PWCF NEWS

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

The Newsletter of Prader-Willi California Foundation
AN AFFILIATE OF PWSA (USA)

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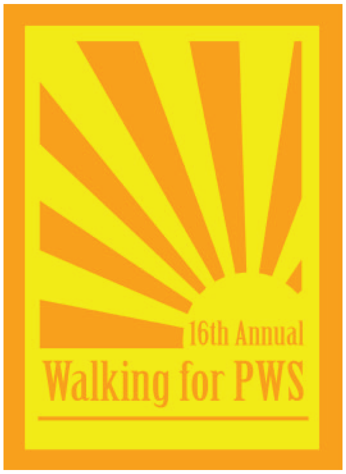
In this issue:



The 16th Annual Walking for PWS is coming up soon!

Why we WALK:

Because

*With an accurate diagnosis people can live **healthier, happier** lives*

Because

*With public awareness comes greater **compassion***

Because

No family should have to feel alone

Because

You can make a difference!

These are just a few reasons to join this year's 16th Annual WALK.

WALK events are planned with families in mind – fun activities for the kids of all ages: music, arts & crafts, face painting and so much more to keep everyone engaged and having a great time! Meet up with old friends and make new ones. When you come to a PWCF WALK event you step into a large network of support and advocacy. Join us.

Raise public awareness with your own personal WALK page! Share your story with family, friends, neighbors and co-workers and ask them to support your cause. Whether or not you're WALKING, create your page at:

www.pwcf.org/WalkingForPWS

Information and Registration

Register at www.pwcf.org/WalkingForPWS

All Events: Check-In at 10:30 a.m.
WALKs start at 11:00 a.m.
Music, Games, Arts & Crafts,
Face Painting...Fun for All!

EVENT DETAILS:

APRIL

Southern California

Sunday, April 24, 2016
Griffith Park
(Near Shane's Inspiration Playground)
4730 Crystal Springs Drive
Los Angeles, CA 90027
Hosted low-calorie lunch *(register by April 20)*
Stay for the fun!

MAY

Statewide Virtual WALK

May 2016

Post a PWS WALK Sign in your yard during May for PWS Awareness Month—or longer! Imagine the awareness we will raise with PWS WALK Signs posted in yards across California… and beyond!

JUNE

Northern California

Sunday, June 26, 2016
Crissy Field
West Bluff Picnic Area
(Under the Golden Gate Bridge)
Long Avenue, San Francisco, CA 94129
Pack your lunch and stay for the fun!

PRADER-WILLI CALIFORNIA FOUNDATION
A Full Life Without Limits

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President - **Roger Goatcher**
Vice President - **Kim Morgan**
Treasurer - **Renee Tarica**
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Web address: www.PWCF.org
Facebook: www.facebook.com/pwcf1

Our Mission:

Individuals with Prader-Willi syndrome should have the opportunity to pursue their hopes and dreams to the full extent of their talents and capabilities. The success of people with Prader-Willi syndrome depends greatly upon the knowledge and support of the community around them. The Prader-Willi California Foundation provides individuals with PWS, and their families and professionals with a state network of information, advocacy and support services.

PWS SUPPORT GROUPS AND CONTACTS

Northern California

SF Bay Area (young child)	Patti McRae	408-920-8003	pattimcrae@sbcglobal.net
SF Bay Area (teen to adult)	Michelle Donaldson	415-290-6282	md@michelledonaldson.com
Sacramento	Diane Kavrell	530-753-5928	diane.kavrell@gmail.com

Central California

(Teens & Adults with PWS)	Paula Watney	559-299-8171	paulawatney@pwcf.org

Southern California

Los Angeles County	Lisa Graziano	310-372-5053	LisaG@pwcf.org
	Julie Casey	818-843-7321	julie.casey@att.net
Orange County	Jenn Paige Casteel	949-735-0472	marchroses@hotmail.com

Inland Region Area

San Bernardino County	Ester Del Real	909-213-5992	esterdelreal@ymail.com

Spanish Speaking

Mercedes Gutierrez (Adults with PWS)	619-822-5742	mercedes.hernandez711@yahoo.com
Kilma Bournigal (Infants/Children with PWS)	760-679-2300	kilmab@hotmail.com
Veronica Garcia (Infants and Children with PWS)	760-357-8189	vbaez92@yahoo.com

Online 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*. Click and follow instructions to join the *PWSProfessionalsExchange* group.

PWSA (USA) Facebook Support Groups
for Families of Children Ages Birth-3 Years
for Families of Children Ages 3-5 Years
for Families of Children Ages 6-12 Years
for Families of Teens
for Families of Adults

International PWS Organization, **IPWSO** offers information about PWS in other languages. Go to www.ipwso.org

PWS SHARE & SUPPORT GROUPS MEETING CALENDAR 2016

Southern California

Beach Cities Health District
514 N. Prospect Avenue, Redondo Beach CA
0-5 Years: Redondo Room (Lower Level/Basement)
6+ Years: Beach Cities Room (Lower Level/Basement)

Sundays: Feb. 21, May 1 – Music Therapy
Sept. 11, 2016
Time: 2:00 p.m. – 4:30 p.m.

Childcare available ONLY for children under age 12 AND with RSVP. RSVP to PWCF at 310-372-5053

Northern California

Support for Families of
Children with Disabilities
1663 Mission Street, 7th Floor
San Francisco

Saturdays: Jan. 23, April 30, Sept. 24
Time: Check-in 10:15 a.m.
Meeting: 10:30 a.m. - 1:30 p.m.

Childcare Available with RSVP .
RSVP to SFCD 415-920-5040 x 135

ASK THE EXPERTS

Dear PWS Professionals: My 3 year old daughter's school has asked whether playing with plastic food items (for example Velcro food items for developing OT skills) can activate the hyperphagia food drive or interfere with attention. Are there any studies on this? What insights can you share?

In my view, no problem. Plastic food does not violate food security.
Linda Gourash, M.D., Developmental and Behavioral Pediatrician, Pittsburgh Partnership Specialists in Prader-Willi Syndrome

There are no studies on this that I am aware of. In my personal opinion, in the scheme of all that we have to worry about, I do not think this is a major issue. I don't think it's going to make the food obsession any more or less. They do have to be careful of the product though. I remember observing my son Matt in a store that had erasers that looked very much like candy. He just had to bite into it just to make sure it wasn't the real thing!
Janalee Heinemann, MSW, Coordinator of Research & International Affairs, PWSA (USA) and Vice President, IPWSO

I agree with Janalee that it isn't a big deal, though there isn't any research on it. I also agree that teens and adults are more likely to test the play food than kids. I have seen them lick stuff that looks like food!
Elizabeth Roof, Ph.D.,Senior Research Specialist, Prader-Willi Syndrome and Williams Syndrome Research Projects, Vanderbilt Kennedy Center

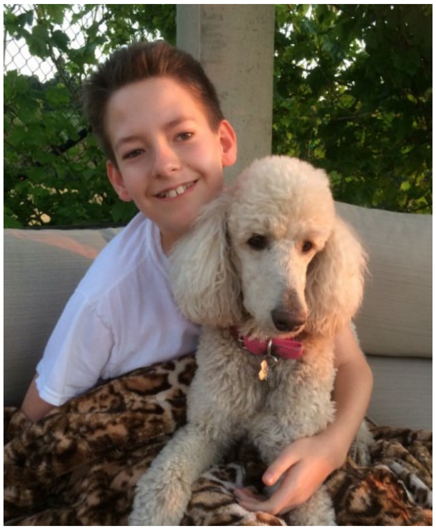
I agree with both Janalee and Elizabeth, and I would add that it's what they do with the food that is important. If the staff is modeling representational/pretend play and put fake food items on a plate, scoop them onto a spoon and bring them to their mouth and say "yum", that's NOT helpful!
Janice Forster, M.D., Developmental Neuropsychiatrist, Pittsburgh Partnership Specialists in Prader-Willi Syndrome

Our next Parent to Parent:

"My older child has a very difficult time wiping her bottom after having a bowel movement. Seems like no matter how much we teach her, her bottom is never wiped thoroughly enough. This is especially difficult while she's at school; either the school staff don't want to help her wipe her bottom (and I don't necessarily *blame* them for not wanting to help with this task!) or my child tries to hold it during the school day to avoid the situation entirely. Do other parents and providers have this same trouble and if so, how do you manage it?"

MARLEY & ME

by Elizabeth Kulkowski



Christian is an 11 year old boy who has PWS (UPD) and Autism. Christian's constant companion, also known as his "BFF", is Marley his Service Dog.

Marley accompanies Christian to all his doctors' appointments, errands with mom, and social outings. Marley alleviates Christian's anxiety, helps calm him down during behavioral episodes, and keeps Christian focused. At home Marley alerts us by barking to any changes (at night) such as his Bi-Pap machine slipping off his face.

Marley has a special leash where we are both able to lead her, Marley is always in the middle. Before Marley came along, running errands with Christian became very stressful because he would pull away from me to dart towards something he wanted to see or pull away in a parking lot as I was putting away groceries. He now knows that he is responsible for Marley and cannot let go of the leash.

Marley is my "wing girl" and life with her has been life-changing for Christian as well as the rest of the family.

Gadget Tip:
New Free PWSA (USA) Phone App Available

In today's world, the way we communicate and learn is through our mobile devices. We search, read, send emails, play, and even work while using our mobile devices. PWSA's new mobile app provides immediate and seamless access to information and resources from PWSA (USA)'s main website. The app also sends notifications to your phone on topics you can choose. Get up-to-date information concerning **research**, **medical**, **crisis/family support** or **fundraising news**. You can also renew or sign-up to be a PWSA (USA) member through the app.

Since 1975, PWSA (USA) has helped PWS families by providing family support, crisis and medical intervention services, and PWS research. In 2015, they provided assistance to over 2,000 families and individuals including caregivers, school personnel, clinicians and researchers. The new PWSA phone app is a valuable supplement to the many services they provide!

To download the app, go to your app store on your mobile device and search for PWSA or you can use the links below for your mobile device.

iTunes: **https://itunes.apple.com/WebObjects/MZStore.woa/wa/viewSoftware?id=1053045380&mt=8**
Google Play: **https://play.google.com/store/apps/details?id=com.theappwizards.appwizard.app54e25f5f6cf0b&hl=en**

Food Tip: TigerNuts
Submitted by Mari Ota of Alhambra

Not actually nuts, TigerNuts are small root vegetables that are gluten-free, allergy-free, raw, vegan, and kosher. They are deliciously crunchy and chewy, a delightfully interesting texture combination. My 9 year old daughter loves TigerNuts for a snack and I love them because they're not only healthy, but it takes some time to eat them and a bit of muscle work to chew them.

TigerNuts are a resistant starch. They are a prebiotic fiber that supports a healthy immune system. One serving is 40% of daily fiber requirements. A serving size is 1 oz and is 120 calories, 2 grams protein, 19 grams carbohydrates.

TigerNuts may be purchased on Amazon... Remember to use Smile.Amazon and choose to benefit Prader-Willi California Foundation!

Our Kids Got Talent
Submitted by Rhonda Faust & Family

Our Angela had her first Cheer regional competition on January 16, 2016. She was the youngest one there and did very well despite how loud the music was in the gym. Our kids surprise us sometimes and adapt to the situation.

EXECUTIVE DIRECTOR'S COLUMN

by Lisa Graziano, M. A.

In her outgoing message, past-president **Julie Casey** shared of finding her passion and harnessing it to help PWS families. At his first Board of Directors meeting as PWCF's incoming president, **Roger Goatcher** challenged PWCF's Board members, consultants and staff to give just one degree more. What both of these leaders are describing are pathways to excellence, a long-standing, driving theme underlying PWCF's leadership. **The pursuit of excellence in services for family members is what PWCF is, has been, and will always be about.**

PWCF's Residential Services Committee, chaired by **Linda Ryan**, is in the process of creating *actual* Standards of Excellence for group home and supported living providers that serve persons with PWS. With these Standards of Excellence we believe professional providers will have a clearer understanding of the quality of service PWCF expects and actively helps providers achieve. Families will also have a clearer understanding of which homes make striving for PWCF's standards of excellence a priority.

PWCF understands that no one can achieve any degree of "excellence" on our own, that each of us – whether we're a newly diagnosed family member or a seasoned PWS professional – will need help, guidance and support along the way. While we applaud the State of California's recent funding of the Department of Developmental Services and hope this will translate into increased funding for services that benefit PWS families, we know ours is a rare and misunderstood medical disorder and that the help our families and professionals need will often come directly from PWCF. And so while PWCF strives for standards of excellence in each and every one of our programs, we place particular emphasis upon achieving a **Standard of Excellence in our education and training programs**. From our focus on educating and supporting young families, to our investment in residential providers, we believe that well educated and supported families and professionals means reduced stress and improved care of *all* persons affected by PWS.

In the early 1980's PWCF held annual "general membership meetings" which later became known as the annual "General Education Meeting," which is now called our Annual State Conference. Whatever they're called our conferences attract the country's top specialists, be they PWS physicians, educators, therapists, and researchers. This year's Annual State Conference will feature specialist **Jennifer Miller, M.D.**, PWS endocrine specialist, and **Harold van Bosse, M.D.**, PWS scoliosis and kyphosis specialist. Held this year in Northern California, mark your calendar now for **November 4** so you don't miss this exciting conference!

But we don't do just big conferences. This year PWCF will host a slew of intimate trainings and workshops. The first Behavior Management Parent Conference occurred in February. For those of you who missed it, a similar training is viewable in DVD format available at www.pwcf.org/shop, with streaming from the website of this DVD and others available soon. A Nutrition Strategies & Tips parent conference will be held in July, and an everything-you-want-to-know-about-the-IEP-process workshop will be held in September. Another behavior management parent conference, another IEP parent workshop, and special needs planning workshops will be scheduled soon as well.

PWCF works hard to achieve a **Standard of Excellence in our provision of awareness, advocacy services, and family support**. We provide gentle support to newly diagnosed families that continues throughout the member's lifetime. PWCF staff is involved with dozens and dozens of advocacy cases each year, ranging from drafting letters of support for school aides, to obtaining Regional Center eligibility, to helping with training in the workplace so that adults with PWS can achieve greater success, success being measured in part by one's feeling of self-worth and being a part of a bigger community. This year PWCF offers many opportunities for families to feel a "part of" something bigger.

PWCF has already held one Family Fun event at the We Rock the Spectrum special needs gym where kids of all ages played while parents relaxed or connected with each other. More Family Fun events are scheduled: Anaheim Angels baseball on June 25 and the Oakland A's on September 10.

PWCF believes that the greater the public awareness of PWS, the greater will be the public understanding and compassion, which in turn helps families feel less alone and isolated. This year's 16th annual *Walking for PWS* events will raise public awareness and bring families together in an atmosphere of complete and utter acceptance. PWCF depends upon the funds generated by these events; the greater the fund raising success of PWCF's WALKs, the greater the funding to support PWCF programs and services. Please support the WALK events spanning from April through June. Go to www.pwcf.org/WalkingForPWCF today!

Also used as a vehicle to raise public awareness and funds, PWCF was accepted as an official charity of the JetBlue Long Beach Marathon & 5K events in October. We encourage you to use this awesome event as an opportunity to develop a daily workout or run regimen: *start training now to participate in either a 5K or a 26 mile run!*

Our PWS Camp in Northern California has for the past 5 years served over 300 campers, granted over $65,000 in scholarships, and provided hundreds of family members with much-needed

Executive Director's Column continued on page 12

New Global PWS Registry

GLOBAL
PRADER-WILLI SYNDROME
REGISTRY

The Global PWS Registry will enhance the understanding of PWS by describing the full spectrum of PWS characteristics. The Registry will also facilitate the completion of clinical trials and other research studies in the field of PWS.

The Global PWS Registry is a comprehensive and secure database, compliant with U.S. Health Information privacy laws and FDA regulations. The Registry is a joint effort by PWSA (USA) and the Foundation for Prader-Willi Research and is managed by the Foundation for Prader-Willi Research. The registry will:

- Document the full range of PWS characteristics
- Enable data trend analysis to generate new insights into PWS and identify areas for additional study
- Facilitate partnerships with university researchers and pharmaceutical companies
- Guide the development of standards of care
- Expedite the completion of PWS clinical trials
- Allow participants to store their PWS medical data in one place
- Accelerate solutions for PWS

PWCF encourages parents and guardians to participate in the Registry. You will be asked to provide details on topics such as developmental milestones, scoliosis, medications, appetite, behavior and other clinical symptoms. Depending on the challenges you have encountered, the registry may take one or more hours to complete. You do **not** need to complete the entire registry in one sitting. Go to: **https://www.fpwr.org/global-pws-registry**

Save the Date for Education & Fun

Family Fun with the Anaheim Angels

June 25 7:00 p.m. Anaheim

Eat Right, Future Bright! Learn Key Nutrition Strategies & Tips for Managing PWS Conference

July 30 9:00 a.m. – 12:30 p.m. Orange

Family Fun Day with the Oakland A's

September 10 1:00 p.m. Oakland

IEP Parent Training

September 18 10:00 a.m. – 2:00 p.m. Redondo Beach

PWCF Annual State Conference

November 5 Northern CA

Don't Forget the Educational DVDs Available:

order online at pwcf.org/shop

PWS Behavior Management Strategies That Work:
Especially for Parents, Extended Family, Babysitters & All Care Providers
Understanding the Student with PWS: Strategies for Success
PWS Residential Staff Training

THE BENEFITS OF ESSENTIAL OILS

by D.L. Sweet

D.L. Sweet

Essential oils have been used for thousands of years for cosmetic purposes as well as for their spiritually and emotionally uplifting properties. The PWCF office staff has met a wonderful woman, D.L. Sweet, who teaches Yoga to seniors in our office building and pops in to visit with us and treat us to a sampling of her essential oil products. D.L. shared information about the essential oils company she works for and we thought we would share it with you.

"Our community of wellness started small in 1993, when Gary Young developed his first organic herb farming and distillation operation. At the time, Gary had already discovered the incredible power of essential oils, but because the quality of available oils varied so greatly, he'd been unable to fully harness their potential. While he knew that pure essential oils had the ability to produce spectacular results, he found that the chemically altered or adulterated oils on the market were often ineffective and even harmful. It is important to know what is in your bottle; quality is important.

"Young Living changed all that. As Gary developed more farmland in Utah and Idaho, he began cultivating lavender, peppermint, melissa, clary sage, and many other herbs. Fueled by a growing demand for pure essential oils, Young Living designed and built the largest, most technologically advanced distillery for the production of essential oils in North America. Our company has also developed the groundbreaking Seed to Seal® process, which preserves the integrity and potency of essential oils. Young Living essential oils are free of toxins, heavy metals, synthetics, and fillers. It is Earth and Kosher certified. We use pure water not public water.

"Lavender is excellent for any skin irritations or stressors and helps with sleep and calming. Our Thieves blend can support a healthy immune system. Stress Away blend can help induce relaxation and reduce occasional nervous tension. Frankincense helps to focus the mind, lift mood and inspire balanced emotions. PanAway Blend helps relax muscles and for occasional aches caused from tension. Helps support cartilage and joint function and healthy bone structure. RC blend promotes a healthy lung function and can help clear the mind or head and promote restful breathing and sleep, soothes the respiratory track when exposed to outdoor irritants."

D.L. would love to answer your questions about Essential Oils and invites you to contact her at dlsweetyoga@gmail.com or (310)489.8373.

YOUNG LIVING™
ESSENTIAL OILS
Independent Distributor

Support **Team PWCF** in the
Aquarium of the Pacific 5K (Oct. 8)
or the Long Beach Marathon! (Oct. 9)

Contact PWCF at 310-372-5053 or info@pwcf.org

For details, visit www.pwcf.org

Join Team PWCF to help
us improve the lives
of those with PWS,

one step at a time.

Did you know: 90 cents out of every dollar
PWCF receives goes directly into its mission?

SCHOOL ACCOMMODATIONS AND MODIFICATIONS

Supports for the Student with PWS from WrightsLaw.org

Some students with disabilities need accommodations or modifications to their educational program in order to participate in the general curriculum and to be successful in school. While the Individuals with Disabilities Education Act (IDEA) and its regulations do not define accommodations or modifications, there is some agreement as to what they mean.

An **accommodation** as used in this document allows a student to complete the same assignment or test as other students, but with a change in the timing, formatting, setting, scheduling, response and/or presentation. This accommodation does not alter in any significant way what the test or assignment measures. Examples of accommodations include a student who is blind taking a Braille version of a test or a student taking a test alone in a quiet room.

A **modification** as used in this document is an adjustment to an assignment or a test that changes the standard or what the test or assignment is supposed to measure. Examples of possible modifications include a student completing work on part of a standard or a student completing an alternate assignment that is more easily achievable than the standard assignment.

Needed modifications and accommodations should be written into a student's Individualized Education Program (IEP) or Section 504 Plan. These changes should be chosen to fit the student's individual needs. It's important to include the student, if appropriate, when discussing needed accommodations and modifications. Asking the student what would be helpful is a good first step. Here are some ideas for changes in textbooks and curriculum, the classroom environment, instruction and assignments, and possible behavior expectations that may be helpful when educating students with disabilities. When reviewing these ideas, keep in mind that any accommodations or modifications an IEP team chooses must be based on the individual needs of student, and the changes must be provided if included in the child's IEP.

Textbooks and Curriculum Books

- Provide alternative books with similar concepts, but at an easier reading level.
- Provide audiotapes of textbooks and have the student follow the text while listening.
- Provide summaries of chapters.
- Provide interesting reading material at or slightly above the student's comfortable reading level.
- Use peer readers.
- Use marker to highlight important textbook sections.
- Use word-for-word sentence fill-ins.
- Provide two sets of textbooks, one for home and one for school.
- Use index cards to record major themes.
- Provide the student with a list of discussion questions before reading the material.
- Give page numbers to help the student find answers.
- Provide books and other written materials in alternative formats such as large print.

Curriculum

- Shorten assignments to focus on mastery of key concepts.
- Shorten spelling tests to focus on mastering the most functional words.
- Substitute alternatives for written assignments (clay models, posters, panoramas, collections, etc.).
- Specify and list exactly what the student will need to learn to pass. Review this frequently.
- Modify expectations based on student needs (e.g., "When you have read this chapter, you should be able to list three reasons for the Civil War.").
- Give alternatives to long written reports (e.g., write several short reports, preview new audiovisual materials and write a short review, give an oral report on an assigned topic).

Classroom Environment

- Develop individualized rules for the student.
- Evaluate the classroom structure against the student's needs (solid structure, firm limits, etc.).
- Keep workspaces clear of unrelated materials.
- Keep the classroom quiet during intense learning times.
- Reduce visual distractions in the classroom (mobiles, etc.).
- Provide a computer for written work.
- Seat the student close to the teacher or a positive role model.
- Use a study carrel. (Provide extras so that the student is not singled out.)
- Seat the student away from windows or doorways.
- Provide an unobstructed view of the chalkboard, teacher, movie screen, etc.
- Keep extra supplies of classroom materials (pencils, books) on hand.
- Maintain adequate space between desks.

Instruction and Assignments Directions

- Use both oral and printed directions.
- Give directions in small steps and in as few words as possible.
- Number and sequence the steps in a task. • Have student repeat the directions for a task.
- Provide visual aids.
- Show a model of the end product of directions (e.g., a completed math problem or finished quiz).
- Stand near the student when giving directions or presenting a lesson.

School continued on page 10

What's Your Passion?

Outgoing President's Message by Julie Casey

Many years ago a friend once asked me what I was passionate about. At the time I didn't feel like I had a really good answer. Sure, there were things I liked and activities I enjoyed but nothing that I truly thought I felt ***passionate*** about. Today, however, if you ask me what I'm passionate about I will, with great emotion and conviction, tell you that I am passionate about helping other PWS families. I will tell you that I am passionate about raising awareness for Prader-Willi syndrome. I will talk your ear off about the benefits of early intervention and growth hormone therapy. I will answer your questions and find resources to help you. I will, with tears in my eyes, tell you how incredibly grateful I am to the founders of PWCF so that when Ryan was born almost 12 years ago I had a place to reach out to and get much-needed support. I will proudly tell you how PWCF is the only organization in California that exclusively serves families with PWS, and that the work we do is crucial. I will speak enthusiastically about how PWCF helps families who have just been diagnosed, trains schools so students with PWS get the supports they need, provides training to residential and vocational providers, advocates for continued Regional Center eligibility and appropriate medical care, runs a PWS camp session (with a second location staring in 2016), and so much more!

So my last day of Board service, after terming out after 9 years, finds me reflecting on my years of service and how my passion has grown. I began my Board service in January 2007 when my son (Ryan) was not quite 3 years old. Ryan was diagnosed when he less than two weeks old and we reached out to both PWSA and PWCF right away, so before becoming a Board Member I was already familiar with the wonderful work PWCF does. However, it really was serving on the Board that sparked my passion for the cause, which has continued to grow over the years. I have learned so much through my time on the Board and, even 9 years later, am still continually impressed with the amazing work we do with limited resources and the outstanding commitment of my fellow Board Members with whom I have had the honoring of serving with through the years as well as our fabulous PWCF staff and consultants. I have met many wonderful members, spoken to the public, presented to medical students, and collaborated with PWSA's Board and staff as well as other chapter leaders. I am proud of the work that PWCF does and of the growth that has been accomplished by the Board during my tenure. It has been an amazing journey and though my time as a Board member is ending (for now), the passion for PWCF's work will never end. I am whole-heartedly committed to the organization; I will continue to serve on several committees and will be at the Board's disposal for whatever they need.

As I bid farewell to you and wish you a Happy New Year, I encourage you to make a commitment for 2016 to get more involved. "More" may be as a simple as sharing more of PWCF's Facebook posts (which helps spread awareness), it may be coming to more events (last year you came to the Walk, this year you commit to coming to the Walk ***and*** the Annual Conference), it may be doing a fundraiser or just fundraising for our Walk, it may be talking to your friends and family about the important work PWCF does; everyone's circumstances are different, so find a "more" that fits your ability and make that commitment. PWCF is your organization and I promise that whatever the more is that you commit to, you will not regret it. As this year's Shining Star campaign says…

Picture a world where everyone understands Prader-Willi syndrome, where everyone touched by PWS receives the education, supports and services they need.

Help us make this is reality. Make 2016 the year you find your passion too.

Thank you for allowing me the privilege of serving you and thereby finding my passion in life. Happy New Year.

2016

New is the year
New are the hopes
New is the resolution
New are the spirits
And new are my warm
wishes just for you

Have a promising
and fulfilling New Year!

See our We Get Mail column on page 18 for PWCF members' responses to Julie Casey's wonderful letter.

School continued from page 8

Time/transitions

- Alert student several minutes before a transition from one activity to another is planned; give several reminders.
- Provide additional time to complete a task.
- Allow extra time to turn in homework without penalty.
- Provide assistance when moving about the building.

Handwriting

- Use worksheets that require minimal writing.
- Use fill-in questions with space for a brief response rather than a short essay.
- Provide a "designated notetaker" or photocopy of other student or teacher notes. (Do not require a poor notetaker or a student with no friends to arrange with another student for notes.)
- Provide a print outline with videotapes and filmstrips.
- Provide a print copy of any assignments or directions written on the blackboard.
- Omit assignments that require copying, or let the student use a tape recorder to dictate answers. **Grading**
- Provide a partial grade based on individual progress or effort.
- Use daily or frequent grading averaged into a grade for the quarter.
- Weight daily work higher than tests for a student who performs poorly on tests.
- Mark the correct answers rather than the incorrect ones.
- Permit a student to rework missed problems for a better grade.
- Average grades out when assignments are reworked, or grade on corrected work.
- Use a pass-fail or an alternative grading system when the student is assessed on his or her own growth.

Tests

- Go over directions orally.
- Teach the student how to take tests (e.g., how to review, to plan time for each section).
- Provide a vocabulary list with definitions.
- Permit as much time as needed to finish tests.
- Allow tests to be taken in a room with few distractions (e.g., the library).
- Have test materials read to the student, and allow oral responses.
- Divide tests into small sections of similar questions or problems.
- Use recognition tests (true-false, multiple choice, or matching) instead of essays.
- Allow the student to complete an independent project as an alternative test.
- Give progress reports instead of grades.
- Grade spelling separately from content.
- Provide typed test materials, not tests written in cursive.
- Allow take-home or open-book tests.
- Provide possible answers for fill-in-the blank sections.
- Provide the first letter of the missing word.

Math

- Allow the student to use a calculator without penalty.
- Group similar problems together (e.g., all addition in one section).
- Provide fewer problems on a worksheet (e.g., 4 to 6 problems on a page, rather than 20 or 30).
- Require fewer problems to attain passing grades.
- Use enlarged graph paper to write problems to help the student keep numbers in columns.
- Provide a table of math facts for reference.
- Tape a number line to the student's desk.
- Read and explain story problems, or break problems into smaller steps.
- Use pictures or graphics.

Behavior

- Arrange a "check-in" time to organize the day.
- Pair the student [with students who are calm and kind.]
- Modify school rules that may discriminate against the student.
- [Teach a nonverbal cue to remind the student of the behavior they should be using.]
- Amend consequences for rule violations (e.g., reward a forgetful student for remembering to bring pencils to class, rather than punishing the failure to remember).
- Minimize the use of punishment; [use rewards frequently]
- Develop an individualized behavior intervention plan that is positive and consistent with the student's ability and skills.
- Increase the frequency and immediacy of reinforcement.
- Arrange for the student to leave the classroom [with supervision] voluntarily and go to a designated "safe place" when under high stress.
- Ignore behaviors that are not seriously disruptive.
- Develop interventions for behaviors that are annoying but not deliberate (e.g., provide a small piece of foam rubber for the desk of a student who continually taps a pencil on the desktop).
- Be aware of behavior changes that relate to medication or the length of the school day; modify expectations if appropriate.

Other

- Use Post-it notes to mark assignments in textbooks.
- Check progress and provide feedback often in the first few minutes of each assignment.
- Place a ruler under sentences being read for better tracking.
- Introduce an overview of long-term assignments so the student knows what is expected and when it is due.
- Break long-term assignments into small, sequential steps, with daily monitoring and frequent grading. • Have the student practice presenting in a small group before presenting to the class.
- Hand out worksheets one at a time.
- Sequence work, with the easiest part first.
- Provide study guides and study questions that directly relate to tests.
- Reinforce student for recording assignments and due dates in a notebook.

Funding for the FAPE Project comes from the U.S. Department of Education, Office of Special Education Programs (Cooperative Agreement No. H326A980004). This document was reviewed by the U. S. Office of Special Education Programs (OSEP), the OSEP Project Office, and the FAPE Project Director for consistency with the Individuals with Disabilities Education Act Amendments of 1997. The contents of this document do not necessarily reflect the views or policies of the U.S. Department of Education, nor does mention of other organizations imply endorsement by those organizations or the U.S. Government.

Rhythm Receives FDA Breakthrough Therapy That May Benefit Patients with PWS

First Breakthrough Designation by FDA's Division of Metabolism and Endocrinology Products

BOSTON, January 7, 2016— Rhythm, a biopharmaceutical company developing peptide therapeutics for rare genetic deficiencies that result in life-threatening metabolic disorders, announced today that the U.S. Food and Drug Administration (FDA) has granted Breakthrough Therapy designation (BTD) to setmelanotide, the company's novel melanocortin-4 receptor (MC4R) agonist, for the treatment of pro-opiomelanocortin (POMC) deficiency obesity. Setmelanotide is in Phase 2 clinical trials for the treatment of rare genetic disorders of obesity caused by MC4 pathway deficiencies.

"Patients with POMC deficiency obesity have extreme and unrelenting appetite and obesity because of impaired function in the MC4 pathway," said Keith Gottesdiener, CEO of Rhythm. "We are pleased to receive this breakthrough designation and look forward to working closely with the FDA as we continue to advance the setmelanotide program."

Breakthrough Therapy designation is granted by the FDA to expedite the development and review of therapeutics to treat serious or life-threatening conditions for which preliminary clinical evidence indicates that the therapy may demonstrate substantial improvement on at least one clinically significant endpoint over existing therapies.

This designation conveys all FDA fast track program features, such as eligibility for rolling NDA submissions and priority review (if supported by clinical data at the time of NDA). Additionally, this designation provides more intensive involvement of FDA staff in a proactive, collaborative, cross-disciplinary review process. Setmelanotide is the first BTD to be awarded by FDA's Division of Metabolism and Endocrinology Products, which is responsible for obesity and diabetes indications.

About Setmelanotide (RM-493)
A new drug class for the treatment of rare genetic disorders of obesity

Setmelanotide is a potent, first-in-class MC4R agonist in development for the treatment of obesity caused by genetic deficiencies in the MC4 pathway, a key pathway in humans that regulates energy expenditure, homeostasis, and appetite. The critical role of the MC4 pathway in weight regulation was validated with the discovery that single genetic defects along this pathway result in early onset and severe obesity. **A Phase 2 setmelanotide trial is ongoing for the treatment of Prader-Willi syndrome (PWS), a rare genetic disorder that causes life-threatening obesity.** Recent scientific evidence implicates defects in the MC4 pathway as the likely cause of the weight and appetite abnormalities in PWS. A second Phase 2 trial is ongoing for the treatment of pro-opiomelanocortin (POMC) deficiency obesity, a very rare, life-threatening genetic disorder of the MC4 pathway associated with unrelenting appetite and obesity.

Keith Gottesdiener, CEO of Rhythm, commented: "Patients with POMC deficiency obesity have extreme and unrelenting appetite and obesity because of impaired function in the MC4 pathway. "We are pleased to receive this breakthrough designation and look forward to working closely with the FDA as we continue to advance the setmelanotide program…The orphan drug designation is an important regulatory milestone as we advance development of setmelanotide for the treatment of Prader-Willi syndrome," said Gottesdiener. "Phase 2 trials are now under way for both PWS and POMC deficiency obesity, and we expect to complete these trials in the first half of 2016."

PWCF's newly elected Board of Directors will serve during the 2016-2018 term:
Rodney Dong
Jacki Lindstrom
Nisha Mehta

At its November 2015 meeting the Board elected the following 2016 Officers:
Roger Goatcher, President
Kim Morgan, Vice President
Renee Tarica, Treasurer
Nisha Mehta, Secretary

PWCF Professional Resources Directory

Do you have an awesome professional on your child or adult's treatment team? Someone who does a great job interacting with your child or adult and provides excellent service? Please let us know so that we may add them to our new Professional Resources Directory so that other families can use them too.

Professional's Name: ____ Phone: ____________________
Specialty (e.g., Psychiatry, Speech Pathologist, Attorney: ____
Contact Information: Address____
Email: ___________________________________ Website: ________________________________

Mail or email this form to info@pwcf.org or complete the form on PWCF.org so we can add it to our directory!

Executive Director's column continued from page 5

respite. To serve even *more* families, PWCF has created a new PWS Camp in Southern California. This year alone we will serve over 100 campers and provide respite to *even more* moms, dads, and siblings.

Now is an exciting time for major advances in PWS research and treatment options. We already have Growth Hormone as a recognized Standard of Care treatment. Supplements such as my personal favorite Coenzyme Q-10 are no longer considered "far out" unconventional interventions. Research trials for potential new anti-hyperphagia and anti-anxiety medications show hopeful promise, more so than ever before in years past. PWCF proudly maintains working relationships with some of the country's top researchers and pharmaceutical companies, helping to recruit patients to participate in these exciting research trials as we strive to achieve **Standard of Excellence in Research Support**.

Administrative Excellence must prevail if PWCF is to keep pace with the ever-growing workload needed to sustain the level of education and training, research support, and advocacy and support programs that PWCF provides. Appointed by the Board of Directors as PWCF's first bonafide executive director since its inception in 1979, **Fran Moss** directed PWCF's progress from the early 1990s through 2002 and took PWCF, working alongside her husband **Frank**, to its next level of excellence. When she needed to step away from the day-to-day responsibilities to attend to the needs of her daughter, the search began for a new director who could take PWCF to the *next* level of excellence. At about the same time, the Board learned I had a skill set that might be a good match, having previously directed a chapter of the American Psychiatric Association. When I accepted the position and began to work for PWCF my son was 3 years old. Unbelievably he is now 17, finishing up his Junior year of high school, and looking forward to going on to college.

College. Seventeen years ago we would never have imagined that college was in his future. Now, as he shows such enthusiasm and aptitude for academia and as we continue to learn how to help manage his environment to reduce his anxiety so that he *can* be successful, college is an option. And so it appears that college may be in *my* future as well, as I make myself available to serve as his environmental support (at least until we find/teach up someone better!). At the end of this year, I will follow Fran's footsteps and step away from the day-to-day responsibilities as PWCF's executive director in order to be available to my son during the next phase of his career. At the Board's discretion I hope to remain active with multiple aspects of PWCF's programs and services.

The Board has already begun its search for PWCF's next executive director who will take PWCF to the *next* level of excellence. If you are interested in reading the job description, believe you or someone you know has the qualifications, interest and enthusiasm to apply for this critical position, please go to our website www.pwcf.org, contact Roger Goatcher at president@pwcf.org, or call me at the PWCF office.

PWCF has a long history of leaders who epitomize the concepts of dedication, integrity, talent, and passion; ordinary people just like you and me whose only differentiation is a willingness to reach out to help, guide, or support someone else, to give just *one more degree*. This willingness is no doubt a critical factor in PWCF's continual progression from one standard of excellence up to the next, and why it is so very special to be a part of the PWCF Team.

STRATEGIES FOR DEALING WITH RUNNING/ELOPEMENT BEHAVIOR

from The Gathered View, 2009, Prader-Willi Syndrome Association (USA)

In the world of worries with Prader-Willi syndrome, one great one is the dangers associated with elopement behavior, or "running." Not all people with PWS exhibit this behavior, but if your loved one with PWS does, there are useful strategies and tips that you can employ to help keep them safe.

Strategies:

- Locks to keep the person in the house.
- Motion detectors to alert others when doors are opened and the person might be leaving.
- Notify law enforcement in case the person gets into trouble or lost; use law enforcement statement.
- Have the person carry in their wallet the PWSA (USA) law enforcement card.
- Most running away occurs for two reasons: (1) Food seeking and (2) to be free from a life of restrictions. The first can be addressed through behavior management and food security. The second can be addressed by trying to build in a sense of freedom and choice into the person's life.
- Contracting with a company/agency that can provide a GPS location of a wandering or lost person.

Tips from a Parent (name has been changed):

"Man oh man, do I know how you feel! My Charlotte is 10 now and has been doing this for over 2 years. I've tried and done all the things you've done. My end result? On the outside of her bedroom door, I've put a magnetic alarm, so as soon as the door opens it squelches, and as soon as it closes, it stops. In her bedroom, I've also placed a baby monitor so if she needs me, all she has to do is talk to me. That way, too, I can hear if her BiPap alarms. I keep the monitor in my room turned all the way up, so if she disconnects hers, I can hear the static and it alerts me that she's up to something. This has worked perfectly for us so far! Her psychiatrist and counselor both fully support this because it keeps her out of trouble without being cruel or endangering her safety by locking the door. She can still get out in an emergency (fire, earthquake, etc.) but she cannot get out without me knowing to food seek, run away, or get into other things she's not supposed to. The alarms I bought were in the pharmacy department at WalMart (for medicine cabinets) and sometimes they're in the home improvement section. Hope this helps!"

"We HAD very similar situations at night and in the day as well. Two years back we decided to go to the annual PWCF general meeting and that was a LIFE-changing decision for the betterment of the entire family. My husband and I were constantly getting up to the sounds of the motion detector alarm at night, which is set above her bedroom door at an angle, and we almost shut the door so if she opens it to get out, it sounds off really loud. She would even try to glue herself to the wall and glide by it and combat crawl. Not to mention at that time we also had a six month old and a two year old, so I was running on fumes of sleep. I was probably near an all time low. No sleep for years can make anyone crazy!

"Anyhow, at the conference we learned from the Pittsburgh [Specialists] that if she knew what and when she would be eating [all meals and snacks], this would help with the seeking, stealing, nighttime foraging, etc. because there would be no anxiety around food and getting food. We set their guidance on behavior and food into action right away. When we would be driving in the car, she would bother us all the way home or anywhere and would throw anything she could get her hands on at us (shoes, toys and clothing) out of frustration. On our way from L.A. to Santa Clara, we promised her that we would stop at 10 am for a snack and at noon for lunch, and we did. [We followed the motto is NO DOUBT, NO HOPE, NO DISAPPOINTMENT. It was instant success for her and us. She started sleeping all night till 7 am and we have put an alarm clock and set it so she does not ask us any longer "Is it morning yet?" She now has a routine for all her activities and meals. I would highly encourage all parents to get the DVD [*Food, Behavior & Beyond, available at pwcf.org/shop*] and watch it in its entirety. Doctors Gourash and Forster have absolutely saved our lives. My daughter's weight has stayed steady and anxiety much lower. Another good point they made was *low expressed emotion* at all times, which seems impossible at 3 am.

"Lack of proper sleep is draining for everyone, including the person with PWS. I personally feel the video and lecture in person was so beneficial that it should be mandatory for parenting a child with PWS. I wish I had the information at the very beginning of life. It would have saved many tears, battles, tantrums, marriage problems, friendships, embarrassing situations in restaurants, public, and the list goes on.

"By the way, we still use our alarm on her door that we got at Radio Shack. My daughter's first escape from the house was at age 5 at the wee hours of the morning. She managed miraculously to give the police, who happened to see her walking, our home address. We did not know that she had even left until the police started pounding on our door at 7 am (she claimed she was walking her doll in the middle of winter with sandals and no jacket). We have now told her to tell police and teachers that she has PWS if she ever gets lost. I slept many nights in the hallway and my husband on the couch. Ever since the conference, we have not had a *single* episode of night waking or wandering."

Expressing Motherhood is the hit, ongoing stage show that has been showcasing people sharing their stories about motherhood onstage since 2008.

A frequent writer for PWCF News, PWCF member, Jessica Patay, wrote a piece about her son that was accepted by Expressing Motherhood. In January at their South Bay event, Jessica was featured onstage reading her piece aloud to a sold out crowd. PWCF is proud to share her piece below with our readers.

Expressing Motherhood has chosen to feature Jessica again at their show in May in Santa Monica. Congratulations, Jessica, and please keep up your great work!

WHEN I LOOK AT HIM

by Jessica Patay

I didn't ask for a disabled child.

But he was given to me on Friday, June 27th, 2003.

MY son--Ryan Bradley Patay.

No mother puts on her pregnancy wish list---"unhealthy child, with a genetic syndrome that NO ONE HAS EVER, EVER heard about, tremendous heartache, a side of stress, preferred moments of depth and wisdom, plus personal injuries like a bruised tailbone."

No mother. And certainly not me.

I cry, I cuss, I pray.

But then sometimes, when I look at Ryan, all snuggled-up on the sofa, I momentarily forget about my anger and my angst, and my hacked-up heart, because all I see is his beauty and peaceful face.

I see his long, skinny limbs outstretched, mouth open, breathing loud. Not quite a snore. His own sounds. It's family movie night, a Friday. And of course, Ryan, our little narcoleptic, lasts half an hour before he is asleep. He even missed the popcorn! How did that happen, when that is all he REALLY cares about?

When I look at my sleeping prince, I am overtaken by an avalanche of love and compassion. I think about his brain, all wired wrong thanks to missing parts of chromosome 15. I think about his muscle tone, so low, so weak, contributing to small frame. How his muscles had to be taught to move, activate and strengthen. Until, at last, at age 3 he walked. FINALLY. With his own Ryan-gait-and-rhythm.

I think of his little hands that can't give a firm handshake. Straw-like fingers with nails that grow way too fast. Nails that undo my skin during meltdowns. The fingers that struggle to close buttons, and zippers. He has yet to learn how to tie his shoes, but I refuse to buy any more baby Velcro sneakers. He is 12 years old now. With pubic hair and hormones.

For a moment, ever so brief, I forget about Prader-Willi syndrome.

I forget about calling 911 when he was so out of control that he lurched at me from the back seat while we were driving home. It too, was a Friday. He was out of his mind anxious and agitated, like a cat ready to pounce at any moment. I pulled over to the side of Via Del Monte, a main artery in our neighborhood. He was clawing and scratching and grabbing at me, practically sitting in the driver's seat with me. I was then balling uncontrollably and could barely get the words out to the 911 dispatcher. We were tracked by my iPhone. Of course, as friends passed by, three cops are trying to help us and I still could hardly talk through my tears. Eventually Ryan calmed down, and one of the officers kindly followed us home.

I was mortified, scared, angry, grieving, and this time, this crisis, I was without compassion. Once again, I could not believe this was my life. This is my Motherhood? Dramatic, traumatic and uncontrollable. When I was breathing in Ryan's newborn smells, I never imagined this happening 12 years later. I never imagined being AFRAID of him.

I look at him and think how tortuous it must be to have his level of anxiety. So riddled daily with insecurity about potential changes or his next meal. He asks and asks and asks about his food schedule and his menu.

"What time am I eating?"

"Where am I eating?"

"Why do I have to wait until 6?! Why can't I eat at 5:30?!"

Motherhood, continued on page 15

SAVE A TREE

RECEIVE PWCF NEWS BY EMAIL

If you'd like to receive your quarterly newsletter by email please let us know at info@pwcf.org. You'll not only be saving a tree, you'll be helping to bring down PWCF's printing and mailing costs!

Of course we are absolutely happy to continue to send your newsletter by U.S. Post if you'd prefer.

Whichever way you read your PWCF News, we hope you enjoy it and find it helpful. Let us know what you think!

* * *

Motherhood, continued from page 16

"What are you making me? How many things will be on my plate?"

In rapid-fire succession over and over.

Only us Prader-Willi families talk about food all the freaking time. All day, every day. It's *exhausting*.

Sometimes, in a "normal-happy" moment, I just see God's gift to our family. That I get to unwrap every day.

I just see the ONE child of mine that everyone says looks like me, with his blond hair and blue eyes.

I just see his grateful heart, and recognize once again HOW MUCH he has taught me--to be grateful for the tiny-priceless-life-moments.

And yet--I don't unwrap this gift every day with joyful expectation.

I flip. I flop. I grieve, I grit my teeth, or I get lost in my love for him.

If this Motherhood Journey were easy-peasy, I wouldn't need an effing tattoo that says GRACE on my wrist. It says GRACE to remind me every day, that I AM ENOUGH, and I DO ENOUGH as his mom.

I needed this inked on my body permanently, because I forget and doubt myself, ALL THE TIME.

I take deep breaths and look at Ryan. I stare at him. I drink in his innocence, his goodness, my boy who's so polite and an immense pain in my…heart.

And in those pure moments, I forget all the "WHAT IFs." And I wonder--how many Fridays do we still have left together?

ARE YOU ELIGIBLE FOR A GAS/ELECTRIC DISCOUNT?

By Emily Dame, Education & Training Coordinator

According to the California Public Utilities Commission some residential customers may be eligible for a discount on their natural gas and electric bill if a full time resident in the home has certain medical needs that require the use of life supporting equipment or additional heating or cooling.

All residential customers are billed a certain amount of their natural gas and electricity use at their utility company's lowest residential rate. This is called the "Baseline Allowance" and it is set depending on what climate zone your home is in and whether it is the utility's "winter" or "summer" season. Extra allowances of natural gas and electricity are billed at the lowest rate for customers who rely on life support equipment, those who have life threatening illnesses, compromised immune systems, or any medical condition for which additional heating is medically necessary. The extra allowances are called Medical Baseline.

One of the symptoms of Prader-Willi syndrome is temperature abnormalities and a risk for hypothermia. Therefore most people with PWS should qualify under the category of "any medical condition for which additional heating is medically necessary." All you need to do is print out the form provided by your gas and/or electric company and get a doctor's certification and signature. www.cpuc.ca.gov/PUC/energy/Electric+Rates/Baseline/medbaseline.htm

For more information contact your utility:

LADWP: www.ladwp.com > Financial Assistance > Physician Certified Allowance Discount

PG&E: www.pge.com > Save Energy & Money > Assistance Programs > Medical Baseline Allowance

Edison: www.sce.com > Your Home > Help with Your Bill > Medical Baseline

SDG&E: http://www.sdge.com > Residential > Payment & Bill Assistance

Southern California Gas Company: www.socalgas.com > Save Money & Energy > Assistance Programs > Medical Baseline Allowance

BOARD CORNER

Summary of Board of Directors Meeting on November 14, 2015

Submitted by Julie Casey

The Board of Directors met in Los Angeles at the Crowne Plaza Hotel the day before the Annual Conference for their last meeting of the year. All Board members except June-Anne Gold were present. Additionally, the following PWCF staff members were present: Lisa Graziano, Executive Director; Emily Dame, Education & Training Coordinator; and Gloria Burns, Office Manager.

The following reports were submitted prior to the meeting and approved for the record: Executive Committee Report, Public Awareness Committee Report, Social Media Report.

The following items were discussed at the meeting:

1. Officers were elected for 2016: Because Julie is terming out at the end of the year, **Roger Goatcher** was elected as the new President to take her place. The other officers agreed to continue serving and confirmed via a vote: **Kimberlee Morgan**, Vice President; **Nisha Mehta**, Secretary; and **Renee Tarica**, Treasurer. Renee, is currently serving as a non-voting member.

2. The Board calendar was set for 2016

3. Executive Director **Lisa Graziano** and Training & Education Coordinator **Emily Dame** presented information about their research and progress on a Southern California location for a new PWS camp session. The Board was very excited about this as camp is a very popular service offered, and have wanted to add a second location to serve more families. Lisa and Emily indicated they were scheduled for an on-site visit to the camp after the conference. Based on the discussion the Board authorized Lisa to make final negotiations for a camp session at Camp Paivika. The Board also determined that any camp scholarships made available would be limited to one per member at either location, and if a member wanted to attend both camp sessions they would have to pay the full amount for the other.

4. Julie reviewed the results of the Executive Director's annual performance evaluation. A survey is sent to all Board members, staff, and consultants to provide feed-back on the Executive Director's performance. Lisa continues to receive high marks; almost all responses were either "exceeds acceptable range of performance" or "acceptable and within range of expected performance".

5. Lisa went over the flow for the conference and reviewed Board Member job assignments.

6. A proposal was made at the last meeting to raise member dues but was tabled until this meeting. After much discussion the Board voted to raise member dues by $5. Dues were last raised in 2006 and since that time services have increased as have operating costs. The increase will begin in 2016.

7. The Board recognized that their PWSA conference scholarship policy was outdated and in need of revision. Lisa will draft an update to be reviewed and approved at the next meeting.

8. **Daniela Rubin** made final edits to the Promising Scholar Travel Scholarship Application which will be distributed to universities and posted on our website. The idea behind this scholarship is to encourage an interest in the study of PWS by assisting researchers in presenting their work at medical conferences.

9. Julie, Emily and Lisa presented highlights of the various PWSA meetings attended:

   Scientific Day (Lisa):
   - Beloranib Update: Presenters reviewed initial results of the Beloranib study and main causing factors for the recent deaths which may be from pre-existing cardiovascular and respiratory complications.
   - Swallowing Risk: New presentation indicating there are problems for those with PWS with swallowing as it is common for food to get stuck in the airway.
   - Oxyctocin: Dr. Miller is positive about the preliminary Phase 1 results.
   - Update on various drugs in their phases of research: Dioxcide is the furthest along but will still take 2 more years of trials.

   Chapter Leaders' Meeting (Julie):
   - Participation and involvement seems to be the same across the various Chapters
   - PWSA (USA)'s Initiatives for 2016 are to: 1) enhance support of newly diagnosed families and provide a new parent mentor program; 2) address diversity issues; 3) continue to provide residential support at the national level and 4) improve financial health of PWSA (USA).
   - Mayim Bialik (from Big Bang Theory tv show) is another spokesperson for PWSA and has a created a new Awareness video that is on the PWSA National website.
   - PWSA (USA)'s Oxcytocin Fundraising Effort and Matching program has been a big success. PWCF will continue with the 2nd matching program as promised.

   Providers' Day:
   - The aging process appears earlier than the general population for reasons unknown.
   - A diet of cooked vegetables, rather than raw

PWCF EVENTS CALENDAR 2016

January 22-24	Fri - Sun	Board Meeting & Retreat	Embassy Suites Irvine
January 23	Saturday	Northern CA Support Group	San Francisco
January 24	Sunday	Family Fun Day	We Rock the Spectrum
February 21	Sunday	LA County Support Group	PWCF Office
March 6	Sunday	Behavior Management Training	PWCF Office
March 15	Tuesday	Board Meeting Evening	Phone Meeting
April 24	Sunday	So. CA Walk	Griffith Park
April 30	Saturday	Northern CA Support Group	San Francisco
May 1	Sunday	LA County Support Group	PWCF Office
June 4	Saturday	Board Meeting	PWCF Office
June 25	Saturday	Family Fun Day	Angels Stadium
June 26	Sunday	No. CA Walk	Crissy Field
July 13-18	Wed - Mon	PWS Camp	Camp Harmon
July 26	Tuesday	Board Meeting	Evening - Phone Meeting
July 30	Saturday	Nutrition Strategies Training	Orange County
August 4-9	Thu - Tue	PWS Camp	Camp Paivika
September 10	Saturday	Family Fun Day	Oakland As
September 11	Sunday	LA County Support Group	PWCF Office
September 17	Saturday	Board Meeting	PWCF Office
September 18	Sunday	IEP Training	PWCF Office
September 24	Saturday	Northern CA Support Group	San Francisco
October 8	Saturday	Aquarium of the Pacific 5K	Long Beach
October 9	Sunday	Long Beach Marathon	Long Beach
Oct. 31 - Nov. 5	Weeklong	Obesity Week	New Orleans, LA
November 4	Friday	Board Meeting	No. CA Hotel TBD
November 5	Saturday	Annual Conference	No. CA Hotel TBD

vegetables, is recommended because cooked vegetables are more easily digested. Drinking sips of water in between bites of food consumption is recommended in order to improve swallowing.
- Muscles of the Esophagus are not pushing all of the food down and can cause reflux and what looks behaviorally like a purposeful rumination.
- There was some controversy over one presenter's using food items as a motivator for exercise.

General Conference (Lisa, Julie, Emily):
- Social competence, empathy, and inferences can be teachable.
- Long-term risks associated with Ketogenic diet.
- Growth Hormone in adults can have benefits post puberty.

All non-profits struggle with generating sufficient income and PWCF is no different. As demand for services increase and the organization continues to expand in order to provide more services to more families, our need for increased income also increases. The board therefore discussed new fundraising ideas. Of course we welcome ideas from the membership for grassroots fundraising.

In addition to the above discussion items the Board reviewed strategic planning items to review future goals and work to move them into scheduled programming and services.

And personally exciting to me, as I worked very hard on moving over all the content, was letting the Board know that the website facelift was completed and the new site was live. We will continue to make improvements to the website and have plans for a more interactive website as we move toward more blog-type posts on a regular basis. The website is a great source of reference material as well as a place to check for PWCF events, so be sure to visit periodically and don't forget to like us on Facebook (www.facebook.com/pwcf1) and follow us on Twitter (@PWCF1).

Though I've termed out and my time on the Board has come to an end (for now), I will continue to serve on several committees and I encourage you to get involved too. We are so lucky to have such a strong organization that provides so many invaluable services, but all organizations are stronger when everyone is active and engaged, so make a commitment in 2016 to increase your engagement in some way. It can be small or large, but take the step and help this amazing organization continue to provide all the assistance they do throughout California.

WE GET MAIL

Dear PWCF: Thanks for such a wonderful and well organized conference in LA. Betty, Nancy and I really enjoyed it! Loved the article about "Preparing Your Child for Thanksgiving." I went over every little food item Barbara was to expect to have for Thanksgiving dinner a few days before and it made the feast way less stressful for all of us because she knew what to expect! (Then of course there was the 2 hr. power walk the next day!) *Sincerely, Karen Benedikt*

In response to Julie Casey's Outgoing President's Message:

Dear PWCF: Thank you for many years of service and the wonderful support you have given to families. I am honored to know you and have you on our team.
Happy New Year, Petra Ali-Martinez

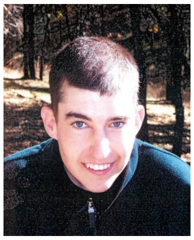
Dear PWCF: Please pass along to Julie our family's gratitude for her service on the Board (9 years! WOW!). She has been a very effective and productive Board member (and President), and her calm and persistent advocacy is an example to us all. We have been very fortunate to have had her dedication to our cause for all these years! *Thankfully, Michelle, Kevin & Cerridwyn Donaldson*

Dear PWCF: Thank you so much for all you did during your time as Board President. You truly "walked the talk"! We all were blessed by all that you did! *Sincerely, Pat Noland*

Dear PWCF: Thank you for all you have done and your passion for our cause. The message is getting out there and it is such an important message. *Carolyn Meyer, Cameron Graziano's grandma*

Michael Kugelman's Eulogy

By Mark Lewis



It's not what you gather in life but what you scatter in life that tells the kind of life you've lived and the kind of person you are.

Today, the most difficult day in our family's life, we gather to say farewell to our son, brother, and friend. To those of you here and elsewhere who know Michael you already are aware of the type of person he was and these words you will hear are already in your memory. To those who were not as fortunate, these words will give you a sense of the type of man he was and as an ideal for which we should strive. Michael has often been described as a gentle and kind soul. He was pure of heart and had great sensitivity for the world around him. He had a way with people that made them feel comfortable around him and infected others to gravitate toward him. Michael exuded kindness and pulled generosity and altruism out of everyone he touched. He was everyone's friend.

To say Michael was polite is an understatement. Since his early years, he showed respect and caring for people all around him. He never had a mean word to say about anyone. As a young boy Michael developed a strong interest in trains, busses and tunnels. He enjoyed attending Camp Lotsafun every summer, cross country skiing in the winter, swimming in the summer and he loved listening to music. He was a happy individual with many plans for his future. Michael enjoyed trips to the Balloon Races, Hot August Nights, Disneyland and Disney World on several occasions, just to name a few.

Michael enjoyed the pleasantries of everyday life. He enjoyed attending his day program and did not like missing any part of it. Friday was his favorite day at his day program because they would go out for special lunch. He was always up for going to the movies, shopping, taking a walk, watching the game show network or just having a good time.

Michael was very fortunate to have wonderful, supportive and kind hearted staff to assist him with anything he needed. He enjoyed the time he spent with them and they enriched his life greatly. He was happy to call them his friends.

As I look out into the crowd I can't help but see just how many lives Michael touched. My family wish to express our heartfelt thanks to all those who have given us needed support, compassion and love throughout this most difficult time. To Dr. Reddy, Michael's oncologist,

Eulogy, continued on page 19

OUR KIDS ROCKED THE SPECTRUM

by Julie Casey

Several families enjoyed PWCF's Family Fun Day in January at We Rock the Spectrum, a gym in Glendale that specializes in serving persons with developmental disabilities.

PWCF rented the space for two hours so that our members could have the place all to themselves! We recognize the importance of providing opportunities for kids and adults with PWS to play and socialize with each other, and the benefit to parents to be able to socialize in a relaxed, food-free, informal setting while their child, whatever their age, has fun.

PWCF member **Rachel Linonis**, who has a 31 year old brother with PWS who lives in Maryland, came to the gym just to help out. Shares the event organizer, Past President **Julie Casey**, "Rachel was great! She played a game with a couple of the kids which was nice because it gave those parents a chance to talk while the kids played – my child being one of them so that I was able to go around and chat with the other parents."

PWCF thanks Rachel and Julie for their dedication to make this a fun event for the kids of all ages and their family members who attended!

Eulogy, continued from page 18

my family can never express enough of our gratitude for your unwavering care, compassion and friendship.
To Michael's huge circle of friends I say thank you for enabling him to experience life at its fullest and providing him support and care. Our family will forever be grateful.

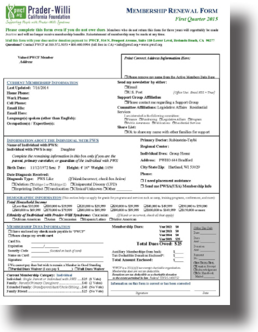
To the Church and Pastor Francis my family extends our most gracious humility for being the recipient of the tremendous outpouring of generosity, understanding, prayer and support.

To everyone, I ask that you never let the mundane obligations of life distract you from the cherished gift of family. Michael, your memory will live on in our hearts and minds and you will forever be in our thoughts and prayers.

MEMBER ACTIVITY

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.

New and renewing Extended Family, Family Friends, and Professional Members are listed.



Your support keeps PWCF strong so that we may provide vitally needed programs and services to persons with PWS, families, and the professionals who serve them.

Renew your membership today!

Renewed Extended Family Members
Judy Soden

Renewed Family Friend Members
Patrick Maxon

Renewed Professional Members
Ashley Phelps-Leak

VOLUNTEERS are Priceless

PWCF thanks **Monzerratt Patino,** a kinesiolgy student working with Daniela Rubin, Ph.D. at CSU Fullerton. Monze is currently translating the Nutrition & Activity Guidelines brochure into Spanish.

PWCF thanks the following individuals for their help to package this year's Member Give Back:
Margaret and Bill Spinelli
Carolyn Meyer and Donn Moll
Mary Williams

PWCF thanks **Rachel Linonis** for volunteering to help at PWS Family Fun Day at We Rock the Spectrum.

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 info@pwcf.org

DONATIONS

January - March 2016

Shining Star Donations

Sirius ($1,000 or more)

John & Joanna Basso in honor of Trevor Ryan
Karen & Russ Benedikt in honor Barbara Olson
Nancy & John Jenkins in honor of Cameron Graziano
Susan & Mark Lewis in memory of Michael Kugelman
Paul Wissmann via KPMG LLP

Canopus ($500 - $999)

Tom McRae (annual donation)
Melinda & Chuck Morrow in honor of Cameron Graziano
Jessica & Chris Patay in honor of Ryan Patay
Gayle Dax-Conroy
Carmen & Roger Stuhlmuller in honor of the Steinhart Family

Alpha Centauri ($250 - $499)

Catherine & Rudy Alvarez in memory of Daniel Alvarez
Patty & Robert Dion in honor of Donna & Tony Franco and Landon Shea
Barbara Gow in memory of Carolyn Gow
Bonnie Gowing in honor of Trevor Ryan
Carol & John Kulluk in honor or Natalie & Steven Inouye "and your precious Sloane"
Phillip D. K. Lee, M.D.
Patti & Tom McRae (monthly donation)
Mr. & Mrs. Robert W. Morgan in honor of Samantha Morgan
Ivette Ramos in honor of Victor Ramos
Michael Tomelloso

Arcturus ($100 - $249)

Rose & Dennis Basson in memory of Yvette Tarica
Lisa Ann Bonk in honor of Nolan Bonk
Frances Braga in honor Yasmin Mathis
Molly Carter in honor of Dan Carter
Suzanne Cassidy, M.D. & Christopher Visher
Sally & Chet Collom in honor of Jennifer Collom
Lisa Dedecker in memory of Kathleen VandeMoortel: Anne, Gary, and Jacob, "In memory of Katie's life. May God lift you all up in prayer and surround you with his love. Katie will be missed by all."
Mary & John Fischer in honor of Dustin Watney
Sara Formslag
Candelaria Garcia in honor of Ignacio Martinez
Linda Hamilton
Donna Griffo-Johnson in honor of Nolan Carl Bonk
Law Office of Janet M. Stroman
Raymond Marchant in honor of Oliver Young
Linda McGee
Kathleen & Stephen Meeker in honor of Anne Meeker
Fran Moss in honor of Melissa Moss
Brian and Ellen Wu in honor of Emma Wu

Vega ($1 - $99)

Kyra Allen in honor of Faith Allen
The Arstein-Kerslake Family
Yasuko & Ira Bloom
Marlene & Thomas Burke in honor of Kean Bracht
Terri Canales in honor of Taylor Canales
Tom & Thelma Davidson in honor of Ian Davidson
William Duggan in memory of Shawn Duggan
Ira Fennessy in honor of Cerridwyn Donaldson
Alan, Terry, and Benjamin Fistner
Sally & Mark George in honor of Luke George
Melvin Goldberg in memory of Yvette Tarica
Rick & Paty Gould in honor of Justin Vitro
Claudia Hansen
Heather Hessell in honor of Ryan Casey
Emily Hirsch in memory of Andrew Norton
Alex Huck
Ms. Sharon Levine
Jennifer Meade in memory of Scarlett Meade
Carolyn Meyer in honor of Cameron Graziano
Kathleen and Ralph Paige in honor of Nicholas Paige
J.P. Reader in honor of Duncan McRae
Patricia & Joseph Reitz in honor of Dustin Watney
Karen Reynolds in honor of Ryan Ramirez
Gordon Schneiders in honor of Ryan Casey
Kathy Swesey in honor of Emily Varni

Valentine's Day Gram Donations

Carolyn Anderson in honor of Peggy Smith
Lisa & TJ Graziano in honor of Cameron Graziano
Lisa Graziano in honor of Anna Kanauka
Lisa Graziano in honor of Cassie & Tod Holdorf
Lisa Graziano in honor of Carolyn Meyer & Donn Moll
Elizabeth & Andrew Greskovics in honor of GiGi Greskovics
Carolyn Meyer in honor of Donn Moll
Patricia Noland in honor of Brent Noland
Secret Admirer in honor of Gloria Burns
Secret Admirer in honor of Emily Dame

General Donations

Adobe (Tom McRae's monthly payroll match)
Joyce Awad
Albert Chun
Sandra Levine in memory of Michael Anatole's father
Masani & Hanif Nassor-Covington
Patti & Tom McRae (monthly donation)
Tom McRae
Timothy Russell

Donations to Support PWS Camp

Suzanne Privette in honor of Samantha Morgan (monthly donation)

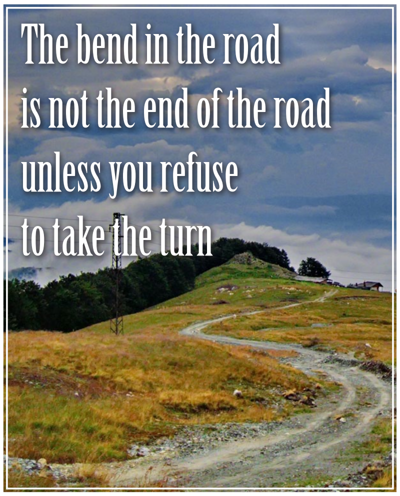
Donations to Support Research

Karen & Russell Benedikt, on behalf of the Benedikt Family Trust to support PWS research conducted at UCSF under the direction of Daniela Rubin, Ph.D.

Grants Received

Beach Cities Health District to support the Behavior Management Parent Conference

MTC Wismettac Foundation to support the translation of critical educational materials into eleven languages



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)