PWCF News

The Newsletter of Prader-Willi California Foundation

An Affiliate of

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

January - March, 2010 ~ Volume 20, Number 1

Get Ready for PWCF's 10th Annual Awareness & Fundraising Events!

WALKING *for Prader-Willi Syndrome*

Central California	**April 24 - NEW!**
Northern California	**April 25**
Southern California	**May 2**

Each year to commemorate national Prader-Willi Syndrome Awareness Month, PWCF hosts awareness and fundraising events throughout California. We are pleased to announce that this year, which marks the 10th anniversary of the *Walking for Prader-Willi Syndrome* events, there will be a new *Walk* in Fresno!

Your support of the *Walk* events is absolutely vital. Your participation helps increase public awareness of the syndrome. Your donation and fundraising helps raise money to support the many programs and support services families need. Each *Walk* offers the opportunity to meet with other families, enjoy fun games, activities and music. Bring your picnic lunch to the Central and Northern California *Walks*, or be treated to a healthy catered lunch in Southern California. Invite your extended family, friends, co-workers, your child's therapist, physicians and teachers to support you as you *Walk* to raise awareness of PWS and funds. **If you live anywhere near a *Walk* location, please come out for the fun and support your loved one, family friend, student, or patient.**

Not able to attend a *Walk*? No worries! Make a tax-deductible donation in honor of your loved one or friend to show your support. Donate a personalized Footprint Sign to be posted along your designated *Walk* path. PWCF has two ways you can help fund raise: by mail or online at **www.pwcf.org/WalkingForPWS.htm.** Your brochure is on its way to you, or feel free to call the PWCF office to request more.

Funds raised through the *Walking for Prader-Willi Syndrome* events support PWS Clinics; PWS group homes; residential and vocational work staff training programs; Support Groups; educational conferences; educational articles including this newsletter, books, brochures, and DVDs; IEP and Regional Center advocacy; toll-free support for Californians, and so much more.

Without your help, we can't continue to do all that we do! Please support this year's 10th Annual *Walking for Prader-Willi Syndrome* events. Have fun, honor your loved one or friend and… *Walk* with us!

In This Issue:

PRADER-WILLI CALIFORNIA FOUNDATION

2010 OFFICERS

President - Ken Knox

Vice-President - Chris Patay

Secretary - Julie Casey

Treasurer - Renee Tarica

2010 BOARD OF DIRECTORS

Julie Casey
Michelle Freier
Ken Knox
Drew Marich
Carl Martens
Tom McRae
Michael Moore
Betty Olson
Christopher Patay
Renee Tarica
Julie Tauscher

Lisa Graziano, M.A., MFT
Executive Director

Fran Moss, Editor, PWCF News

514 North Prospect Avenue
Suite 110—Lower Level
Redondo Beach, CA 90277
800-400-9994 (CA only)
310-372-5053 (Phone)
310-372-4329 (Fax)

E-mail: PWCF1@aol.com
Web address: www.PWCF.org
Facebook: www.facebook.com/pwcf1

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

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Wendy Young	415-924-7025	wmydmy@gmail.com
Sacramento	Diane Kavrell	530-753-5928	brandon.kavrell@cexp.com
San Luis Obispo Santa Barbara/ Ventura Counties	Hope Liddiard	805-461-0191	The Lidds@charter.net
Santa Clara/Santa Cruz/ Monterey Counties	Elizabeth Kulkowski	408-776-3533	

Central California

Fresno/Kern/Kings Madera/Mariposa Merced/Tulare Counties	Jennifer Rinkenberger (Infants & Children)	559-434-6641	jenrink@mac.com
	Debbie Martinez (Teens & Adults)	559-227-0294	martinezds@gmail.com

Southern California

Los Angeles County	Lisa Graziano	310-316-8243	tlcgraz@aol.com
	Julie Casey	818-843-7321	julie.casey@att.net
Orange County	Jenn Paige Casteel	949-547-1467	marchroses@hotmail.com

Inland Region Area

San Bernardino/ Riverside County	Maria & Ken Knox	909-421-9821	teachknox@aol.com

Spanish Speaking

Mercedes Rivera (Adults with PWS)	619-822-5742	mercedes_rivera2002@yahoo.com
Maria Knox (Adolescents with PWS)	909-421-9821	teachknox@aol.com
Kilma Carillo (Infants and Children with PWS)	760-427-1100	kilmab@excite.com
Veronica Baez (Infants and Children with PWS)	760-357-8189	vbaez92@yahoo.com

On-Line Support

PWCF Online Information Sharing Group for Members. This online information sharing group is for PWCF members. To join the group, go to www.yahoogroups.com. In the search box under the heading “Join a Group” enter *PWCFmembers*. When the *PWCFmembers* group name appears, click and follow instructions to join.

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

PWSA Online eSupport Groups. **www.pwsausa.org Click Enter. Click Support.**

for Families of Children Ages Birth-5 Years
for Families of Children Ages 6-12 Years
for Families of Teens
for Families of Adults
for Siblings
for Spanish-Speaking Families
for Military Families
for PWS + Autistic Symptoms
for Persons with PWS
for Grandparents

International PWS Organisation

IPWSO offers information about PWS in other languages. www.ipwso.org

Parent to Parent

How do you manage diet and weight control of your family member with PWS when on a home visit from his/her residential setting?"

When my daughter comes for a home visit she stays anywhere from two to four weeks. Knowing her normal caloric intake, by weighing and measuring I subtract approximately 200 calories per day so that there is wiggle room for the special occasions. In addition, weather permitting, she walks for an hour each day. There may be minimal weight gain when she returns from her home visit. *Fran, parent of Melissa, age 37.*

Since I can't lock my refrigerator or freezer, I go through them before Julia arrives and take out anything that she shouldn't have. I'll either throw it away or give it away. I keep the chips and all the other high-calorie snack foods out of sight and placed up high, out of her reach. I keep all of our money secured away so she can't take it to purchase food outside of the house. And finally, I purchase lots of healthy food choices and have them already at home so we don't have to go to the grocery store while she's here. *Jacki Lindstrom, parent of Julia, age 24 ½.*

Next issue's Parent to Parent question is, ***"How do you decide whether or what kind of sex education to provide to your child/adult?"*** To submit your response to this question or to send a new question, email, fax or send it to PWCF!

* * *

Gadget Tip

National Call Systems makes a new device that may be helpful to monitor kids and adults with PWS who like to leave their beds and bedrooms in the middle of the night. The new Ghost Cord cordless pad and monitor function with no cords between the pad and the monitor This alarm monitor system functions with GhostCord alarm pressure pads for the bed with an audible and visual alert. The cordless pad talks to the monitor using wireless technology (patent pending). Monitor can be placed outside of room to provide a quiet room environment with the alarm alerting the caregivers in the hallway! For more information visit www.allcallsystems.com

Food Tip

The following food tip was sent by PWCF member Fran Moss of Camarillo

Oroweat/Arnold's makes a new product called Sandwich Thins. The Thins come in 100% Whole Wheat, Multigrain and Honey Wheat. Shaped like a burger bun, they are only 100 calories, have 5 grams of fiber, 5 grams of protein and only 1 gram of fat. Other flavors include Seedless Rye and Whole Grain White. You can find this product at Costco and various grocery stores.

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

Patient Assistance Programs

New Pfizer Patient Assistance Program for Unemployed Americans

MAINTAIN is a new patient assistance program that can help eligible people in financial need continue to get their Pfizer medicines if they are unemployed and do not have prescription coverage. There are more than 70 Pfizer primary care medicines, including Genotropin growth hormone, available through the program. Once accepted into MAINTAIN, patients will remain enrolled for up to one year or until they become insured, whichever comes first.

Who is eligible for MAINTAIN? Individuals and their immediate family members are eligible for the Pfizer MAINTAIN program if they:
- Became unemployed on or after January 1, 2009
- Were prescribed and taking Pfizer medicines for at least 3 months prior to becoming unemployed and enrolling in the program
- Lack prescription drug coverage
- Can attest to financial hardship

Pfizer reserves the right to change or cancel the MAINTAIN program at any time. MAINTAIN is not available to residents of Puerto Rico and US territories. MAINTAIN is part of Pfizer Helpful Answers®, a joint program of Pfizer Inc and the Pfizer Patient Assistance Foundation™.

How to apply for MAINTAIN? The application process is easy and straightforward. People who think they may qualify should:
- Get the application form by calling 866-706-2400 or visit PfizerHelpfulAnswers.com to download a copy
- Complete the easy, one-page application
- Gather the required documents (proof of unemployment)
- Mail in all documents with the completed application
- Pfizer will typically process the application within 2 to 3 weeks.
- If approved, Pfizer medicines will be sent directly to the patients' home.

Are there other options for those who do not qualify for MAINTAIN? For those who do not qualify for the Pfizer MAINTAIN program, there may still be help available through Pfizer Helpful Answers®, a family of patient assistance programs for the uninsured and underinsured who need help getting Pfizer medicines. To find a program that may be able to help, call toll-free 866-706-2400 or visit www.PfizerHelpfulAnswers.com.

FALL SEVEN TIMES.
STAND UP EIGHT.

UnitedHealthcare Children's Foundation Offers Medical Assistance Grants to Families Nationwide

UnitedHealthcare Children's Foundation (UHCCF) offers grants to help parents and caretakers pay for children's medical needs and equipment not fully covered by insurance. Parents and caretakers across the country can apply for grants of up to $5,000 for health care services not covered by insurance that will help improve their children's health and quality of life. Examples of the types of medical services covered by UHCCF grants include: speech therapy, physical therapy and psychotherapy sessions; medical equipment such as wheelchairs, braces, hearing aids and eyeglasses; and orthodontia and dental treatments.

The UnitedHealthcare Children's Foundation is a public charity with its own board of directors, operating independently from UnitedHealthcare. UHCCF is a nonprofit 501(c)(3) organization that strives to enhance either the clinical condition or quality of life of children who have health care needs not fully covered by commercial insurance. UHCCF funding is provided by contributions from employees of UnitedHealth Group as well as individuals and corporations. For more information or to apply for a grant visit www.uhccf.org.

PWCF Membership Age Statistics

PWCF Board member Chris Patay recently analyzed the ages of our families' child with Prader-Willi syndrome. We thought you may find the results interesting.

> The median age of persons in California with Prader Willi Syndrome is 15. That compares to the median age in the US of 36.
> 35% of persons with PWS are 10 years old or younger.
> 66% of persons with PWS are age 21 and under.
> 90% of persons with PWS are under the age of 40.
> 28.1% of persons with PWS are between the ages of 21-40.
> 75.5% of persons with PWS over the age of 20 are 40 years old or less.
> 9.2% of persons with PWS are over the age of 40.
> The oldest known person with PWS in California is 55 years old.

Notes Chris, "Even without having further information (e.g., life expectancy, percentage of persons living in group homes, etc.), it appears there will be a significant need for new group homes in the future to accommodate persons with PWS."

PWCF is working with the Richard DeLone Special Housing Project to survey the current and future residential needs of families who are raising a child or adult child with Prader-Willi syndrome. If you have not already completed your **Residential Services for Persons with Prader-Willi Syndrome Questionnaire** please contact PWCF so that we may send one to you.

Executive Director's Column

Lisa Graziano, M.A.

New Year's celebrations have come and gone, as have Valentine's and St. Patrick's Day festivities. Good food and drink typically go hand-in-hand with such observances, so like all parents of a child or adult with Prader-Willi syndrome, I am sometimes somewhat ambivalent about where, whether, or how we celebrate certain occasions. On the plus side, recurring holidays demarcate the current year from the previous one and hold out the promise that *this* year I *will* do all of the fantastic things I planned to do last year but didn't. And so, after tidying up from the Christmas madness, I vowed to climb up to the attic and wrestle down the boxes containing our wonderful collection of Valentine's Day trimmings. "This year will be different!" I told myself. Of course before I could actually enjoy rediscovering the red splendor tucked away in those boxes for so long, I needed to focus first on priorities. Family celebrations and classroom parties were just around the corner, so before each party I needed to prep, inform or confirm with teachers and family about Cameron's special dietary restrictions and monitoring needs. Then I needed to plan for how to prepare Cameron for what he could expect, as well as what he should *not* expect, at each party. Oh, and I needed to stop at the grocery store to pick up the healthy snacks and appetizers I needed to send with him to school and bring to the family party. Alas, by the time I finished my planning and preparing for the essentials, Valentine's Day had come and gone, the boxes were still collecting dust in the attic rafters, and the Presidents were staring me down, with St. Patty just behind them, begging me to do a better job commemorating them than I did for poor St. Valentine.

Yes, planning takes a lot of time and energy. But planning is what creates success, and everyone working for Prader-Willi California Foundation has been busy not only planning but also doing. No doubt like you at home, the first quarter of 2010 has been a busy one. Plans for awareness-raising events, educational events, training programs, support plans, long-term strategies, and fundraising events are in full swing. There is indeed a lot planned for 2010, as you will read in this and future newsletters.

It is very good news for us that obesity is once again in the national public eye. No matter what our political persuasion it cannot be argued that the current administration has placed healthcare squarely in the spotlight and the First Lady's campaign against childhood obesity brings increased public attention to the devastating consequences of obesity and emphasizes the need for healthier eating habits and increased physical exercise. California schools are beginning to encourage parents to pack their child a *healthy* snack and lunch, teachers are more frequently discouraging classroom birthday celebrations with cupcakes and candy, and some schools are going so far as to remove soda from their campus vending machines. Albertson's grocery stores, for whom PWCF has provided educational programs, is helping consumers become more health conscious with their *Nutrition IQ* to help shoppers "make better-informed, better-for-you choices on the spot as you shop." The California Association of Superior Court Investigators continues to reach out to PWCF to learn more about what judges need to know about PWS. These shifts in public strategy are absolutely positive ones for children and adults with PWS.

Each New Year offers the opportunity to take stock, reassess where we're devoting our attention and energy and make adjustments if necessary, and renew our commitment to those most important to us: our spouse, our partner, our children, our family, and the organizations on which we receive support and guidance. I hope you will renew your commitment to Prader-Willi California Foundation with your generous donation and with your continued membership. As always, I encourage you to please let us know when and how we may provide support or assistance to you, your family, your student, or your patient.

No, my house may not always get decorated for every holiday and the Christmas lights may hang over the garage well into March, but the really important, essential things do always seem to get done good enough. And there's always next year…

Renew Your Membership

PWCF
Membership Renewal
Dues Form - 2010

☑ *Yes! Renew my membership today!*

Your 2010 Member Renewal/Dues Form is on its way to your mailbox. Please complete your Form as soon as you receive it and renew your membership with Prader-Willi California Foundation. Can't afford some or all of your annual dues? Check the box that requests a Dues Waiver and PWCF will gladly sponsor your membership for you. No changes to your data and you want to pay by credit card? No problem! Just contact the PWCF office and we'll take your credit card information and process your online membership renewal. Please support Prader-Willi California Foundation by renewing your membership.

National Center for Learning Disabilities' Spanish Resources for Reading

There is an exciting new area created on the *Get Ready to Read!* web site www.getreadytoread.org designed especially for Spanish-speaking parents of preschool-aged children.

Parents and families can now connect with a host of Spanish resources designed to make early literacy and learning fun for young children as well as provide practical tips to help parents communicate with educators.

If you are a parent, NCLD encourages you to share these free resources with your friends and your child's teacher. If you are a teacher or day care provider, you are encouraged to share these resources with your families and colleagues. We hope you find these resources helpful in your work to support the educational needs of all young children.

Recursos en Español

- Herramienta de Observación
- Difusión Virtual (Webcasts)
- Listas de Verificación Literarias
- Páginas con Consejos para el Desarrollo Temprano
- Aprendiendo a Conocer a mi Hijo
- ¿ Deberia estar Preocupado?
- Actividades para la Alfabetización Temprana

Bienvenido al área de recursos de lenguaje en español para padres! Los recursos que encontrará en esta sección fueron diseñados especialmente para padres de niños de preescolar y de jardín de infantes.

Por favor explore este sitio para encontrar muchas actividades divertidas e ideas para hacer que el aprendizaje de la lectura sea entretenido para su hijo.

Además, usted encontrará una variedad de información en el área de la educación temprana sobre este tema, que podrá compartir con el maestro o proveedor de cuidado infantil, cuando converse sobre sus ideas y preocupaciones concernientes al desarrollo del aprendizaje temprano de su hijo.

Para cualquier maestro que esté visitando esta sección, estos recursos son beneficiosos para apoyar sus esfuerzos de involucrar a las familias de sus estudiantes!

Todos los recursos son gratuitos y lo alentamos para que los comparta con otros padres, maestros y proveedores de cuidado infantil.

Herramienta de Observación
Use esta herramienta de observación con niños de 3-5 años. El puntaje le mostrará si las destrezas de prelectura de su hijo son fuertes, débiles o intermedias. Luego utilice las actividades para el desarrollo de las destrezas literarias en su hogar, así como también otros recursos entretenidos para mejorar estas habilidades de alfabetización.

Difusión Virtual (Webcasts)
¿Le gustaría aprender más sobre cómo fortalecer las destrezas literarias de su hijo? Explore nuestros entretenidos webcasts que lo introducirán a nuestra herramienta de observación de la prelectura, actividades para el desarrollo de las destrezas y otros recursos divertidos. (La duración de cada webcast es de aproximadamente 8 minutos.)

Listas de Verificación Literarias
Use una de estas listas de verificación literarias para entender mejor los componentes de un espacio amigable para la lectoescritura, y aprenda sugerencias para mejorar estos espacios, que aunque sea en pequeñas dimensiones, estos cambios serán muy importantes.

Páginas con Consejos para el Desarrollo Temprano
Aprenda más sobre el tipo de destrezas que su hijo está desarrollando en el preescolar o jardín de infantes, así como también formas sencillas de reforzar estas habilidades en el hogar.

Aprendiendo a Conocer a mi Hijo
Ayude al maestro o proveedor de cuidado infantil de su hijo a conocer mejor a su niño, compartiendo información importante con ellos.

Debería estar Preocupado?
Este recurso le provee consejos sobre cómo conversar con el maestro o proveedor de cuidado infantil de su hijo sobre sus preguntas relacionadas con el desarrollo de su niño.

Actividades para la Alfabetización Temprana
Use una o más de estas actividades literarias gratuitas con su hijo. Estas harán que el refuerzo de las destrezas literarias tempranas sea divertido para usted y para su niño!

Get Ready to Read! is a program of the National Center for Learning Disabilities. These resources are provided free of charge.

Qualifications of Special Education Teachers

The requirements about qualifications of special education teachers track the highly qualified teacher requirements in the No Child Left Behind Act. The requirements for related services providers and paraprofessionals did not change. IDEA 2004 requires states to take measurable steps "to recruit, hire, train, and retain highly qualified personnel to provide special education and related services." Wrightslaw correctly notes that "There is no 'right of action' such as the right to sue a state or school district because a teacher is not highly qualified. However, parents may file complaints about inadequately trained teachers with their State Department of Education."

No Child Left Behind Facts and IDEA Requirements for Special Education Teachers

The purpose of the Individuals with Disabilities Education Act (IDEA), as amended in 2004, is to "ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living."

IDEA defines "highly qualified" special education teachers as shown below, and requires all special education teachers to meet that definition. It also offers states some flexibility to work within their systems to meet the teacher requirement provisions of IDEA and the No Child Left Behind (NCLB) Act of 2001. In California all teachers of core academic subjects, including special education teachers, must demonstrate subject matter competence in each core academic subject taught as described in the 2007 NCLB *Teacher Requirements Resource Guide* (DOC; 383KB; 40pp.). In addition, to be compliant with IDEA, all individuals who teach students with disabilities must hold the appropriate special education credential.

Definition of "Highly Qualified" for Special Education Teachers

In general, for any special education teacher, the term "highly qualified" has the meaning given the term in section 9101 of the Elementary and Secondary Education Act of 1965. The following is an excerpt of Public Law 108-446, Individuals with Disabilities Education Act, as Amended in 2004, Section 1401(10)(A-F).

Requirements for Special Education Teachers - When used with respect to any public elementary school or secondary school special education teacher teaching in a State, such term means that 1) the teacher has obtained full State certification as a special education teacher (including certification obtained through alternative routes to certification), or passed the State special education teacher licensing examination, and holds a license to teach in the State as a special education teacher, except that when used with respect to any teacher teaching in a public charter school, the term means that the teacher meets the requirements set forth in the State's public charter school law; 2) the teacher has not had special education certification or licensure requirements waived on an emergency, temporary, or provisional basis; and 3) the teacher holds at least a bachelor's degree.

Special Education Teachers Teaching to Alternate Achievement Standards - When used with respect to a special education teacher who teaches core academic subjects exclusively to children who are assessed against alternate achievement standards established under the regulations promulgated under section 1111(b)(1) of the Elementary and Secondary Education Act of 1965, such term means the teacher, whether new or not new to the profession, may either 1) meet the applicable requirements of section 9101 of such Act for any elementary, middle, or secondary school teacher who is new or not new to the profession; or 2) meet the requirements of subparagraph (B) or (C) of section 9101(23) of such Act as applied to an elementary school teacher, or, in the case of instruction above the elementary level, has subject matter knowledge appropriate to the level of instruction being provided, as determined by the State, needed to effectively teach to those standards.

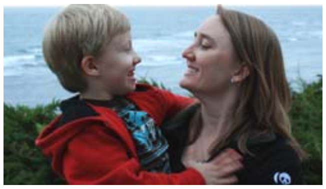
Special Education Teachers Teaching Multiple Subjects - When used with respect to a special education teacher who teaches 2 or more core academic subjects exclusively to children with disabilities, such term means that the teacher may either 1) meet the applicable requirements of section 9101 of the Elementary and Secondary Education Act of 1965 for any elementary, middle, or secondary school teacher who is new or not new to the profession; 2) in the case of a teacher who is not new to the profession, demonstrate competence in all the core academic subjects in which the teacher teaches in the same manner as is required for an elementary, middle, or secondary school teacher who is not new to the profession under section 9101(23)(C)(ii) of such Act, which may include a single, high objective uniform State standard of evaluation covering multiple subjects; or 3) in the case of a new special education teacher who teaches multiple subjects and who is highly qualified in mathematics, language arts, or science, demonstrate competence in the other core academic subjects in which the teacher teaches in the same manner as is required for an elementary, middle, or secondary school teacher under section 9101(23)(C)(ii) of such Act, which may include a single, high objective uniform State standard of evaluation covering multiple subjects, not later than 2 years after the date of employment.

Continued on page 13 ...

Board Corner

PWCF Board of Directors Meeting January 9, 2010

By Julie Casey, Secretary



The Board of Directors met for the first meeting of the New Year at the PWCF office in Redondo Beach. All members were present except Betty Olsen and Ken Knox. Additionally, consultant Fran Moss and Executive Director Lisa Graziano were present. After the meeting was called to order our newest Board Member, Julie Tauscher was welcomed and briefly introduced herself. The Board then set dates for the year's Board meetings and elected officers for the year. All prior officers will remain in their positions for another year: Ken Knox as President, Chris Patay as Vice President, Renee Tarica as Treasurer and Julie Casey as Secretary. Lisa Graziano provided a Board Orientation reviewing a brief history of PWCF and outlining the role and responsibilities of Board Members.

The remainder of the meeting discussed the following topics:

Treasurer's Report and Finances: Renee Tarica reported that she has received the final entries for 2008 from the accountant and that she and Lisa Graziano will be meeting with the accountant to review all new IRS policies, etc. Renee advised that all Board members will receive a full report which needs to be carefully reviewed in order to approve for tax filing. Renee reported that two recent grants have been issued to support the PWS Clinics at to Genetic Medicine Central CA ($6,435) and Children's Hospital of Orange County ($7,320). Renee distributed an investment statement summary. She also reported that the bank we use was purchased by Bank One, and the bank that manages one of our CD holdings was also purchased by a new bank. She indicated that these takeovers shouldn't have any impact on how business is handled. Lisa Graziano distributed an income statement for 2009 but noted that the interest figures for the year are not known yet pending year-end statements from the investment firm. Lisa also noted that even given the depressed state of the economy, General Donations and Shining Star donations received were above expectations. Lisa also presented a draft budge for 2010 which was discussed and approved. During the budget discussion the Board was reminded (proper disclosure was made) that our printing services are provided by Tarix Printing which is owned by Board member Renee Tarica's husband. The discussion noted that PWCF saves a considerable amount due to this arrangement and therefore a motion was made and approved to allow the continued use of Tarix Printing.

Executive Director's Report: Lisa Graziano noted that she did not have a written report as usual this time due largely to the fact that one of the computers in the office crashed just prior to the Board meeting. She reported that they were able to recover the data and she is in the process of shopping for a replacement computer. Lisa also indicated that she is looking for an additional volunteer for the office and is working with the new grant writer (a grandparent of a child with PWS who is a professional grant writer who has offered her services) to get her started on some projects. Lisa indicated that several new families have joined since November.

Strategic Planning: A significant amount of time, led by Drew Marich, was spent on reviewing progress on past goals and discussing future goals:

Fundraising: Drew leads this group and set a goal of $150,000 for the year which is anticipated to be accomplished through the following campaigns:

1. *Walking for Prader-Willi Syndrome* awareness and fundraising events – by adding a third location in Fresno this year which will increase income
2. Develop Corporate Sponsorship/Donation Plan - re-vamp the corporate solicitation letter and create a DVD photo compilation to use as part of the corporate solicitation plan
3. Opportunity Drawing Plan to Raffle a Timeshare
4. Shining Star Campaign

Residential Training DVD Project: Consultant Fran Moss is the lead on this project and reported that the script is done and ready to be approved by the film producer. The DVD is now planned to be an hour and they need to decide filming locations and a person/s to do the voice-overs. Fran reported that she's set a completion due date of June 15th.

Improve PWCF Website: Tom McRae is the lead on this goal and reported that he has talked with the new web consultant and has a meeting scheduled for January 15th after which he will report back to the Board and then proceed with the list of desired changes.

Improve Public Awareness: Michael Moore is the led on the Public Awareness committee and reported that the Warrior event date has changed and will now likely be on March 27th. Unfortunately, due to Clint Hurdle's new job he will not be able to attend. Michael also commented that legislative issues are another area that PWCF should be involved in to raise awareness. An employee of AC approached Michael at the General Education Meeting (GEM) expressing his interest in helping with this aspect. Michael has had one phone conversation with him and will pursue this relationship to develop this aspect of awareness. Along this same topic Michael noted that the House did pass a Bill to have a National PWS Awareness Month and Julie Casey asked for confirmation that the Board felt this was something PWCF should support when it comes before the Senate. The Board agreed that PWCF should lend

Continued on page 9 ...

Board Corner continued from page 8 ...

support to this legislation. Likewise Michael mentioned the ABLE (Achieving a Better Life Experience) Act which PWCF should also be supporting. Finally Michael notes that PWCF should be issuing press releases for all *Walks*, the GEM, etc. Julie Casey added that our Facebook fan page (www.facebook.com/pwcf1) is another aspect of public awareness and hopes to continue to grow the fan base.

Improve Board Communication Tools: During the Board Orientation Julie Casey presented information on Wiggio which is a group communication website which she set up for the Board members a couple months ago to improve Board communication. She also noted that this goal is also being actualized through the use of task lists generated after each Board meeting and more activity by the Executive Committee.

GEM Organization (improve long-range planning): Lisa Graziano noted that this goal is basically accomplished as we do have the next 2 years speakers lined up.

Create phased long-term plan to make progress on our major long-range goal: Chris presented an overview of our long-term objective ("To create a PWC campus in California that provides residential, vocational, recreational and social opportunities for people with PWS") and some proposed objectives and timelines. It was determined that a sub-committee is needed to meet more frequently to move this goal forward. It was also decided that by the next meeting all Board members should write down their ideas, being as specific as possible, for what this finished goal would look like in order to help the sub-committee move forward.

Residential Services Liaison Committee Report: In addition to the update on the DVD project reported above, consultant Fran Moss presented a written report of her contact with the group homes noting that the Chula Vista ARC home in San Diego County currently has two openings. Fran also reported that one of the grants issued to a group home several months ago has yet to be spent. This led to a discussion that the Board should establish more detailed procedures and requirements for grants.

Awareness Committee Report: Mostly updated above under strategic planning, but it was also noted that the Southern California *Walk* is scheduled for May 2nd and that the Northern California *Walk* date should be set soon as well as the Fresno date. Tom McRae advised that the Northern California planners could not obtain the permit until this week which was why the date had not been confirmed yet, but now that scheduling is available the date will be confirmed ASAP.

Program Committee Report: Lisa Graziano distributed a financial statement for the 2009 GEM showing the cost at approximately $15,000; half which ($8,000), was, thankfully, covered by grants received. Lisa reported that the speakers for the 2010 conference are set, but we need to find a Northern California hotel. Lisa also reported that Family Day at the Painted Turtle is scheduled for March 13th. A grant to the Painted Turtle in the amount of $8,000 was approved by the Board. It was again discussed that the Board's desire is to pursue a PWS family weekend at the Painted Turtle for 2011.

Prior to adjourning, the Board discussed policies on email voting between meetings and determined that if the vote is unanimous the vote is valid. The Board will inquire further regarding the legality of email votes that are not unanimous.

Although sitting in a meeting room most of the day is not my preferred way to spend a weekend I am continually impressed by the dedication, passion and thoughtfulness that each of the Board members put into the generous donation of their time and talents. I feel privileged to work with such a fine group of people and always leave our meetings feeling inspired. Remember that we are always looking for future Board candidates and committee members, so if any area discussed above is of interest to you please contact any of the Board members or Lisa at the office.

Be a Shining Star

If you haven't already made your Shining Star donation to support your loved one or family friend, Prader-Willi California Foundation encourages you to make your donation today! You receive the tax deduction while persons with PWS and their families reap the benefits of your generosity. Shining Star donations support PWCF's programs and services that improve the quality of life of someone with PWS. Please make your donation today and be a Shining Star!

Article Review *The Skinny on the Fats* by Kristen Allott, ND, LAc

Submitted by Lisa Graziano

If you're anything like me then you often feel bewildered about what constitutes a healthy diet, especially when it comes to understanding carbohydrates or what it means to eat "good" fats or "bad" fats. I recently read this article written by Kristen Allott, ND, LAc and found it interesting and helpful. Because I know so little about nutrition, I'll quote Ms. Allott often.

"Not all fats are created equal," writes Ms. Allott. "Increasing good fats in your daily nutrition and avoiding refined carbohydrates - which become bad fats in your body - can help improve your overall health." This is exceedingly good advice when it comes to providing a healthy diet for our loved one with Prader-Willi syndrome. Current understanding of the best overall diet for someone with PWS is to maintain a low percentage of carbohydrates to a higher percentage of protein intake. But honestly, I ask, what do "fats" have to do with carbohydrates? Fortunately, I was about to find out.

Ms. Allott notes that "In order to increase the good fats and decrease the bad fats, you must first know where to find them on food labels. Next time you're in the grocery store wander around and notice all the labels that say "Low-Fat" and notice what you associate with that advertising. When I offer groups on label reading, people often bring in labels for their healthy foods labeled "Low-Fat." However, when you turn over the package and read the Nutritional Facts, you find it's not so healthy."

What she writes next surprises me as I gave my son this snack on a daily basis when he was younger. "A classic example of this is rice cakes. One rice cake is 70 calories, 0 grams of fat, 15 grams of total carbohydrates, 1 gram of fiber and 2 grams of protein. There is very little fiber in a rice cake, which makes it a refined carbohydrate. Additionally, the total carbohydrate to protein ratio is about seven to one. For most people, this type of ratio will make them hungry and perhaps anxious or irritable two hours later." If 'most people' feel irritable two hours after eating a rice cake snack, then I certainly want to be extra cautious when it comes to my son with PWS! I wonder if adding peanut butter, which is a higher protein food, to that rice cake might take that edge off…

I am further intrigued when I read, "…insulin will clear the sugar from the meal in about two hours and we will want to eat again. If we ignore that signal we can then become anxious, irritable or fatigued … Both the high refined carbohydrate snack and the [desire to eat more] behavior makes it more likely for us to put on additional weight, because the extra refined carbohydrates will be converted into fat by insulin. In other words, foods that say "Low-Fat" are typically high in refined carbohydrates because they have been manufactured, and can become high-fat in our bodies." Oh dear!

Ms. Allott writes, "Refined carbohydrates make us feel hungrier, while vegetable dietary fats make us feel satisfied. In fact, fat intake is so important that there is part of our brain called the ventral medial hypothalamus that monitors for fat and is one of the mechanisms that tell us that we are satisfied with a meal." I wish I knew more about whether/how the ventral medial plays into the symptoms of PWS…

Ms. Allott advises that, "The best fats… are the vegetable fats. Olive oil is a great source of good fat, and you use it as salad dressing, drizzled over appetizers such as mozzarella cheese and tomatoes, drizzled over vegetables such as broccoli, broiled brussels sprouts or asparagus, and baked sweet potatoes. Other examples of snacks that are satisfying are avocado with lemon/lime juice and a little sea salt, olives from the olive bar at Whole Foods, a handful of nuts such as almonds, cashews, hazelnuts, and pecans; nut butter (almond/cashew/ peanut) with carrot and celery sticks or apple slices. The nice thing about the vegetable fat is the variety and many ways to mix it up and it's relatively inexpensive. Another vegetable fat that's good to have in your diet occasionally is coconut fat. Coconut fat contains a fatty acid, called lauric acid. This is a medium chain fatty acid that is especially useful to the immune system."

Parents and care providers of persons with PWS must be cautious when using olive and coconut oils, nuts, sweet potatoes, etc. because they are higher in calories, but the overall message remains: We must be aware of the need for a low carbohydrate diet, not be fooled by "low fat" labeling, use vegetable fats such as olive oil, and of course, serve lots of green vegetables with meals and snacks.

Creating a Strong, Supportive, Healthy Marriage and Family

Part I

By Lisa Graziano, M.A., MFT

A few years ago Janalee Heinemann, M.S. and I presented at a PWSA(USA) conference on the challenges that face couples raising a child with PWS and how couples can come together to meet those challenges. This article is the first in a four-part series that will present information about the fundamentals of a healthy marriage in general, and provide insights into the unique challenges that PWS imposes on families so that couples have greater tools with which to build a strong, healthy marriage that sustains a strong and healthy family unit. For a copy of the article in its entirety, contact the PWCF or the national PWSA(USA) office.

All marriages are presented with various stressors which ebb and flow throughout the couple's lifetime. Having a child who is diagnosed with Prader-Willi syndrome presents an additional degree of stress on any marriage. It is not *what* stressors a couple are challenged with, however, that predict the strength of the marriage, but rather *how* they manage those stressors.

All couples disagree, fight, feel exasperated, angry, stressed, and hurt at various times throughout their marriage. Couples in healthy marriages disagree and fight about the same things couples in unhappy marriages typically fight about – money, sex, in-laws, chores, childrearing – but they fight in such a way that somehow communicates an overall caring about the other, an overall regard for the other's ideas, concerns, opinions, wants and needs. They know that keeping the relationship healthy is more important than the thing they are fighting about, and that if their marriage is strong they *will* find a way to resolve the issue. They also know that not *every* problem *can* be solved.

There is not just *one* way to have a strong, healthy marriage. A healthy relationship is created when the couple creates a style of relating with each other that works best for *them* based upon their individual personalities, beliefs, and life experiences. There are, however, certain characteristics that are shared by couples who have a healthy marriage.

1. Deep Friendship Couples who have a mutual respect for each other, who truly enjoy each other's company, and who stay in tune with their spouse's day-to-day world are the happiest. Happy couples know each other's likes, dislikes, personality quirks, hopes, dreams, fears, stresses, and knee-jerk reactions to stressors. "They have an abiding regard for each other and express this fondness not just in the big ways but in the little ways day in and day out." (Gottman 1999) Couples who have created a healthy marriage have a genuine caring and respect for their partner and they generally treat each other well.

In unhealthy marriages couples criticize, disparage, undermine, become cynical, sarcastic, defensive, devalue the friendship, ignore each other, live separate lives, and are often lonely and depressed.

2. Sense of Purpose In strong marriages couples share a sense of purpose for their marriage. For some, an overriding purpose of marriage may be to connect with another human being in order to create a safe haven within which to pursue individual hopes and dreams. For others the purpose of marriage may be to have children and raise them to become responsible adults who then marry and have children of their own, thus perpetuating society. For a spouse who holds the latter belief, having a child with PWS may present a particular challenge and present an added loss.

Our own personal beliefs about marriage, whether conscious or not, are shaped and influenced by our experiences within our family of origin and will influence what we think our married life should be like (fantasy), what we do to achieve that fantasized life, and ultimately how we behave toward and interact with our spouse.

In a healthy marriage, the couple is able to value and support their partner's individual hopes and dreams and work together to create shared family goals.

3. Stay Connected Couples in healthy marriages stay emotionally connected with each other. They turn *toward* each other, whether it's during times of excitement or times of stress. They don't dread sharing their fears, stress, or disappointments. They look forward to sharing good feelings or good news with their partner. They reminisce about their shared experiences, good and bad.

4. Shared Authority Couples in a healthy marriage seek out the advice, opinions, and experience of their spouse. They don't make major decisions that might affect the family without their spouse's input or before first discussing it. Even when they don't agree with their spouse's opinion or concerns they don't belittle or disparage them. They know how important it is to the marriage to learn more about *why* their spouse believes as they do, and they bear in mind their spouse's concerns while discussing the best course of action. Couples in a healthy marriage work together cooperatively for the good of the entire family.

Continued on page 12 ….

Marriage and Family continued from page 11 ….

The Impact on Marriage When a Child Has Prader-Willi Syndrome

"Unfortunately, the odds are against *any* marriage lasting "until death to us part." Half of all divorces occur within the first seven to eight years, and the divorce rates jumps to 64% after 15 years. The divorce rates for second marriages is as much as 10% *higher* than first timers! (National Center for Health Statistics)

All change, whether welcome or unwelcome, is stressful. Having a baby certainly presents a change to the couples' family structure and places a tremendous amount of stress on any marriage. In a study by Gottman (1999) one of the major causes of marital dissatisfaction and divorce was the birth of the first baby.

Receiving the diagnosis of Prader-Willi syndrome creates *massive* stress and usually triggers feelings of loss, depression, and grief. As the child grows, new stressors replace or compound previous ones.

Each of us reacts to stress depending upon our individual character makeup, temperament, family-of-origin and life experiences, and learned coping strategies. Our reactions to stressors reflect the way we choose to protect ourselves from becoming overwhelmed, which for couples who have a child with Prader-Willi syndrome represent some of the *highest* levels of stress. Like other couples who have a child with a disability, the stress created by PWS will impact the couple; they will respond by beginning or continuing to work together as a united team to respond to the new challenges they face, or they will turn away from each other and begin the process of disengaging from their marriage. *This is a critical dynamic in the marriage of a couple who has a child with PWS and will impact the entire family dynamic throughout the years ahead.*

Having a child with PWS often provokes a sense of loss, often multiple losses. Loss can be composed of many intense emotions including sadness, grief, despair, anger, guilt, fear, worry, isolation, loneliness, shock, jealously, shame, and guilt. Some reactions to loss are humanly common: denial (this isn't *happening* to me!), anger (why is this happening to *me*?), bargaining (I promise I'll be a better person *if…)*, depression (I don't *care* anymore), acceptance (I'm *ready* for whatever comes). These feelings are not necessarily felt in that order and there should be *no* presumption that they progress through "stages" or that once they are worked through they never need to be experienced again.

Feelings of loss can be devastating. We experience a loss of the excitement and joy we imagined we'd feel after the birth of our baby; a loss of the ease and normalcy we see others around us appearing to enjoy; a loss of friends or relatives or work peers we leave behind when they can not accommodate to our new needs; the loss of becoming a grandparent; the loss of the fantasy we had once created for our child's, our self and our family's future.

Having a child with Prader-Willi syndrome means we will probably experience *chronic* loss or *chronic* grief. Grief doesn't leave us completely, but the intensity of the feelings does lessen over time and new dreams for the future can be created. This lessening of the intensity of feelings may be considered a kind of "acceptance" and can be defined as a coming to terms with the loss. Each new developmental phase our child progresses through may kick up feelings of loss and grief. While we may come to some kind of "acceptance" today, *tomorrow's* circumstances may trigger a re-experiencing of denial or anger or depression or all three simultaneously. Additionally, any new losses tend to stir up previous losses, which can intensify the feelings associated with the new loss.

Worden, Leick and Davidsen-Nielson (1991) describe four basic tasks that individuals need to achieve in order to integrate their experience of loss into their life and move toward investing in a new life without the lost loved one. These can be applied to the parents of a child with Prader-Willi syndrome, though they will occur again and again throughout the marriage and the child's lifetime: 1) Recognize the loss; 2) Release the emotions of grief; 3) Develop new skills (take on new role, make new contacts, friends, support network. Incorporate the experience of the loss into one's identity. The opportunity for personal growth and development is seen in this part of grief work; and 4) Reinvest emotional energy in the present.

Of particular challenge to parents of a child of any age who has PWS is the fact that spouses may very well be at different emotional places. While one parent may be closer to the realm of "acceptance" and ready to make an action plan, their spouse may be fully involved in denial, guilt, anger or depression. It is important to remind ourselves that we *must* allow our own process to proceed at its own pace *and we must tolerate and support our partner's process as it proceeds at its own pace.*

Whether our child was recently diagnosed or we've been managing the diagnosis for quite some time, for the sake of the strength of our family it is important to strive toward incorporating the four characteristics of a "healthy" marriage into our own relationship, and remind ourselves that there's not an emotion we feel that has not already been felt by another – and probably our own spouse! While it may sometimes seem so, as Carolyn Loker, mother of Anna and long-time advocate for parents of a child with PWS, often says, no one need feel alone.

Part II will appear in the next newsletter edition and will review common stressors on newly diagnosed families and on established families, and will provide strategies for improvement.

Special Education Teachers continued from page 7 ...

Nonpublic Schools

A nonpublic school (NPS) is a private, nonsectarian school that contracts with an LEA to enroll students with disabilities in an individualized education program and is certified by the CDE. Special education teachers in nonpublic schools are required to meet the credential requirements of IDEA and NCLB. Education Code Section 56366.1(n) requires all teachers in nonpublic schools to meet the same credentialing requirements as those for public school teachers. This statement means that NPS special education teachers need to hold a valid California special education credential or a valid CCTC Education Specialist Internship Credential for no more than three years. A temporary certificate, Provisional Internship Permit, Short-Term Staff Permit, Emergency Permit, or credential waiver does not fulfill the requirement.

Paraprofessionals

Paraprofessionals do NOT need to meet the NCLB requirements if they are working with 3 year-old through 22 year-old students who have severe disabilities and who function at a preacademic level. If instruction is not in a core academic subject area and is primarily for personal care and life skills, the paraprofessional does not need to meet the NCLB paraprofessional requirements. The IDEA, as amended in 2004, allows paraprofessionals who are appropriately trained and supervised, in accordance with state law, regulation, or written policy, to be used to assist in the provision of special education and related services for children with disabilities. NCLB requirements apply only to the paraprofessionals assisting in instruction in Title I programs, those paid by Title I in a Targeted Assistance program and to all, including special education paraprofessionals, in Schoolwide Title I schools.

Professional Development

Professional development support is available to help special education teachers meet the NCLB and IDEA teacher requirements. California delegates the responsibility for special education paraprofessional standards, training, and supervision to the special education local plan area (SELPA). The primary purpose of NCLB, Title II, Part A funds is to assist all teachers, including those in special education, to meet the NCLB and IDEA teacher requirements by the end of the 2006-07 school year. In addition, Title I requires a set-aside of between 5 and 10 percent of LEA funds to address non-NCLB compliance. It is important to consult with the school district's categorical programs director to discuss how these monies may be accessed.

> We are, each of us,
> angels with only one wing, and
> we can only fly embracing each other.
> ~ Luciano Decrescenzo

We Remember

Daniel John Alvarez

3/6/1989 ~ 1/16/2010

Daniel Alvarez, son of PWCF members Catherine and Rudy Alvarez, died on January 16 following complications related to GI issues. Daniel died just shy of his 21st birthday, but he was anything but shy! He was outgoing, caring, gave the most affectionate bear-hug hugs, was a great fan of the color purple, was a wonderful brother, and a much loved son. I was honored to have been able to attend Daniel's memorial service where family and friends shared stories of their humorous and often touching interactions with Daniel, and where Daniel's brother and mother poignantly recounted their wonderful memories of him. Hundreds of people attended the service; there were few dry eyes. Daniel John Alvarez loved life. Indeed, he loved greatly, was greatly loved, and will be greatly missed. *Lisa Graziano*

R. Glenn Roe

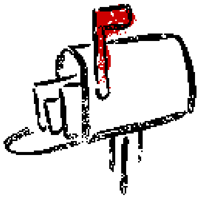
8/17/1951 ~ 2/16/2010

For more than 20 years Glenn has been a part of our lives. He will be missed greatly by friends, family, and the Developmentally Disabled community. We first met Glenn when Alta California Regional Center contracted with TTSR (Training Toward Self Reliance) to work with our son Jason, who has Prader-Willi syndrome, on Time and Money Management Training. In the mid-1990s a new contract and relationship developed with Glenn and TTSR when he led a team including his long-time friend Paul Wurst to develop and manage a supported living program for Jason. Glenn and Paul had already successfully developed and implemented the very first PWS supported living program in CA for a Sacramento area client which continues on today. After a couple years of planning, Jason moved into supported living in the Fall of l996 and continues to be successful. Glenn managed Jason's program for over 11 years first through TTSR, then Glenn and Paul's company "My Home" and finally with Glenn's company "Covenant Supported Living Services." After Glenn moved his company to the Redwood Coast, Jason's program moved back with Paul and his company, Options in Supported Living.

Glenn was especially in tune with the needs and idiosyncrasies of folks with PWS. He had attended several PWSA Conferences and had been a presenter at care provider meetings. He also participated in PWCF educational meetings, Supported Life Meetings, and was an excellent resource in the world of Prader-Willi syndrome. Unfortunately, Glenn's life was cut short in a tragic car accident caused by a drunk driver.

Thank you Glenn for all the years of CARING!! *Bill and Judy Castle*

PWCF Gets Mail…



Dear PWCF: Thank you for taking the time to come out to our agency and talk to our staff about Prader-Willi Syndrome and the Prader Willi Foundation. Your informative and personal story of this disorder was very much appreciated by our staff. Many of our therapists verbalized that they have a greater understanding of the challenges that parents of children with serious illnesses face on a daily basis now, as well as a much greater understanding of Prader Willi Syndrome. We wish you much success in your efforts to educate others about PWS. Sincerely, *Christina Moreno, LMFT, AV Training Liaison and Michael Bernath, PhD, Staff Therapist of Valley Child Guidance Clinic*

~~~~

Dear PWCF: I just wanted to thank you and the Board of Directors for the award you sent me. That was a big surprise, I never expected it. I appreciate all of the great effort you all make to help families. I was honored to have been able to do something. Thanks for giving me the opportunity. I will be happy to work with you again. Sincerely, *Carina Chaij*

~~~~

Dear PWCF: Thank you very much for your help and support [with our appeal for Regional Center eligibility]. I hope everything will go the way we wish for. Even not, we're satisfied that we spoke up for Lindsay. We don't give up without [a] fight! Without you and [the] organization's help, we didn't know what to do. So again thank you very much. We'll let you know the result when we know it. Thank you very much, *Tony Wang and Mari Ota*

SAVE THESE DATES

Walking for Prader-Willi Syndrome

April 24 – Central CA
April 25 – Northern CA
May 2 - Southern CA

Watch your mailbox for your brochure, call the PWCF office to receive additional brochures, or visit www.PWCF.org

General Education Meeting
November 6, 2010

Featuring
Janice Forster, M.D.
Linda Gourash, M.D.
Pittsburgh Partnership
Specialists in Prader-Willi Syndrome

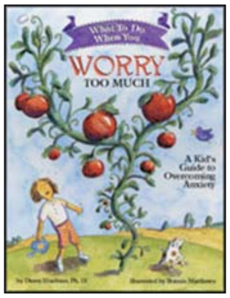
Northern California location

Volunteer Recognition Corner

For their volunteer work, PWCF recognizes with appreciation and thanks:

PWCF recognizes **Kimberly Pratto-Storr** for the extraordinary amount of time and work she devoted to create a new awareness and fundraising DVD. The DVD features various wonderful and touching photos taken at previous *Walking for Prader-Willi Syndrome* events. The photos are set to Miley Cyrus' powerfully emotional song *The Climb*. We have received authorization from the song's authors, producers, and other copyright holders. When this new tool becomes available, we'll let you know!

PWCF expresses its interminable gratitude to **Renee Tarica** who serves as our Treasurer. The tasks the IRS requires of a non-profit charitable organization continue to increase and become ever-more complex, complicated and time-consuming. Renee takes on these tasks without complaint. Her devotion to PWCF is the stuff that makes us strong.



Included with this newsletter is an order form for the *What To Do* books series written by Dawn Huebner, Ph.D., psychologist and anxiety expert who presented at PWCF's 2009 General Education Meeting. Every book is packed with helpful strategies and tools. PWCF earns income for every book sold, so order yours today!

MEMBERSHIP ACTIVITY
January-March 2010

Please note that because we are fortunate to have the majority of our families renew their membership each year and in the interest of space, effective January, 2009 we will no longer list renewing Individual and Family members. We will continue to list all new members and all renewing Extended Family, Family Friends, and Professional Members.

New Extended Family Members
Paul Graziano

Renewed Professional Members
Bobbi McGann, LCSW, Children's Hospital of Orange County

PWSA (USA) Announces New Management Team

PWSA (USA) recently announced that they are no longer employing the executive director hired in November of 2009. Instead of utilizing an executive director, PWSA will operate from an Executive Management Team. The six-member Team will consist of Janalee Heinemann (former executive director and current Director of Research & Medical Affairs); Evan Farrar (former active executive director and current Crisis Counselor and member of the Professional Providers Advisory Board); Mary K. Ziccardi (former member of the Board of Directors and current member of the Professional Providers Advisory Board); John Heybach (Co-Chair, Board of Directors); Ken Smith (Co-Chair, Board of Directors); and Sharon Middleton (Business Manager). PWSA's office staff and volunteers are long-term veterans with a great deal of experience with not only PWS but with the day-to-day operations of the Association. For more information about PWSA (USA) feel free to contact them at 800-926-4797 or visit their website at www.pwsausa.org.

Important Oral Hygiene Information

Saliva production is regulated by three pairs of salivary glands: the Parotid Gland, the Sublingual Gland, and the Submandibular Gland. For reasons not completely understood, these glands don't operate efficiently in individuals with Prader-Willi syndrome. As a result, people with PWS often have thick, sticky saliva, don't produce sufficient amounts of saliva, and subsequently experience the symptoms of dry mouth.

A dry mouth can interfere with the smooth movement of the tongue, cheeks and lips and interfere with swallowing and the production of sounds and clear speech. A dry mouth also means the teeth are not being bathed in important enzymes necessary to fight bacteria that cause tooth decay and gum disease.

Decreased saliva causes dry mouth symptoms that may look like:

Bad breath
Thick, sticky saliva
"Crusting" around the corners of the mouth
Cracked lips
A dry, rough tongue
Bleeding gums
Impaired speech articulation

Products which help stimulate the body's production of saliva can reduce or eliminate many dry mouth symptoms and dental problems. Most people find Bioténe oral hygiene products helpful. Laclede Inc. makes Bioténe Antibacterial Dry Mouth Toothpaste (for young children, a pea size amount twice daily should be fine), Oralbalance Mouth Moisturizing Gel; Bioténe Dry Mouth Chewing Gum (sugar free); and Bioténe Antibacterial/ Alcohol-Free Mouthwash. Biotène's fluoride-free *First Teeth* toothpaste is made especially for babies. Bioténe toothpaste is available wherever toothpaste is sold. If Bioténe toothpaste doesn't improve your child's/adult's dry mouth symptoms, see your dentist for a prescription medication made especially to reduce dry mouth symptoms.

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

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

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

DONATIONS ~ January—March, 2010

Shining Star Donations

Sirius ($1,000 or more)

Anonymous Donation in honor of Linda, Mark & Trevor Ryan
Jacki & Jeff Lindstrom in honor of Julia Lindstrom
The Nararo Foundation
Linda & Mark Ryan in honor of John W. Basso

Canopus ($500 - $999)

Anonymous Donation in honor of Linda, Mark & Trevor Ryan
Nancy & John Jenkins in honor of Cameron Graziano

Alpha Centauri ($250 - $499)

J.P. Lindstrom, Inc. in honor of Julia Lindstrom and in memory of Robert Lindstrom
Judy & Bob Morgan in honor of Samantha Morgan
Betty Olson in honor of Barbara Olson
Jessica & Chris Patay in honor of Ryan Patay

Arcturus ($100 - $249)

Catherine & Rudy Alvarez in memory of Daniel Alvarez
Hasmukh & Bernard Amarasekera
Karen & Russ Benedikt in honor of Barbara Olson
Lisa Ann Bonk in honor of Nolan Carl Bonk
Mary & Holger Bracht in honor of Kean Bracht
Terri & Tayler Canales in memory of Susan Gonzalez
Judy & Bill Castle
Thelma & Tom Davidson
Elisabeth & Robert Fuller
Barbara & David Gow in memory of Carolyn Gow
Mary & William Graziano in honor of Cameron Graziano
Elizabeth & Andrew Greskovics in honor of Georgia Greskovics
Vonda Hardcastle in honor of the Goatcher Family
Mary & Paul Hill in honor of Oscar Hill
Karen & Tim Jobe
The Kaiser Family in honor of Cameron Graziano
Rita & James Koerber
Miriam & Elias Liberman in honor of Yvette Tarica
Linda McGee
Lynn & Chuck Morrow in honor of Cameron Graziano and in memory of Olive, Max and Mel
Fran Moss in honor of Melissa Moss
Mark Ojeda in honor of Eric Ojeda
Mary & Joe Pichirallo
Rose M. Sakurai
Kim & Mark Savit in honor of Haley Kavrell
Nikki & Joseph Theveny in honor of Trevor Ryan
Plonneke Thoolen
Amy & Paul Wissmann
Brian Wu in honor of Emma Wu

Vega ($1 - $99)

Laureen & Dominic Adeniran in honor of James K. Adeniran
Cindy Arstein-Kerslake
Marilyn & John Bintz in memory of Paige Bintz
Bev & Bud Bush

Shining Star continued ..

Jay Kavanagh in honor of Brad Kavanagh
Maria & Ken Knox
Carolyn & Tom LaBossiere
Linda Hamilton in memory of Renate Wagner
Bouchra & Jason Mathis in honor of Jasmin Mathis
Janice Nakagawa, Ph.D. in honor of Richard Delone
Lianne & David Noddle in honor of Yvette Tarica
Kathy & Ralph Paige
Norma Rosas in honor of Anthony J. Alvarez
Joyce and Norman Smith in honor of Justin David Hibbard
Margaret & Bill Spinelli in honor of Cameron Graziano
Paul, Maggie, Ron and Kathy Thompson-Bergmann in honor of Oliver Young
Fred K.Tonai in honor of Amy Tonai

~~~~~~~~~~

Donations in Honor of Nick Moran's 80th Birthday

Diane & Leslie Peacock

Donations in Honor of Samantha Morgan

Suzanne Privette

Donations in Memory of Daniel Alvarez

Scope Industries
Margaret Chung
Zoi Eysselein
Rose & Christopher Gaynor
Kathy Outcalt
Leilani Pascual
Terry Roberts
Suzanne & Robert Stein
Deborah Wylie
The Yeh Family

Donations in Memory of Sergeant Ray Casey and in Honor of Ryan Casey

Patricia & Richard Casey

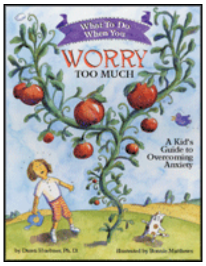
General Donations

Ana Amaya-Garcia
Malea & Rich Bonk
Thelma Cruz
Laura & Ray Esau
GoodSearch
Nancy & Jim Kaiser in honor of Cameron Graziano
The LaChance Family in honor of Oliver Young
Tom & Patti McRae via Adobe System Matching Gift Program
Mayuri & Vankat Paruchuru
Cullyn & Michael Russell in honor of the Delone Family
Carol & Maurice Williams
United Way of Stanislaus County

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

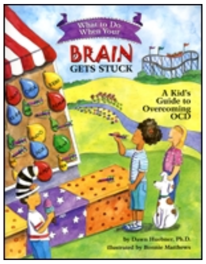
What To Do Book Series
Written by Dawn Huebner, Ph.D., Psychologist and Author
Published by Magination Press with illustrations by Bonnie Matthews.

Dawn Huebner, Ph.D. presented at PWCF's 2009 General Education Meeting
and has made her wonderful books available to PWCF as a fundraiser. Order your books today!



What To Do When You Worry Too Much: A Kid's Guide to Overcoming Anxiety
Did you know that worries are like tomatoes? No, you can't eat them, but you can make them grow, simply by paying attention to them... If your worries have grown so big that they bother you almost every day, this book is for you. *What to Do When You Worry Too Much* is an interactive self-help book designed to guide 6 - 12 year olds and their parents through the cognitive-behavioral techniques most often used in the treatment of generalized anxiety. Metaphors and humorous illustrations make difficult concepts easy to understand, while prompts to draw and write help children to master new skills related to reducing anxiety.

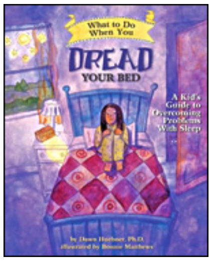
What To Do When Your Temper Flares: A Kid's Guide to Overcoming Problems with Anger
Did you know that anger is like fire? It starts with a spark, igniting us with energy and purpose. But it can also blaze out of control, causing lots of problems. If you're a kid whose temper quickly flares, a kid whose anger gets too big, too hot, too fast, this book is for you. *What to Do When Your Temper Flares* guides children and their parents through the cognitive-behavioral techniques used to treat problems with anger. Engaging examples, lively illustrations, and step-by-step instructions teach children a set of "anger dousing" methods aimed at cooling angry thoughts and controlling angry actions, resulting in calmer, more effective kids.



What To Do When Your Brain Gets Stuck: A Kid's Guide to Overcoming OCD
Did you know that people have brain sorters that keep their brains from getting cluttered with unnecessary thoughts? Sometimes these brain sorters get mixed up, though, holding onto thoughts that frighten kids. If this has happened to you, if it's hard for you to feel safe or sure of yourself because scary thoughts have gotten stuck, this book is for you. *What To Do When Your Brain Gets Stuck* guides children and their parents through the cognitive-behavioral techniques used to treat Obsessive Compulsive Disorder. This interactive self-help book turns kids into super-sleuths, able to recognize and more appropriately respond to OCD's tricks. Engaging examples, activities, and step-by-step instructions help children master the skills needed to break free from the sticky thoughts and urges of OCD, and live happier lives.

What To Do When You Grumble Too Much: A Kid's Guide to Overcoming Negativity
Did you know that life is like an obstacle course? It's exciting and fun, but full of tricky spots to get through. If you're a kid who feels so frustrated by those tricky spots that it's hard to enjoy the good things in life, this book is for you. *What to Do When You Grumble Too Much* guides children and their parents through the cognitive behavioral techniques used to treat negative thinking. Lively metaphors and illustrations make difficult concepts easy to understand, allowing children to see life's hurdles in a new way. Step-by-step instructions, along with prompts to draw and write, help children master new skills to get past those hurdles, transforming negative thinkers into happier, more positive kids.

What To Do When Bad Habits Take Hold: A Kid's Guide to Overcoming Nail Biting and More
Nail biting. Thumb sucking. Hair twirling. Scab picking. Shirt chewing. Do you have a habit that's hard to stop? A habit that embarrasses you or gets you in trouble? If so, you're not alone. Lots of kids have habits they wish they could lose. But habits are stronger than wishes. They lock on, holding you tight. Even if you want to break free, you can't. Unless you have the keys. *What to Do When Bad Habits Take Hold* guides children and their parents through the cognitive-behavioral techniques used to treat a variety of habits. Engaging examples, lively illustrations, and step-by-step instructions teach children a set of habit-busting strategies in the form of "keys" to unlock the chains holding their habits in place.



What To Do When You Dread Your Bed: A Kid's Guide to Overcoming Problems with Sleep
Wouldn't it be great if you could climb into bed, snuggle under your covers, and fall asleep without any fuss or fear? Without listening for noises or thinking about bad guys? Without an extra drink, or an extra hug, or an extra trip to the bathroom? Bedtime is tough for many kids. If you're a kid who dreads your bed, and are convinced that nothing short of magic will make nighttime easier, this book is for you. *What to Do When You Dread Your Bed* guides children and their parents through the cognitive-behavioral techniques used to treat problems with sleep. Fears, busy brains, restless bodies, and overdependence on parents are all tackled as children gain the skills they need for more peaceful nights.

What To Do Book Series
Order Form

$13 Each

PWCF earns income from each book sold!

Please make check payable to “Prader-Willi California Foundation” and mail with Order Form to
PWCF, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277

Quantity Ordered

- ☐ **What To Do When Bad Habits Take Hold**
- ☐ **What To Do When Your Brain Gets Stuck**
- ☐ **What To Do When You Dread Your Bed**
- ☐ **What To Do When You Grumble Too Much**
- ☐ **What To Do When Your Temper Flares**
- ☐ **What To Do When You Worry Too Much**

Ship to:
Name: ____

Address: ____

City/State/Zip: ____

Phone: ____ Total Enclosed: $__________

Office Use Only

Date Rcvd: ________
Amount: $_________
Check #: __________

☐**This is a gift. Enclose a note “The enclosed book(s) are a gift to you from ________________________.”**