventions that are routinely offered to persons diagnosed with autism.

Stay tuned for further updates when the DSM-5 is finalized and released in May 2013.



Executive Director's Column

Lisa Graziano, M.A.



Unbelievably, we come to a close of 2012. For some who have lost a long-held dream or a loved one, this has been a year of great loss and deep sadness. For others who've watched their child thrive and grow into a wonderful gentleman, young lady or woman, it's been an exciting 365 day journey. Whichever your experience PWCF has been working hard to meet the growing needs of our families and professional care providers who likewise are working hard to support someone with Prader-Willi syndrome. Each of our programs and services supported our vision *to help children and adults with PWS pursue and achieve their individual dreams and goals to the fullest extent of their talents and capabilities.*

During this year PWCF served over 800 members who live within every county of California as well as live or work in other parts of the country. Many of our articles and DVDs were requested by families and professionals who live in other parts of the world including Ireland, Italy, Turkey, and France. Specifically, PWCF expended this year's income and some savings to provide the following supports and services to families and professionals:

Educational Activities---PWCF produced four newsletter issues. Each issue contained important medical information, research-related information, educational articles, and stories of support and hope written by and for parents and care providers. We produced a Behavior Management Training Series that benefited families, teachers, behavioral therapists, Regional Center case managers, vocational and residential service providers. Children with PWS have visited medical schools to bring students first-hand insight into what it's like to have Prader-Willi syndrome. We have been steadily working to create a new and improved website to bring even more educational, awareness, and support services to families and to the public;

Annual Conference---PWCF produced a state educational conference that brought valuable knowledge and support to parents and professionals. We held a simultaneous Youth & Adult conference that served children and adults with Prader-Willi syndrome and their siblings. This annual conference serves to increase the public's awareness by recruiting university students in such fields as special education, physical and occupational therapy, pre-med and nursing students, psychology and social work students to help with the Youth & Adult Program;

Summer Camp---PWCF hosted our second annual summer camp, the only camp in California that exclusively serves persons with PWS. We provided all 63 member attendees with a scholarship to reduce their cost to attend camp. Working in cooperation Easter Seals Camp Harmon, we provided six fun-filled days to campers and wonderful respite for their families and care providers;

School Trainings---We provided in-service trainings at schools and provided support at IEPs meeting. Important information about how PWS can impact a student with PWS improves the quality of support that student receives. Remote, on-line access training is available for hard-to-reach schools;

Multidisciplinary Clinics---PWCF supported three PWS Clinics. Each Clinic provides state-of-the-art treatment to children and adults with PWS. We are working to support the creation of a PWS Crisis Clinic;

Residential and Work Site Support---PWCF completed our *Prader-Willi Syndrome Residential Staff Training* DVD this year, thanks to the hard work of Residential Services Consultant Fran Moss and DVD producer Albert Salaz, which is now being distributed nationally. We continue to retain the services of Theresa McGrath, PWCF's Professional Residential Services Training Consultant, to provide in-person, individualized training programs to group homes, vocational work sites and Regional Center staff. PWCF Residential Services Committee members will visit annually every group home in California. This year, Fran Moss and Board members Paula Watney and Whitney Bras are making their way through California to visit every group home;

Family Support---PWCF hired our new Family Support Coordinator, Katherine Crawford, to provide even greater assistance and support to families. We hosted Support Group meetings, maintained our online information sharing Yahoo groups, our 24-hour PWS-related Medical Crisis Line, and our statewide toll-free 800 line. We personally spoke with each and every newly diagnosed family, sent each a personalized Information Packet, and sent all new members a Member Handbook & Records Keeper 3-ring binder. Each new family was connected with an experienced Parent Mentor who provides ongoing information and support;

Individualized Advocacy Services---PWCF's advocacy assistance helped families obtain the supports and services they need including Regional Center eligibility, group home placement, one-to-one school aide support and other educational services, behavioral intervention services, inpatient hospitalization support, advocacy for growth hormone medication prescription and insurance coverage, and grief and autopsy support. More "casual" conversations with many more families and professionals provided information that helped them advocate for themselves with greater success;

PWS Research---PWCF supported state and national research by working with local universities, teaching hospitals, researchers, and scientists to help recruit research subjects and disseminate research materials to families.

Our work with families and professionals is vitally important as PWCF is the *only* organization in California that is dedicated solely to serving the needs of persons with PWS and their families. PWCF's Board of Directors is a hard-working and dedicated group of parents and professionals. PWCF's staff works hard to meet the needs of the hundreds of people we serve. PWCF has accomplished much in the past 33 years. But much, much more needs to be accomplished in the years ahead. Your membership and support is greatly needed and greatly appreciated so that PWCF may continue its much-needed work. Keep informed, attend events, help whenever possible, and ask for help whenever needed. Remember, you are not alone. As Petra Martinez-Ali, mother of an 18 year old with PWS, recently said, *"Now that I am in regular contact with your association, I have asked myself why it took me so long to come to you for aide and support. The conclusion I came to was this: All my energy throughout my son's life has gone for his care. I did not have the extra energy to even make an extra call to talk about him. I realize now that I was in the role of a Hero and very often felt isolated and alone in my struggles in caring and management of him. I now realize that your association is helping me carry my load and making it lighter. I have sincere gratitude for all you have done for me and just listening to me in my pain. I wish I had availed myself to you earlier. I am thrilled to have you now and look forward to life-long communication and support."*

SSI vs. SSDI: A Primer

By Katherine Crawford

How are they alike?

SSI and SSDI are both programs that pay out monthly benefits in the form of a check to help support an individual with disabilities (or a family with a child affected by a disability). Both programs are administered by the Social Security Administration (SSA), and both programs have the same legal definition of “disability”. Both programs are also affected by employment, but each one is affected differently.

What is SSI?

SSI stands for “Supplemental Security Income”, and is intended to give aid in the form of extra income to individuals and families in need for necessities like food, clothing, and shelter. In order to be eligible, you must be **disabled** (or aged 65 years and up, or blind), have **limited income and resources**, be a **US citizen** (or lawfully admitted permanent resident/lawfully admitted alien), and be currently a **resident of the United States**.

Does Prader-Willi syndrome count as a disability?

Yes it does, for both SSI and SSDI.

What is the definition of “income” for SSI?

Income includes **earned income** and **unearned income**. Earned income is wages, including self employment and sheltered workshop payments. Unearned income is income from other sources such as unemployment, pensions, VA, Social Security benefits, State disability payments, and cash gifts.

What is the definition of “resources” for SSI?

Resources include cash, bank accounts, land and personal property, cash value of life insurance, and anything else owned of value. However, some resources are excluded from this calculation. **Examples of excluded resources include:** one home that is the place of residence, one automobile, household goods, a wheelchair (or similar item for mobility), and burial plots and burial funds up to \$1500.00. If your child wants to save money for college or continuing education, with a Plan to Achieve Self-Support (PASS) you can exclude this college savings from counting as resources. To repeat the point: SSI does not count an individual’s automobile, home, or household goods (microwaves, refrigerators, etc.) against them as resources. SSI is intended to support and supplement income, not to force the needy to liquidate their transportation and necessary home resources before they can qualify for eligibility.

What does “limited income and resources” mean? Am I eligible?

Without going into too much math, “limited income” is poverty level income. As such, it is slightly higher for families than for individuals. If you are a parent with a low income (or no income) and have a child with a disability, SSI is intended to lend a helping hand with food/clothing/shelter. If your child is an adult, enrolling with SSI could help them especially if they can only work a limited amount of time, and thus are monetarily impoverished. In general, the higher your paycheck, the lower the SSI check will be. That said, it is still better to work AND get SSI if you are eligible. Go to the SSI eligibility links at the end of this article for more information about specifically calculating “limited income”. Resources for an adult with a disability are limited to \$2000 if they are single and \$3000 if they are married. Resources for a child with a disability are calculated based on their parents’ resources. A married couple is allowed \$3000 in resources, and a single parent/guardian is allowed \$2000. Then, anything over those amounts is counted as a part of the child’s \$2000 resource limit.

IN SHORT: For parents of a child with disabilities, a couple can have a maximum of \$5000 in resources (\$3000 in parent resources, \$2000 deemed child resources), and an individual parent can have a maximum of \$4000 in resources (\$2000 in parent resources, \$2000

deemed child resources). An adult with disabilities can have up to \$2000 in resources if single, or \$3000 if married. (Remember, this excludes a house, a car, and household goods.) Overall, it’s harder for a family with a child with PWS to be eligible, but easier for an adult with PWS to be eligible.

Is there a waiting period after I apply for SSI?

No, there is no waiting period.

If I’m eligible for SSI, should I still work?

Yes, you will always be financially ahead if you work while receiving SSI. It is designed to reward work. While it is true that SSI benefits shrink as earned income grows, the program is designed so that monetarily you come out ahead if you work.

For example, if an individual does not work and receives SSI alone, they receive \$854.40. However, if that same individual earns \$1,000 in wages, they receive \$396.90 from SSI, earning \$1,396.90 total. (This is based on SSI calculations, which we’ll leave out here for the sake of time. This is just an example for reference.)

What is SSDI?

SSDI stands for “Social Security Disability Insurance”. SSDI is a sort of insurance, like the name suggests, and is ideally a safety net in case you suddenly become disabled or you were born with a disability. It is paid for through Social Security taxes.

What do you need to be eligible for SSDI?

To be eligible, you need to be both disabled (PWS counts) and “insured”. Like other forms of insurance, you have to pay into it first: SSDI pays benefits through Social Security taxes. If you work and pay into Social Security, you are considered “insured”. For the child with PWS who has never worked, they are still eligible for SSDI if one of their parents are 1) receiving Social Security retirement or disability benefits OR 2) have died and have worked long enough under Social Security. The SSDI disabled adult “child” benefits continue as long as the individual remains disabled.

How does work impact SSDI?

SSDI assumes that your disability prevents you from working on a regular basis. Adult individuals with Prader-Willi syndrome can work, but must not have “substantial earnings”. The definition increases year to year. In 2012, this means the adult with PWS can earn up to \$1,010 per month and still be eligible for SSDI.

If the individual receives more than \$1,010, they enter a Trial Work Period (TWP) of nine months during which they still receive full SSDI benefits. The Trial Work Period is intended to give individuals the flexibility to try working more without endangering their benefits. The TWP months do not have to be consecutive, and are counted within a 60 consecutive month rolling period.

After the Trial Work Period, the individual enters a three month Grace Period, where SSDI payments are suspended but the individual will receive an additional three months of payment. If the individual has successfully held a job with a paycheck greater than \$1,010 for over a year, they enter an Extended Period of Eligibility for the next 36 months. They no longer receive benefits, BUT if their paycheck falls at or below \$1,010 for any month during this time, they receive SSDI benefits for that month.

Is there a waiting period after I apply for SSDI?

Yes, there is a five month waiting period after you apply to SSDI.

Information on websites can be found on page 18

Adults With Prader-Willi Syndrome and Decisions Regarding Least Restrictive Environment and the Right To Eat

This Policy Statement was approved by the PWSA (USA) Board of Directors in 1998. It is reprinted here as it is as timely now as it was then.

The quality of life for persons with mental retardation has improved significantly over the past two decades. This can be attributed, at least in part, to changes in societal attitudes and standards of care, often accompanied by legislative supports. Thus the concepts "inclusion," "least restrictive environment," and "the dignity of risk" in the context of community-based "supported living arrangements" have opened many new avenues of opportunity previously denied these adults. When applying the concept of "rights" to persons with developmental disabilities, however, it must be remembered that current disability rights laws were formulated primarily in consideration of those with physical disabilities. Uncritical application of these "rights" to persons with cognitive disabilities without regard to possible consequences may lead to tragic outcomes. While specific medical etiologies for any given disability may not always be of overriding importance in determining services and supports, there are, nonetheless, specific genetic syndromes and recognizable neurobehavioral patterns that present serious considerations that must be addressed in the development of a service plan. Thus, for instance, the type and level of support services for persons with Prader-Willi syndrome are relatively independent of their level of mental retardation and are much more related to the medical and neurobehavioral implications of the specific syndrome.

Developing an appropriate social milieu for individuals with Prader-Willi syndrome means creating an environment where the least restraints are present; however, environments of least restraint do not maximize freedom in an unbridled sense but are designed to help individuals achieve their fullest possible potential. Environments must become more restrictive when lesser restraints fail to protect the physical or emotional well-being of the person or to protect the person from doing avoidable harm to themselves or to others.

The issue of adults with Prader-Willi syndrome deciding whether they "want to diet or not" is just such an issue. The dialog that raises this issue is framed by the concept "least restrictive environment" or "client rights." The argument generally is that strict dietary management is "too restrictive" or that locking food abrogates "rights." A second issue is whether restricting spending money (to limit ability to buy food) violates the personal rights of adults with Prader-Willi syndrome. In many states, the agencies and group homes that specialize in Prader-Willi syndrome are increasingly criticized as being too restrictive, and as violating consumer rights. Many of these programs have been ordered to increase client access to food, to move clients into less restrictive settings, and to give clients control of their diets (Cormier, 1995; Goff, 1995; Greenswag et al., 1995). Although easier access to food may be a strong desire for individuals with Prader-Willi syndrome, it is a dangerous and medically neglectful practice. In too many cases, such practices have led to medical emergencies or to premature deaths related to complications of obesity. This growing trend is both alarming and tragic.

Failure to restrict access to food is tantamount to medical neglect. To illustrate, let us draw a parallel with diabetes. Diabetes results from a failure of the pancreas to produce adequate insulin. Thus, the person with diabetes must maintain a calorie- and carbohydrate-restricted diet while taking supplemental insulin. Failure to rigidly follow this regimen leads to elevated blood sugars and, ultimately, death. No caregiver home would think of telling diabetics that their diet was "too restrictive" or that restricting access was an abrogation of rights.

The management of the eating behaviors in persons with Prader-Willi syndrome is based on similar physiologic failures and is equally medically critical. In this instance, there is a genetically based inability to sense satiety, combined with a decreased utilization of calories, resulting in an elevated production of fat tissue. A failure to experience satiety leads the person to continue eating far beyond physiologic or nutritional needs. This overeating combined with elevated fat tissue production leads to rapid and morbid obesity. This rapid obesity overtaxes the heart and leads to complications that can include sleep apnea, diabetes, hypertension, and cardiopulmonary compromise. This physiologically driven eating behavior is no more under cognitive control, nor amenable to cognitive remediation, than is the failure of the pancreas to produce insulin in diabetes. Further, there are, to date, no medical, pharmacologic, or behavioral treatments that fix or cure this biological malfunction. Bioethicists dictate that informed consent requires the capacity to consider, and fully understand, the pros and cons of both sides of a decision issue prior to making a decision. Since by their own physiology, persons with Prader-Willi syndrome cannot decide "not to eat," therefore they cannot responsibly decide the converse: "to eat, or not to diet." Thus, to allow such decisions under the guise of "restriction of rights" is both medically and ethically unsound. Failure of the care-giving environment to maintain a rigidly managed diet or to supervise food access leads to the previously described rapid weight gain and can easily result in cardiopulmonary compromise and death. Such a failure in a medical setting would lead to charges of malpractice. Such a failure in a certified living environment may arguably lead to equally serious legal consequences.

Nonetheless, in the past three years, several persons with Prader-Willi syndrome have been placed in less restrictive environments under the argument of "rights." To date, several have died and the rest have been placed in more restrictive settings or rushed to critical care due to cardiopulmonary crises. Most have gained over 100 pounds in less than six months with the attendant acute medical complications. Clearly, restricting food is not an abrogation of rights; it is the standard of care for a person with Prader-Willi syndrome. Failure to restrict food and allowing a person to eat themselves to death is, in fact, a removal of "rights" to a protected environment.

Continued on page16...

AHEAD With Horses, Inc.

(Accelerated Habilitation Education And Development)

AHEAD With Horses, located in Southern California, has over 40 years of experience providing innovative, unique, highly motivating and effective therapy, education and recreation through horses and related experiences to disabled/disadvantaged/special-needs children and has earned recognition educationally, medically and scientifically. Through vaulting (gymnastics on a moving horse), even severely disabled children learn and achieve with the goal of enabling them to lead more independent and productive lives.

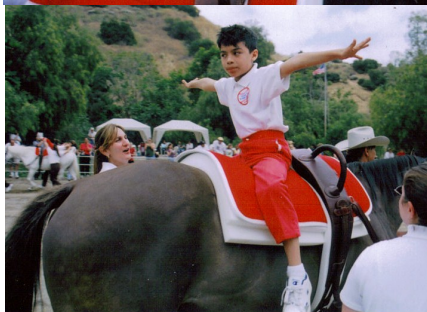


EVERY CHILD LEARNS and ACHIEVES and FINDS SUCCESS.

Program services are comprehensive and through horses combine the benefits of physical, occupational, speech, educational and recreational therapy and other developmental services such as behavior management, sensorimotor services, etc.

Many children begin the program unable to lift their head, cannot use hands or arms, move legs, crawl, sit, stand or walk, focus attention, follow directions, control behavior, or speak. We have seen hundreds of children say their first words, take their first steps, and reach many other milestones never thought possible.

AWH specializes in children, 12 & under, with multiple and severe disabilities including: autism, Down syndrome, cerebral palsy, developmental delays, chromosome disorders, spina bifida, epilepsy, hypotonia, cognitively challenged, blind, deaf, and many other disabilities and medical conditions.



If you would like to find out more about our program in Shadow Hills or mobile programs on the Westside of Los Angeles, which days and times are available or cost, call (818) 767 – 6373 ~ www.AHEADWithHorsesLA.org

Explaining Prader-Willi Syndrome: One Parent's Letter

Letter submitted by John Storr

Parents and caretakers for an individual with Prader-Willi syndrome sometimes find themselves in the uncomfortable position of having someone outside of their circle making incorrect assumptions about them and their loved one. In the example below, the daughter had gotten "stuck" on an issue and missed her therapeutic horseback riding lessons as a result. When the father initially tried to explain, he could tell that the instructor was unsympathetic, implying that the father hadn't handled things well and ought to have just put her in the car in spite of her objections. The father composed the email included below to help explain the situation. After receiving this email, the instructor gained a greater insight into Naomi's syndrome and as a result became more understanding towards the father's responses as well. It is a good example of turning an uncomfortable social situation into an opportunity to educate and inform.

[Dear Instructor],

I'm sorry too that we couldn't make it. I know that Naomi does enjoy the lessons. And I love how much you get her to do. Those lessons are a highlight of our week.

Naomi and I had picked out riding gear a couple of weeks ago – short leather boots, used riding pants, and then those things that loop under the boot and cover up the lower legs -- chaps? When I picked her up from school Wednesday and reminded her of her new gear -- which I had in the car so she could change before the lesson -- she said she wanted to wear a different shirt than the one she'd worn to school (she was with her Mom the last two days).

I took her to my house, but she refused to wear any of her shirts, saying they did not go with her new riding outfit. I told her that she would miss the lesson if she couldn't just wear one of her shirts, and that it would be a real shame. I reminded her that you and the horses and the rest of the team were waiting for her. I said I could call the stable and see if you all had a shirt there, but she refused to do that.

Unfortunately, this kind of thing is a hallmark of Prader-Willi syndrome, and it's probably the hardest thing about the syndrome. People with the syndrome of all ages can get mentally stuck on things. They have a remarkable capacity to be stubborn and obstinate. They lack the ability to put things in a bigger context and realize that the thing they are obsessing about is not really that significant. They are often said to be lacking in executive brain skills -- the ability to act like an executive, look at the big picture, and take action. They get lost in the weeds. They lack judgment.

Coupled with that, they have an oppositional-defiant streak a mile wide. Once they get stuck, they are quite happy to do battle with someone who tries to override them.

Continued on page 16...

Food & Behavior Management

An overview of how to manage food and behavior when caring for someone with Prader-Willi Syndrome

Prader-Willi syndrome affects multiple systems in the body and causes many different symptoms. Many of these symptoms are very serious and some of them are life-threatening.

People with Prader-Willi syndrome (PWS) experience a host of challenges including weak muscles, problems with balance and coordination, developmental delays, speech and language problems, temperature regulation problems, orthopedic problems, and sleep problems to name a few.

Food and Weight Challenges

Prader-Willi syndrome is best known for its symptom called “hyperphagia” which means literally “over eating.” For reasons not yet understood, the brain of someone with PWS drives the individual to want to eat as much food as possible all of the time. Persons with PWS feel a constant drive to eat that is *never* satisfied no matter *how* much food is eaten. At the same time, metabolic rate slows to about half what it should be. If caloric intake is not significantly reduced and strictly controlled, persons with PWS will quickly gain an enormous amount of weight leading to morbid obesity and premature death. People with PWS are vulnerable to sudden death due to choking, stomach rupture, or stomach necrosis.

Just because someone has PWS doesn't mean they are destined to become obese. People with PWS can absolutely maintain a healthy weight, but it takes constant and continuous supervision from not only their parents or primary care providers, but from *everyone* in whose care they are entrusted.

Behavioral Challenges

Second only to hyperphagia on the list of PWS challenges is the misbehavior that many people with PWS exhibit.

The brain of someone with PWS causes individuals to feel a global sense of anxiety, think oppositionally, have a low tolerance to frustration, be argumentative, and react to disappointment and frustration with tears or anger. Regardless of age, persons with PWS can exhibit temper tantrums that can include yelling, foul language, hitting, kicking, sitting and other refusal behaviors.

It's important to understand how persons with PWS typically think and react so that you can better avoid the behavioral problems that are common in persons with PWS.

Strategies to Manage Symptoms

There are currently no known medications that eliminate or even reduce the insatiable appetite that is the hallmark symptom of PWS. There are, however, therapeutic and environmental interventions that can help manage weight, improve behavior, save lives, and improve the quality of life of *all* who are impacted by Prader-Willi syndrome.

Food Security

People with PWS cannot manage their own food intake because their brain tells them to eat as much food as possible which means they must depend upon everyone in their environment to make sure they are safe around food. The *Principles of Food Security*, a concept coined by PWS specialists Linda Gourash, MD and Janice Forster, MD, describe the basics of how to manage the food environment:

No Doubt that appropriate foods will be served at the appropriate time *plus*
No Hope/No Chance that extra, unauthorized foods can be obtained *equals*
No Disappointment No disappointment means fewer behavioral problems

People with PWS need to know *that* they will eat and *when* they will eat. Having a written schedule when meals and snacks will be served is very helpful because once it's written, it's often not argued about. Stick to the schedule as persons with PWS cannot be expected to be flexible.

It's helpful for the person with PWS to eat every 2 1/2 to 3 hours. Eating this frequently, however, requires a daily diet *very* low in calories, fat, and carbohydrates. Some people with PWS cannot exceed 800 calories per day.

Never use food as a reward or punishment. For someone with PWS food must be as stable as oxygen, *never* contingent upon good behavior and *never* taken away for poor behavior.

It is imperative to follow the menu instructions *exactly* as dictated by the parent. Because the metabolic rate is very slow, every calorie consumed by someone with PWS can potentially cause weight gain. Giving someone with PWS extra food causes not only weight gain but gives them hope that they will receive extra food from you later, and that hope will likely lead to a behavior problem some time down the road. There are many ways other than food to provide a special treat or show you care such as stickers, small toys, time playing together, employing the individual as your special helper, and hugs.

Continued on page 10...

Food and Behavior Management continued from page 9...

Before offering the individual with PWS food, ask the parent outside the presence of the individual with PWS what food options you may offer.

Secure and lock up all food sources. Almost all families who live with someone with PWS lock their refrigerator and food pantry. Not only does locking away food keep the individual with PWS safe, it tells their brain that food is not available and reduces the hopeful anxiety they feel to obtain that food. In addition, secure wallets, purses, and loose change because children and adults with PWS know that money can purchase food. Stealing is a symptom of PWS.

You will show the person with PWS and their family that you care about them by securing all food sources and by following all parental instructions.

Behavioral Interventions

It's important to familiarize yourself with how PWS typically impacts the brain so you can minimize or avoid behavior problems. In general, work to create an environment that is predictable, positive, and free of stress. Use positive words, praise and encouragement; use a calm tone of voice; use rewards such as your attention, stickers or small toys; and engage the individual as your 'special helper.'

Anxiety Almost all persons with PWS feel an underlying degree of anxiety all of the time and do best when they know what to expect and what is expected of them. Create a written schedule of the day's activities including approximate timing of all snacks and meals. "Paint a picture" of new activities or situations; talk about what things might look or sound like, what can be expected to happen, etc. Talk about your expectations of behavior, and make a plan for what will happen if there is a behavior problem. Stick to the schedule to the extent possible as persons with PWS cannot be expected to be flexible.

Low Tolerance to Frustration Almost all people with PWS have difficulty managing feelings of frustration and disappointment. To the extent possible, eliminate the potential for frustrators and disappointment and use positive-toned language. For example, the person with PWS says, "I want to go to the movies" but you know you can't schedule it today. Instead of saying, "No, we can't do that today" reply, "That sounds great! I'd like to go to the movies too! Today we need to xyz. Let's see what movies are playing and plan to go tomorrow!"

Hyper-Reactive Almost all people with PWS can be described as "hyper-reactive," meaning they tend to become overly upset about a seemingly minor incident. When someone with PWS becomes upset it's best not to try to talk to them out of their upset as this will cause them to become even *more* upset and work even *harder* to show you how upset they are. Instead, immediately and calmly demonstrate understanding and empathy as this will help them recover more quickly. For example, "You want to see a movie today. You don't want to wait. I'm so sorry." Then stop talking or only occasionally and calmly repeat their upset. People with PWS are often concerned with "fairness." Sometimes it is calming to agree that something is unfair in order to show that you understand their upset. "You're right, it's not fair and I am sorry."

Oppositional Most people with PWS are oppositional; the brain reflexively thinks, "No!" Strategies to counter this are to refrain from giving "yes or no" choices. For example instead of asking, "Are you ready to get dressed now?" give two or three preferred choices such as, "Do you want to get dressed in 3 minutes or 5 minutes?" As much control over things the individual with PWS perceives he or she has, the better will be their behavior.

Inflexible People with PWS often have a difficult time transitioning from one thought or activity to the next. Give prompts to end a conversation about a particular topic: "This has been fun to talk about xyz. You can say one more thing and then let's talk about something else." Give incremental prompts before moving to the next activity. For example, prompt, "Five minutes before we need to leave... Ok, 3 minutes before we need to leave so start putting away your books... Ok, 1 minute. Everything should be put away. Get your shoes on." Some people with PWS move more slowly so make sure you carve out lots of time for transitions.

Never give in to a temper tantrum or a sit down strike whether it's for food or anything. Once you give in you have taught the person with PWS that next time you will eventually give in if they just cry louder, longer, or behave with increased aggression.

Have patience. And then have more patience. People with PWS typically process or think about things a bit more slowly and may need extra time to comply with a request.

Have fun! When the needs of the individual with PWS are addressed there will be few if any behavioral problems. So, enjoy the time you spend in the company of your loved one or friend with Prader-Willi syndrome!

This article is also available in brochure format. Contact the PWCF office to request your free copy, or purchase multiple brochures at .25 each.

Use PWS Thank You Cards and Raise Awareness of Prader-Willi Syndrome

These cards are beautifully designed by a child with PWS. Blank on the inside, these cards are perfect for those after-the-holidays-thank-you notes as well as throughout the year.

10 cards per set // \$10 per set // Two sets for \$18 Plus \$3 shipping & handling

Yes! Please send me _____ sets

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City/State/Zip: _____

Phone _____ Email: _____

I've enclosed my check made for \$ _____ Made payable to Prader-Willi California Foundation

Please charge \$ _____ to my Visa MC AMX

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Card No.: _____ Exp. Date: _____ Security Code: _____

Email: _____

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Call PWCF at 310-372-5053 to place your credit card order over the phone

Front of Cards:



Back of Cards:



Artwork on this card was designed by a child with Prader-Willi Syndrome (PWS). PWS is a life-threatening medical disorder that affects one in 10,000 - 15,000 people. PWS causes multiple symptoms including weak muscles, global developmental delays, learning disabilities, behavioral problems, and its hallmark symptom, an insatiable drive to eat and lack of feeling full. While there are helpful therapeutic interventions, no known medication controls the insatiable appetite, making true independent living impossible. Persons with PWS need continuous supervision every day, every moment of the day, throughout the duration of their lives. The stress on families is enormous.

There is no cure for PWS yet, but there is hope. And you can help.

Prader-Willi California Foundation, a non-profit 501(c)(3) charitable organization, is dedicated to providing education, advocacy and support services to people with PWS, their families, and the professionals who care for them.

To learn more about PWS or to make a tax-deductible donation contact

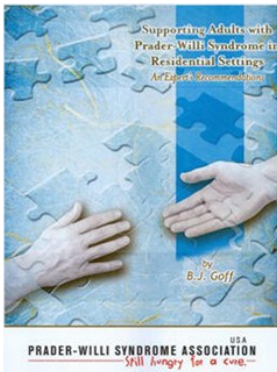
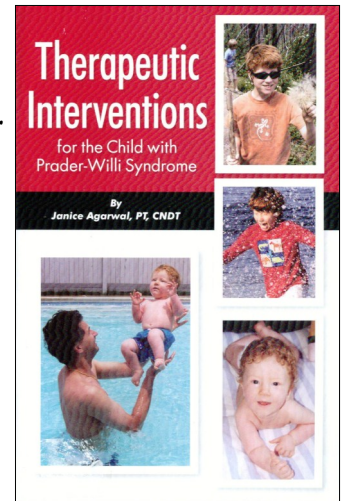
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New Physical Therapy Book Now Available!

Physical Therapist and parent **Janice Agarwal** has written an extraordinarily helpful new book packed with information about therapeutic interventions. *Therapeutic Interventions for the Child with Prader-Willi Syndrome* will help parents understand just what physical therapy is, when interventions should ideally begin, who can provide these services, who can help pay for them, and even how and why physical therapy is helpful. The book provides a nice description of interventions throughout every age group from infants, through grade school, all the way through adulthood. There is a chapter on Sensory Integration which describes the vestibular, proprioceptive, tactile, and oral-motor systems and includes a long list of activities that even parents can do to address their child's deficits in these areas. *The book is a wealth of information and should be in the PWS library of every parent!*

Order yours for only \$10 directly from PWSA (USA) at 800.926.479



Supporting Adults with Prader-Willi Syndrome in Residential Settings

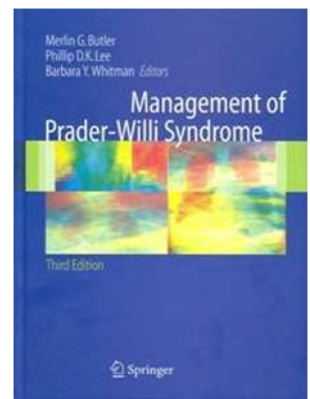
This publication provides providers, caregivers, and parents of those with Prader-Willi syndrome (PWS) an extensive manual covering residential care issues. The manual includes management strategies, suggestions for all phases of life in the residence, provider/parent relationships and many more helpful ideas offered by B. J. Goff, Ed.D. This book is a great partner to PWCF's *Prader-Willi Syndrome Residential Staff Training DVD*. *Every caregiver supporting a person with PWS should own a copy of this excellent resource.*

Order from PWSA (USA) at 800.926.4797. Single copy: \$15. Two or more copies \$12 each

Management of Prader-Willi Syndrome Third Edition, 2006

The most comprehensive reference in the world on the diagnosis and care of individuals with Prader-Willi syndrome. "... edited and written by the very best in the field and updated with the latest research ... the single best resource of information and support for the next several years" —Louise Greenswag and Randell Alexander, Editors of both prior editions of the textbook

Order from PWSA (USA) at 800.926.4797. PWSA Member Price \$50; Nonmembers: \$75



Prader-Willi Syndrome Residential Staff Training



PWS Residential Staff Training DVD

PWCF and PWSA (USA) created this DVD to provide Residential Service Providers with critical information about how PWS impacts their residents. Viewed consecutively or independently, each of 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. Each DVD order includes a Home Study Note Taking Guide and a Home Study Examination. PWCF will send a Certificate of Training upon passing the Home Study Examination.

Order from PWCF at 310.372.5053 or in CA 800.400.9994. PWCF Member Price \$25; Nonmembers: \$35

Prader-Willi Syndrome Research Opportunities

Causes of Excessive Appetite, Obesity, and Cognitive Problems Associated with PWS



Children and adults with Prader-Willi syndrome are invited to participate in a clinical study sponsored by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, which is part of the National Institutes of Health (NIH). The purpose of the study is to learn more about the causes of excessive appetite, obesity, and cognitive problems associated with PWS. Participation involves providing medical records and blood samples (may be drawn locally and mailed-in), and if interested, further evaluations at the NIH Clinical Research Center in Bethesda, Maryland. There is no cost for participating in the study.



Eligible participants will be compensated for their time and transportation costs. For more information, contact: Joan Han, MD, Principal Investigator, (301) 435-7820, hanjo@mail.nih.gov or Melanie Hicks, BA, Study Coordinator, (301) 402-6762, PWSresearch@mail.nih.gov, Department of Health and Human Services, National Institutes of Health, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development.



CHLA Research Study: Can Exenatide help patients with Prader-Willi Syndrome lose weight?

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 series of 4 blood test 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 the 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 related medication
- ◆ Must NOT have a current or 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 your participation

Contact Person: Parisa Salehi, MD, Office: (323) 361-8816, Email: psalehi@chla.usc.edu

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



Research on Cognition and Everyday Behavior in Children with Prader-Willi Syndrome

Study Title: The Relationship of Executive and Adaptive Skills in Prader-Willi and Down's Syndromes. A clinical psychology (neuropsychology emphasis) doctoral student at Wheaton college is conducting dissertation research to better understand how a very important thinking process called executive functioning relates to the everyday behaviors of youth with Prader-Willi syndrome. Findings from this study may provide valuable information about how to improve treatment strategies and daily functioning of affected children.

This project requires a parent or legal guardian to fill out a few questionnaires taking approximately 30 minutes. If you are an interested parent of a child diagnosed with PWS aged 5 to 19 years old, please contact Patrick Hall at phall777@gmail.com or (630) 815-8553 and I will send you the questionnaires with a postage-paid return-addressed envelope. Participation will be completely confidential. This investigation has been approved by the Wheaton College Institutional Review Board.

There is a scarcity of research examining the role of executive functioning in youth with Down Syndrome (DS) and Prader-Willi Syndrome (PWS). However, the cognitive, behavioral, and neuropsychological characteristics of DS and PWS documented in the extant literature suggest these persons are vulnerable to executive dysfunction. Although several studies have shown executive functioning deficits on performance-based neuropsychological measures in DS and PWS, whether these deficits are manifested in the everyday behaviors of affected youth has received little attention.

Continued on page 14...

Research continued from page 13...



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 Medical Center 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



Study of Adolescent Siblings: Vanderbilt Kennedy Center is interested in how having a brother or sister impacts adolescents. Families with 2 children, both between the ages of 12 and 18, are invited to participate in an online survey. Families with and without children with disabilities are invited to participate. One adolescent and one parent will be asked to:

- Go to the Survey Link <https://redcap.vanderbilt.edu/surveys/?s=RbeQdw>
- Respond to questions about himself or herself and his/her family. Parent survey is 20 minutes; adolescent survey is 15 minutes.



For your participation, you will be entered in a drawing for one of 40 \$50 Target gift cards. You will have approximately a 1 in 10 chance of winning a gift card.

Contact: Carolyn Shivers, MS, Graduate Student 330-704-6291 / carolyn.m.shivers@vanderbilt.edu

Congratulations to the 2012 President’s Award Recipients

Whitman Donaldson in recognition and appreciation of his contribution to educate the general public through his book *The Science of Prader-Willi*

Kristin & Sam Cropper in recognition and appreciation for organizing the awareness and fund raising event *Putt for Prader-Willi Charity Golf Tournament*

Christopher Patay, Esq. in recognition and appreciation of his tenure on the Board of Directors, his service as Vice-President, and his ongoing efforts to improve the lives of those with Prader-Willi syndrome

Wendy Young in recognition and appreciation for her years of dedication to and organization of the North Bay PWS Support Group

Tom McRae in recognition and appreciation of his coordination and leadership in the effort to bring PWCF’s website into the 21st Century

Lisa Graziano in recognition and appreciation for 10 years of outstanding service and dedication as Executive Director and for your perseverance in working to improve the quality of life of all people with Prader-Willi



When My Daughter Was Born

by Mary Jane Morris



My daughter was born on March 28, 1992. I wasn't there.

I'm not sure what time it was. I don't know how the labor was. I didn't have any pain. My husband remembers it seemed something was wrong.... but maybe not....."hard to tell," he said.....I am the step-mom of my 21 year old daughter with Prader-Willi syndrome. I met her one evening after a date with her dad. I asked her what she was going to do that summer. She said she didn't know.

Her dad and I met online in 2007 after both of our spouses left for personal greener pastures. I knew right away he was the one for me. He's much more sensible.

We talked every day, usually a couple of times a day. He was good about that; listened to me, asked all the right questions. He paid attention. I liked him.

During those calls, we talked about what seemed like everything. We lived more than 60 miles apart and so we had no choice but to take our time and get to know each other. Since both of our divorces were fresh we also knew we had to heal ourselves first.

I told him about my ex, my two grown and gone from home sons, how divorce and empty nest came in the same six months for me without much warning.

He mentioned his ex-wife, spoke of his son and grown daughter in college. He said his son was living with his mom. His middle daughter, Lauren, was living with him. That's her name....Lauren.

I got invited to do things with Lauren and her dad. The first invitation was to a San Diego Charger's game. She was there with her younger brother. My favorite picture of her dad and me? Lauren took it that day.

Dad and I started seeing each other more seriously after both of us dated others and found that what we had was better. We didn't rush. We were best friends before we ever got serious.

Then in 2010, very quietly, and without fanfare, he suggested I Google 'Prader-Willi' before we moved in together.

I got the news about PWS like a lot of people I've read about; alone and with only Internet descriptions. After being given this term I'd never heard of before, I was amazed at the list of symptoms and characteristics. I had a thousand questions. I felt what every parent feels; scared of the unknown, scared if I would be a good mom, scared for Lauren's future happiness. It felt permanent in a different way than anything I'd ever felt ever before. Could I handle it?

A friend at work said she knew about Prader-Willi syndrome. She said families have to lock the cabinets and the refrigerator to keep the child safe from food. Like everyone else who loves to eat and hears that for the first time I said, "sounds like a good idea for me too." We chuckled at the thought.

Actually, a lot of what I read seemed like a good idea for all of us; regular schedules, regular exercise, daily calorie counting and weigh-ins, routines and lists and having a good attitude every day, letting go of little things and focusing on the positive. How hard could this be? Stick to the rules and you were home free, right?

Lauren is considered "high functioning" and many people can't tell there's anything different about her. Her weight has always been an issue but her original family didn't lock up much. If an argument goes too far she will melt down. (Don't we all?) She repeats herself. She falls asleep riding in the car, but if you ask her about it she'll tell you it's by choice. She had back surgery and knee surgery and a thousand doctor visits by the time I met her at age 17. She has a high pain tolerance and was a real trooper during her treatments, I hear. She's timid about new situations but then jumps right in once she gets it. She wants to do whatever everyone else is doing, but sometimes had to sit by the sidelines for reasons not really clear to her. She had failure to thrive as a baby and knows she was tube fed, is proud of her parent's sacrifices for her, but Prader-Willi was not openly discussed.

Lauren is sweet and loyal and devoted. She loves unconditionally. A "Good Egg" her dad calls her privately. (His highest compliment.) They spent all their time together, did chores together, saw movies (lots of movies!). Lauren is the best buddy her dad ever had... that *anyone's* ever had. They took me into their hearts and lives. Now there are three of us. We call ourselves "The Three Musketeers." My own family had grown and gone and I missed terribly the family things of everyday life. These kind people restored me.

Lauren's dad is an amazing man. He never once added Lauren's life into the equation of "us" until we became serious. We had a normal, wonderful courtship of our own. The 60 miles between our homes played a part in that but he never said a word of his life being the least bit different or Lauren being extra special. He lives for Lauren but I didn't see that until I became a part of their daily life. Then what I saw made me love him even more.

Continued on page 19...

In the Trenches

Vol. 10

By Jessica Patay

It's TRUTH-TIME. In honor of my 10th *In The Trenches* submission, I will share 10 ways I have blown it as a PWS mom.

We, as parents and caregivers of a child or adult child with Prader-Willi syndrome, are all trying our best to provide what our special peeps need. We read, we research, we go to endless appointments, we read newsletters like this, we attend behavior training sessions, we follow food schedules and life schedules and implement car rules and safe eating rules, AND WE REALLY TRY to maintain a calm environment. We desire for our child (all our children) to succeed as best they can. *And we are working so very hard.* Hard. All the time.

Then we blow it. Or at least I do. Here are the 10:

- ◆ I lost my cool. I yelled at Ryan.
- ◆ I rewarded with food (the whole family).
- ◆ I gave in to a tantrum.
- ◆ I triggered a tantrum with my impatience with the 583rd question of the day.
- ◆ I did not monitor calories.
- ◆ I did not do proper priming before an activity or event or change in schedule, and therefore paid the price with a tantrum.
- ◆ I used negative consequences (took away his beloved CD player) even though they don't work. (And I know they don't work.)
- ◆ I gave up on the token system because *I was sick* of having to be uber-consistent with it, month after month.
- ◆ Used a threat to motivate him to do what I needed him to do.
- ◆ Are we at #10 yet? You get the idea...



When I make these mistakes from time to time, hopefully not all in one day, I beat myself up horribly and feel that darn mommy guilt. Again. The guilt monkey sitting on my shoulder loves to taunt and berate me to no end. And I accept it for a little while. Then I tell myself, we all do it. We all make mistakes. Yes, even the ones who seem to have it all together and tell you they “never ever yell” at their kids.

We must give ourselves a little grace once in a while. We are imperfect people living in an imperfect world with an imperfect family dynamic going on. Why do we (or just me) need to place unrealistic expectations on ourselves to NEVER EVER make a mistake as we parent? Do we need to beat on ourselves over and over? I think not, my friends.

GRACE. Give yourselves some today. Forgive yourself for the mistakes you made and move on. Know that you are, that we are, absolutely making a difference in our children's lives despite mishaps and blunders. OH YES, WE ARE.

Enjoy more thoughts on Jessica's blog: “*She Runs a Good Race~Mothering is a Marathon.*” <http://jessicapatay.wordpress.com/>

Least Restrictive Environment continued from page 7...

Is it not a paradox that we would allow someone with Prader-Willi syndrome the “right” to eat themselves to death, but if someone without such cognitive limitations were to threaten suicide, the caregiver that failed to provide suicide restrictions would be found guilty of lack of protection? So we will protect those who are cognitively normal from their own self-destructive impulses, but argue that someone who has cognitive limitations and has physiologically driven eating behaviors has the right to eat themselves to death.

In planning the care-giving environment for persons with Prader-Willi syndrome, some contradictions are evident. While persons with Prader-Willi syndrome need extensive food support, they show fewer needs for support in other aspects of their lives. Indeed, many persons with Prader-Willi syndrome show competencies and decision-making abilities outside the food arena. Nonetheless, until there are medical or pharmacologic interventions for this physiologically driven eating behavior, structured environments with restricted access to, and intake of, food must be standard care for persons with Prader-Willi syndrome.

Some will argue that these recommendations conflict with concerns with choice, personal rights, and least restrictive environment. We do not take issue with these philosophical goals. Instead we assert that the appropriate frame of reference is the “least restrictive environment,” given that the individual has Prader-Willi syndrome. Indeed the concept “least restrictive environment” is meant to imply “as normal a life as possible within the framework of a given disability.” Too often it is translated as: “Despite your disability, you will live as though you are normal.” Society's efforts to undo a previously created “social disability” may ultimately lead to a completely restricted environment when appropriate limit setting is insufficient. Persons with Prader-Willi syndrome must be uniquely considered as least restrictive goals are put into practice in order to prevent further deaths and to promote a fuller quality of life.

Bike Riding Skills Through iCan Bike



Formerly known as *Lose the Training Wheel*, iCan Bike helps children and adults with disabilities learn how to ride a bike!

iCan Bike understands that the vast majority of people with disabilities never have the experience of independently riding a conventional two-wheel bicycle during their lifetime. Defying these odds is why iCan Bike exists.

In the summer months and during school breaks iCan Bike partners primarily with local charities, parks and recreation departments, colleges and universities to provide the bike camp program. Bike camps consist of up to five 75-minute sessions per day with a maximum of eight riders per session. A full camp will serve a maximum of 40 riders. The number of riders depends on the size of the facility and the availability of volunteers.

iCan Bike Camps in 2013 in California

City: Yuba City
Hosted By: Family SOUP
When: June 17 – 21
Contact: brian@sgtrees.com
Where: River Valley High School, 801 El Margarita Rd.
Yuba City CA 95993

City: Aliso Viejo
Hosted By: DSAOC and UCP-OC
When: August 5 – 9
Contact: jharvey@dsaoc.org
Where: Soka University 1 University Dr., Aliso Viejo CA 92656

City: San Diego
Hosted By: Crimson Speech, Language, Research & Treatment Ctr
When: August 12 – 16
Contact: kendall.dann@gmail.com
Where: Sol City Sports Center at Aliant University 10455 Pomerado Rd.
San Diego CA 92131

iCan Shine is a nonprofit, tax-exempt charitable organization under Section 501(c)(3) of the IRS Code. For more information visit www.icanshine.org



One Parent's Letter continued from page 9...

You had suggested on the phone that I just put her in the car with a shirt -- basically, override her objections. That would probably be a good solution for a kid who did not have Prader-Willi syndrome. But unfortunately, I already know where it would lead. She would be very upset, but she would also battle back -- if I carried her to the car, she would flop on the floor. If I forced her into her booster seat and forced her seat belt on, she would unbuckle it as soon as I left to drive the car, and she would be back on the floor. I have been down that route, and it's a dead end.

The best thing is to try to anticipate the things that will set her off, and steer around them. If that fails, and I end up with a problem like I had yesterday, I've learned to stay calm, explain to Naomi the consequences of her actions, try to come up with solutions, and generally just roll with the punches.

After our phone call, I did explain to Naomi that she had one more lesson next week, and then a makeup, but that if she missed the lesson, she would not be able to do the makeup. It's appropriate that Naomi experiences consequences for her actions.

During the lesson time, we went shopping, and Naomi did pick out a shirt for riding. So I don't anticipate any problems like this again. It's reasonable for you to wonder if it really was the shirt that was throwing her, or if she was having some problem with the lessons. But I think it really was just the shirt.

I will tell Naomi about the new horse. Thank you for being understanding. The behavior problems in Prader-Willi syndrome can really make you tear your hair out, unless you realize that it's part of their disability. Knowing that makes me more patient with her.

See you next week!



Dear PWCF: Thanks so much for the training packets! These are awesome. I really appreciate all the support you guys give to care providers! *Linda Hamilton, Owner, Lee Street Homes*

Dear PWCF: We just received the complimentary set of education and training materials, thank you so much. Since associating with PWCF my staff and I have been able to grasp a better understanding of PWS and the individuals we serve. As we progress with training and support through PWCF we know that we are prepared to provide the best support we can. On behalf of our individuals and our agency, thank you. *Melissa Hernandez-Lindenbaum, Supported Living Coordinator, CAPC, Inc.*

Dear PWCF: Thank you for the Prader-Willi California Foundation's generous gift of \$8,500 to the Prader-Willi Syndrome Clinic at Rady Children's Hospital-San Diego. We are deeply grateful that you have chosen to help us make Rady Children's one of the best pediatric hospitals in the nation. The Prader-Willi Syndrome Clinic at Rady Children's is a multidisciplinary clinic which manages the medical, nutritional, developmental and behavioral needs of children with Prader-Willi syndrome. Children who come to the clinic are seen by a clinical geneticist, pediatric endocrinologist, nutritionist and social worker. We take pride in the special services we are able to offer to children and their families and know that special people like you make it all possible. Your donation helps us provide the compassionate care that is an integral part of our total healing environment, as well as ensuring we have the resources to buy state-of-the-art equipment and fund critical research. On behalf of all those who ultimately benefit from your generosity, thank you. Together we are building a brighter and healthier future for the children of San Diego. Sincerely, *Carol D. Damon-Scherer, Interim Executive Director*

Dear PWCF: I was just reading the latest PWCF Newsletter and that's great that you are signing up with eScrip! I have been in charge of the eScrip program at my children's school for about 4 years now and it is a great program! If anyone would like to "pick my brain" about the program and how to become more comfortable with the online info., just let me know. *Karen Benedikt, Barbara Olson's sister*

Dear PWCF: Thank you for giving us the opportunity to attend this wonderful conference. We learned invaluable information that is going to help us with our son. We are also really fortunate to meet so many wonderful families that offer to help us and support us as well... Again thank you for all the work you do and for your support. Please if you think I can be of any help don't hesitate to let me know at any time I'll be delighted to help. Gratefully, *Diana Vega, parent of 6 year old*

Dear PWCF: I appreciate you having me perform at your event yesterday. I met some truly wonderful and inspirational people and learned about a condition which I had no previous knowledge. Thank you for the opportunity to share some laughter and magic. It was a heartwarming experience. *Patrick Reed, Comedy Magician*

The Weight of a Glass of Water

A young lady leading a stress management class walked around the room with a raised glass of water. Everyone knew she was going to ask the ultimate question, 'half empty or half full?' She fooled them all...

"How heavy is this glass of water?" she inquired with a smile. Answers called out ranged from 8 oz. to 20 oz.

She replied, "The absolute weight doesn't matter. It depends on how long I hold it. If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance. In each case it's the same weight, but the longer I hold it, the heavier it becomes."

She continued, "And that's the way it is with stress. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won't be able to carry on.

"As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden, holding stress longer and better each time practiced.

SSI vs. SSDI continued from page 6 ...

Have further questions? Check the websites below, or call SSA toll-free at the number below

SSI & SSDI Information Line:

1-800-772-1213

SSI eligibility for adults:

<http://www.ssa.gov/ssi/text-eligibility-ussi.htm>

SSI eligibility for minors:

<http://www.ssa.gov/ssi/text-child-ussi.htm>

http://www.ssa.gov/disability/disability_starter_kits_child_eng.htm

SSDI for adults:

http://www.ssa.gov/disability/disability_starter_kits_adult_eng.htm

SSDI for minors:

<http://www.ssa.gov/dibplan/dqualify10.htm#age22>

When My Daughter Was Born Continued from page 15...

He works full-time and sometimes has to travel for work, but after his divorce he did all the driving everywhere for all the things a young girl needs or wants to do. Like a lot of teenagers she always need to be some place: school, band practice, social activities, shopping. He waited patiently in parking lots across our small town thousands of hours to give her everything he could give her. He never made plans without her being thought of first. Still doesn't. He kept her when her mom moved on in her own life, and he never took his eyes off what was good for Lauren. He basically did high school all over as he got his daughter through every assignment. He had the usual single-dad worries of raising a girl with all of the 'growing-up-a-girl' issues.

Lauren was mainstreamed in school from the start. She's had an IEP, and received Regional Center help until she was three; after that they were on their own. They knew she had PWS, but she almost didn't. There was nothing he kept her from; they just adjusted themselves to make it work: swimming, soccer, the high school band. But Dad had goals and dreams for his daughter he wasn't sure how to accomplish.

Grooming and clothes and boys and sex talks were not his strong suits, and every day he got closer to these issues needing to be addressed. There was no discussion of she "can't" anything in life, so as she grew older and wiser and approached high school graduation, she had a lot of questions. There were heartbreaking moments. She asked me very direct questions as our friendship grew. Why couldn't she drive? Why can't she go with her friends most places? Why doesn't she work? Why isn't Dad applying for college with her like he did with her older sister? Why is he sooo over-protective?

Teaching Lauren about her having Prader-Willi syndrome and how to care for herself and why she is the wonderful person she is became our family goal. Mainstreaming is a wonderful gift her family gave her all those years. Her high functioning is a direct result of including her without mention of any special needs. Now it was time to explain PWS to the nicest girl on Earth. No one wants this for their child or for themselves. I often said it felt to me like I brought PW into the family *with me* as the time I got here is exactly when all those important talks needed to happen. To walk the walk and talk the talk, I often had news or plans no one was interested in hearing.

I contacted the national Prader-Willi Syndrome Association and they sent us a ton of information. The very same things I read about, I gave her to read. I had intended to go over them and discuss them with her, but she took the pages from my hand and began reading to me. She knew some symptoms and had not experienced others. Our path through contact with the PWSA (USA) and then with the Prader-Willi California Foundation saved us. Solutions, suggestions, and support came from each encounter. Our first trip to a support group had Dad nervous. What could he contribute, he wondered? Turns out, a lot. There were shocked new parents dealing with the news. There were little ones who hadn't started to thrive well enough and parents who were bracing for the changes that would come. There were parents with fully grown kids who were still looking for safe paths for their children. Dad had a lot to say that day and we went home charged up.

That same day we met a wonderful family who live near us who also has a high functioning daughter ten years older than Lauren. From day one to this day, the Leitheim family has been our local guiding light of how PWS care is done well. We could project forward and see Lauren being this happy and safe. Our gratitude to the PW associations and the Leitheims can never be repaid. It would take another whole letter to tell you how much we owe everyone who helped us.

As a step-mom I don't always feel I have the same control of my emotions and grasp of everything that Dad does. He seems to have an ability to pick it up and put it down when he needs to. He "gets" PW and how to react. And how not to. I have been scared and overwhelmed at times. I don't have 20+ years of experience talking with Lauren about everything she wants to talk about. I use the same answers I would give to any child of mine. I have made Lauren mad, I have failed to back down when I should have. I have been scared to venture too far and disturb Dad's trajectory of what he wants for Lauren. I feel the need to help and yet a fear of interfering and getting it wrong. I worry that if I fail one of them, I fail both of them.

Being a lifetime salesperson (I'm a real estate broker), I have jumped in with both feet and am determined to be a "good PW Mom." (My highest compliment I can give these amazing parents.) I asked for services and support when it wasn't necessarily requested by Dad or Lauren. I have pushed and annoyed and been forgiven. I have been given credit when credit didn't matter. I have been passed over for credit when I thought I deserved it. I have laughed at the sweetness and cried at the set backs.

They are my family now.

The really good news is in our time together and with Dad leading the way, we have accomplished so much. Lauren was reestablished with the Regional Center, receives SSI, and now has a job through the Department of Rehabilitation. She is dating. She wants a full life with everything that everyone else wants. With support, we get there a little more every day.



General Educational Meeting continued from page 1...

Visit a public place, such as a coffee house, and make up stories about the customers based upon the customers' eye-contact, physical presence, and other behavioral outputs. Who knows whom? What is their relationship: are they co-workers, friends, boyfriend and girlfriend? Do they like each other? Are they happy to be there? What are they thinking/talking about? Pausing tv shows and commercials to discuss the social interactions can also be very helpful to increase the individual's social thinking skills. For more information about Social Thinking and a list of trained therapists visit www.socialthinking.com



Speaking on the **Medical Management of PWS** was **Suzanne Cassidy, M.D.** who covered an incredible range of medical treatments from infancy through adulthood. The symptom of hypotonia (low muscle tone) is the most consistent feature of PWS and is not a muscle abnormality but results from altered the signals from the brain. Symptoms of low muscle tone in infancy and childhood include delayed motor skills, congenital hip dislocation, strabismus (a condition where the eyes don't properly line up), and/or reflux (a condition when the stomach leaks its contents into the esophagus). After infancy, hypotonia can lead to poor coordination, decreased physical activity, poor posture, scoliosis/kyphosis and/or higher fat muscle to bone ratio. The treatments for low muscle tone include exercise and physical activity at least 30 minutes daily, physical therapy and occupational therapy, careful monitoring for scoliosis, and growth hormone treatment. Dr. Cassidy addressed Coenzyme Q-10, a naturally occurring substance involved in energy production in all cells, especially muscle cells, that collects the toxic breakdown products of oxygen. Low CoQ-10 levels cause reduced energy expenditure, muscle dysfunction, and disorders of energy metabolism. While there are no controlled studies of CoQ-10, many families see improvements in vari-

ous areas. There are no known serious adverse effects if used in recommended doses, which start at 1-30 mg/kg/day for infants, and 60-100 mg/day in older children and adults.

Dr. Cassidy reminded the audience that obesity is the major cause of illness and death in persons with PWS. Factors leading to obesity include the excessive drive to eat (hyperphagia), decreased calorie needs, decreased vomiting, and decreased pain perception. She noted that while there are currently no medications to treat hyperphagia, there are trials underway (discussed in June-Anne Gold's, MD presentation). She advised that surgical interventions (stomach banding, stapling, etc) are not safe options. She stressed the importance of following intervention protocol: low calorie diet, lots of physical activity, growth hormone, secure food sources (locked to decrease anxiety); routinize meals and snacks, carefully plan for holidays and parties, weekly weighing, reward for compliance and success (not with food), and regularly follow-up with physician or dietician.

Dr. Cassidy noted that deficiency of growth hormone (GH) is well demonstrated in PWS. Growth hormone replacement therapy increases lean body mass; decreases fat mass; increases energy expenditure; improves motor skills, strength, agility and endurance; increases respiratory muscle forces; creates a more normal body shape, hand/foot size, and facial appearance if started early; and potentially improves cognitive ability. Contraindications to GH treatment include severe obesity (treat first); uncontrolled diabetes (get it under control); untreated severe obstructive sleep apnea (get it treated); active cancer; and/or active psychosis. The recommendation is to start GH treatment early in life, continue controlled diet and exercise, and monitor GH regularly. Other hormone problems in PWS include low testosterone (in boys) and estradiol (in girls) which cause a lack of development of secondary sex characteristics. Treatment is sex hormone replacement. Hypothyroidism (low thyroid hormone) occurs in approximately 10-25% of persons with PWS and is easily treated. While there is no consensus on whether, when, or how to test for central adrenal insufficiency (poor adrenal response to stress), Dr. Cassidy advises it should be considered at times of surgery, severe illness, or trauma. Dr. Cassidy emphasized the need to provide sex education to teens and adults with PWS and to consider birth control because there have been a small number of women with PWS who have become pregnant and given birth. Dr. Cassidy concluded her presentation noting that the future is bright for persons with PWS, with improved health care and education, improved public understanding of the issues faced by persons with PWS and their families and caregivers, and improved understanding of the cause and biological development of PWS, all leading to improved treatments.



June-Anne Gold, M.D. presented the **Hot Topics from the 2nd International Hyperphagia Conference and 26th Annual PWSA (USA) Scientific Meeting** held in Baton Rouge in October. Dr. Gold summarized the research that was presented at these meetings and explained what the research findings mean to families. Induced Pluripotential Stem Cell research is an exciting new area in which scientists are looking at skin fibroblasts (a particular type of cell) from persons with PWS and Bardet-Biedl syndrome (another syndrome that has the hyperphagia/food drive as a symptom) to learn more about each syndrome at the cellular level and potentially develop new treatments. In another research study, scientists are looking at Vagus Nerve Stimulation (VNS) as a treatment for the hyperphagia/food drive symptom. Three individuals with PWS have had the device implanted just under their skin that stimulates the Vagus nerve. While the effects of VNS on eating characteristics are unclear, there does appear to be positive effects on mood and behavior with few side effects,

and thus far VNS appears to be safe and acceptable treatment option. In another study, a new weight loss medication called Beloranib appears promising. Drug trials using PWS mice show females lost 1 kg/week over a 4 week period. Dr. Gold reported that while it is still early in testing, Beloranib shows some promise to lower insulin levels, increase energy expenditure, increase weight loss and reduce food intake. In still another study on a medication to manage hyperphagia, researchers are looking at Metformin, but with great caution as there is concern about a side effect of slowing down the stomach's emptying of food which is already delayed in many to most persons with PWS.

Continued on page 21...

General Educational Meeting continued from page 20...

Though not new research, Dr. Gold outlined the phases of hyperphagia: Phase 0- Prenatal in utero phase. Phase 1-Hypotonic and not obese. Phase 1a-Difficulty feeding with or without failure to thrive with poor appetite/feeding and poor weight gain (0-0.75 years). Phase 1b-No difficulty feeding/growing steadily along growth curve, not overweight with normal growth velocity and improvement in appetite (0.75 – 2.08 years). Phase 2a-Weight increasing *without* significant increase in calories (2.08- 4.50 years). Phase 2b-Weight increasing *with* significant increase in calories. This is when the food seeking begins but not yet insatiable appetite (4.5 – 8.0 years). Phase 3-Hyperphagic, food-seeking drive (age range is variable from 8.0 years or 3.0 – 15.0 years, with some people never experiencing Phase 3). Phase 4 is where some people no longer have an insatiable appetite.

Another exciting treatment, intranasal administration of Oxytocin producing neurons, is currently in the process of approval with the National Institutes of Health and the Institutional Review Board. Patients with PWS who received a single administration of Oxytocin displayed significantly increased trust in others, decreased sadness tendencies, and had less disruptive behavior in the two days after administration. A study looking at growth hormone treatment (hGH) showed patients with PWS who received growth hormone had a higher bone mineral density than those who did not receive hGH. Finally, Dr. Gold presented new research on animal models. Having an animal model allows researchers to study PWS and test hopeful new therapies. Up until recently there was only a mouse model for PWS. Unfortunately, there are significant limitations to studying PWS in mice because PWS mice don't survive past the "failure to thrive" stage. At this year's Hyperphagia conference, researchers presented a new PWS pig model. In addition to being able to survive past infancy into the hyperphagia stage, these animals are also more genetically similar to humans. The hope is that with a model closer to human PWS, scientists will be able to more quickly unlock future therapies for appetite management and weight control.



The final presentation, **Menu Creations by Mamma Deb**, was actually presented by **June Stockbridge**, Director of Easter Seals Camp Harmon, who filled in for Debbie Granger who is critically ill. June spent time with Debbie in the hospital and learned as much as she could about how Mamma Deb thinks about and prepares her healthy and delicious meals for our PWS Camp session. Deb suggests getting a good diabetic cookbook because they have such healthy recipes and include healthy substitutions. For example, desserts are often made replacing liquids with Diet 7-Up, or using applesauce to replace fats. Don't tell your camper, but Mamma Deb's delicious mashed potatoes are actually mashed cauliflower prepared to taste just like mashed potatoes with a fraction of the calories! Deb highly recommends www.CalorieKing.com for meal planning. When she puts together a meal, she divides the plate into thirds: a third portion is a protein, a third is a vegetable, and a third is a salad. She likes to serve salad at both lunch and dinner and likes Newman's Own packaged dressings. She makes the protein look larger than it really is by pounding the meat to make it flatter and wider. Snacks are always mainly a protein. Any unanswered parent questions were collected and will be sent to Mamma Deb, along with a get well soon card signed by many of her Camper fans.

This year's program included Share Sessions during the lunch hour was highly valued by participants. The Business Meeting was held during the lunch hour and featured an overview of PWCF's financial state by Treasurer **Renee Tarica**; an introduction of current Board members and Board Candidates by Nominating Committee Chairperson **Kimberlee Morgan**, who as Secretary also presented the Minutes from the 2011 meeting; and an overview of the Foundation's accomplishments this year was presented by Executive Director **Lisa Graziano**. President **Julie Casey** presented the 2012 President's Awards (see page xx). Vice President **Chris Patay** called for questions or comments from the audience and then adjourned the 2012 Business Meeting.

This year's General Education Meeting was another awesome success, as reflected in the Evaluation Forms which once again rated speakers overall as "Excellent" and the overall conference itself as "Excellent." A sampling of comments includes, "It was really nice to be able to connect with other parents." "I found the share sessions very helpful." "Thank you! We really appreciate it!" "Hearing the individual stories of how other families have coped with diagnosis at different ages/stages." We hope next year even more families and PWS professionals will attend the conference scheduled to be held on November 2 or 16 in Los Angeles.

PWCF'S CAMP AT EASTER SEALS CAMP HARMON ~ JUNE 20-25, 2013

Save the date for PWCF's 3rd annual PWS Camp at Easter Seals Camp Harmon *exclusively* serving persons with Prader-Willi Syndrome ages 8-65.

Camp Harmon is located in Boulder Creek, California in the beautiful Santa Cruz Mountains. Prior years' programming included a welcome campfire, daily swimming, arts & crafts, a hike, impromptu basketball games, quiet time, a wagon ride, horseback riding, a dance and the *best* camp counselors! 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 exceptionally delicious. Above all, access to food is strictly secured. Camp Scholarships are available to PWCF members in good standing that bring registration costs down to \$500 (PWCF will pay \$226 of your registration!). Non-member price is \$726. Campers LOVE PWCF's PWS Camp! For more information about programming, menu, or if you need help registering online, contact PWCF 310.372.5053

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 is grateful to each of our donors for helping us 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 don't 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 2012

SHINING STAR DONATIONS

Sirius (\$1,000 or more)

Nancy & John Jenkins in honor of Cameron Graziano
Monique & Peter Thorrington in honor of Ryan Patay

Alpha Centauri (\$250 - \$499)

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Jessica & Chris Patay in honor of Ryan Patay
Wandering Back Home in memory of Steven B. Kandarian and
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Grandpa Pete & Grandpa Bill
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MEMBERSHIP ACTIVITY

October - December 2012

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 Family Members

Sarah Ferrari

Renewed Extended Family Members

Judy Soden

Renewed Professional Members

Zylina Andaya Oliva – New Life Homes II
Suzanne B. Cassidy, MD – University of California,
San Francisco
Linda Hamilton – Lee Street Homes I & II
Omar Noorzad, PhD – Tri-Counties Regional Center
Rosary Oliva – Lucky Homes 2
Daniela Rubin – CSU Fullerton
Melanie Silverman, MS, RD, IBCLC – Feeding Philosophies
Joe Tontodonato – Arc of San Diego

Prader-Willi California Foundation is a non-profit 501(c)(3) public charity. Established in 1979, PWCF is the *only* organization dedicated *exclusively* to serving the needs of Californians impacted by Prader-Willi Syndrome. PWCF is comprised of parents, extended family, friends, dedicated professionals and care providers, and is supported solely by dues and donations.

Prader-Willi California Foundation proudly maintains an affiliation with the national Prader-Willi Syndrome Association (USA).