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PWCF ANNUAL STATE CONFERENCE WOWS

PWCF's Annual State Conference, held on November 5 at the Hilton DoubleTree Sacramento, was a great success and featured some truly amazing speakers. Titled, *PWS: Past, Present and Future*, the conference provided a look at where PWS has been, where we are now with treatment and interventions, and where medication research is taking us in the future. Meeting Packets containing the speakers' handouts are available for purchase from the PWCF Office.

Special thanks to the Program Committee for their work: **Lisa Graziano, chair, Emily Dame, Diane Kavrell, Tom McRae, Petra Ali-Martinez, Julie Casey, Linda Ryan, Daniela Rubin, Ph.D., Kimberly Storr, Elizabeth Greskovics, Jacki Lindstrom, Roger Goatcher, Kim Morgan, Kim Cain, and Jennifer Wolkensdorfer.** Thank you to Kimberly Storr who served as the conference photographer

Pediatric endocrinologist **Jennifer Miller, M.D.** began the day presenting the positive effects of growth hormone therapy for both children *and* adults. She educated attendees about several supplements commonly used for reducing symptoms such as skin picking (NAC supplement); reducing vitamin deficiencies (vitamins B and D), and supplements and medications to treat excessive daytime sleepiness and obsessive symptoms. She shared the status of some very promising drug trials including oxytocin, carbetocin, setmelanotide and diazoxide. She shared information about the availability of a new blood test, the Roche AmpliChip CYP450 Genotyping Test, that reveals which medication categories will be most and least effective for an individual's biochemistry.



Jennifer Miller, M.D.



Ken Smith

PWSA (USA)'s Executive Director **Ken Smith** provided information about the vast array of services PWSA (USA) provides to families and professionals throughout the United States. The most common request for support is Medical Crisis (35%), followed by requests for support with School Issues (27%). Due to the growing demand for crisis response, PWSA retains three Crisis Counselors, two Medical Crisis Counselors, as well as counselors to assist with education and residential support. There is a great deal of support available to families, both newly-diagnosed and veterans, as well as a tremendous amount of resources available for the professionals who serve them.

Ken shared how PWSA and PWCF frequently work together to help families, and ended by extending an invitation to all to attend the national conference in Orlando, FL from November 15-18.

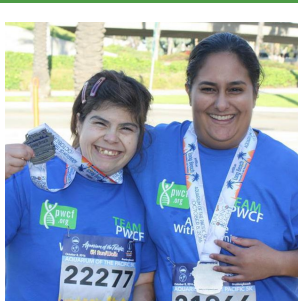
In the afternoon, families met in age-based share sessions to discuss matters relevant to their child's stage in life. These sessions are always extremely popular among families as there is no substitute for sitting in a room chatting with people who truly understand what you're going through.

Suzanne Cassidy, M.D., a geneticist and pioneer in the study and treatment of PWS, provided attendees with an historical perspective of PWS, noting the advancements made over her 35-year career. In 1979,



Suzanne Cassidy, M.D.

ASC, continued on page 6



See pg. 12 for Team PWCF!

2016 Officers

President - **Roger Goatcher**
Vice President - **Kim Morgan**
Treasurer - **Renee Tarica**
Secretary - **Nisha Mehta**

2016 Board of Directors

Whitney Bras
Rodney Dong
Roger Goatcher
June-Anne Gold, M.D.
Diane Kavrell
Jackie Lindstrom
Tom McRae
Nisha Mehta
Kimberlee Morgan
Daniela Rubin, Ph.D.
Jennifer Wolkenstorfer

Lisa Graziano, M.A., Executive Director
Katherine Crawford, Graphic Designer

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)

Email: info@pwcf.org
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.yahogroups.com. In the search box under the heading "Join a Group" enter *PWCFmembers*. When the *PWCFmembers* group name appears, click and follow instructions to join.

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

PWSA (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 2017

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)

Check www.PWCF.org for upcoming dates.

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

Check www.PWCF.org for upcoming dates.

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

PWCF RECOGNIZES TWO SPECIAL WOMEN

PWCF's Board of Directors presented two special awards to two very special individuals.

Fran Moss received an award for *Devoted Executive Director*.



Fran started with the organization like so many of us, as a parent looking for information and support. She volunteered to do many of the administrative and support tasks, which grew as the number and needs of families grew. She was elected to the Board of

Directors which was working at that time to get PWS recognized by the State as one of the "automatic" Regional Center eligibilities. Came pretty darn close, too – got the bill all the way up to the governor's desk only to be vetoed and die there. In the early 1990s, as part of what was known as The California Project, PWCF received funding to visit all of the Regional Centers as well as pay a very small salary to support the growing administrative and support needs of the organization. And so, PWCF's first Executive Director, Fran Moss, was born. For the next 11 years Fran ran the office, organized Board meetings, organized events, conferences, put together the newsletter, *everything*. Hers was the voice you heard when you called the office needing information, guidance, and support. Countless families shared year after year how appreciative they were of Fran's work on their behalf. And though she officially retired her position at the end of 2002, she remained active and involved with PWCF, rarely missing a Board meeting or major event, sharing her historical memory and calm wisdom. The Board of Directors honored Fran for her dedication and commitment to PWCF and the families we serve with a vase that reads, "Devoted Executive Director." PWCF's current executive director, Lisa Graziano, presented Fran with her vase and shared, "On behalf of PWCF's Officers and Board of Directors, we thank you and honor you, Fran, for all you have given to PWCF, the families, and the professionals throughout your decades of service."



Fran writes to the Board:

"I want to thank Lisa and the Board of Directors for honoring me at the annual meeting for my role as Executive Director for PWCF from 1991 through 2002.

I am grateful to those who started the Foundation for entrusting me with the challenge of opening the first office. Working with our PWCF families, group home administrators, and State agencies is at the top of the most rewarding things I have ever done."

An award was presented next to **Renee Tarica** for her *Lifetime Dedication to PWCF*.



Renee has been a part of PWCF for almost as long as PWCF's been in existence, over 35 years. Renee has been involved in *every* aspect of the organization on an almost daily basis, and given everything she has to ensuring PWCF's stability... and we do mean "given." All of Renee's 35 years with PWCF have been on a *voluntary* basis. She has served as PWCF's financial "rock" for decades, worked hard to make every fund raising event a successful one, and accounted for every donated penny. Renee has seen more board members come and go and attended hundreds of board meetings, yet she's never lost her temper or even raised her voice... and for anyone who's ever served on *any* Board knows, *not* losing your temper at a meeting even *once* is quite a feat!

Lisa Graziano presented the award to Renee and shared, "I have had the personal pleasure of working with Renee for the past 14 years and there is probably no one in this universe I respect more than you, Renee, for your character, gentle spirit, and internal strength. It is my honor to present to you, on behalf of PWCF's Board of Directors, this vase that reads, "Lifetime Dedication to PWCF."

Renee writes to Board Members and friends:

"I am very grateful for the honor bestowed upon me for my lifetime dedication to Prader-Willi California Foundation. It has been my pleasure working with you all who have become like family. It is amazing to have been involved with the Foundation from its beginning and watch it grow to what it is today. I will always do what I can to continue helping those who have been afflicted with this rare syndrome. May the Foundation continue to grow from strength to strength. Many thanks for the beautiful vase."

FOOD TIP: BAI BEVERAGES

Submitted by Cameron Graziano



Brasilia, Brazil -- sounds fancy, doesn't it? Exotic. Romantic, maybe. Definitely adventurous. It sounds like a faraway place that boasts exciting, captivating faraway things. Can you imagine if one of those things was unbelievable flavor? And other things were antioxidants? How about five calories and just one gram of sugar per serving? Can you imagine all that? You should start. Because that's what's inside each bottle of Bai. Exotic flavors include Brasilia Blueberry Congo Apple Pear, Costa Rica Clementine, Kula Watermelon, Malawi Mango, Ipanema Pomegranate, and Limu Lemon.

Looking for something a little more upscale for that teen or adult with PWS in your life? Try Bai Bubbles.

Available at most grocery stores including Vons, Ralphs, Target and Walmart.

PWCF PARTICIPATES IN KIDS GROWTH FOUNDATION'S WALK



Julie Casey and Emily Dame attended the 4th Annual *Walk for Kids' Growth* event at Griffith Park, Los Angeles in December. They shared information about PWS with attendees who dropped by our booth, gave out coloring pages to the kids, and encouraged attendees to take a spin at the wheel for a PWS awareness-raising prize.



Feeling gratitude and not expressing it
is like wrapping a present and not giving it.

~ *William Arthur Ward*

RESEARCH PARTICIPANTS NEEDED

CSU Fullerton is excited to invite families to participate in a study investigating a parent-led physical activity program for children ages 4 to 7 years old with and without PWS. A child ages 4-7 years with or without PWS and one parent per family are invited to participate.

We will train your family to do a 12-week home-based program with activities and games that stimulate the development of motor skills. Your family will receive all play materials and our curriculum of games at no cost. The study will require three short visits at CSUF and two playdates (one at CSUF and one at a location of the parent's choosing). During the visits your child will have height and weight measured and will complete movement-related tests. Parents will complete questionnaires and a recorded interview.

Children will receive a bag of toys (\$10 value) and parents a \$20 gift card following the first and last visit. Parents will be reimbursed for mileage (up to \$40 round trip) for the visits to CSUF. For non-local families interested in participating, arrangements for travel expenses may be available (please inquire with our study staff). Families may keep the all the materials when the program is over.

For information please visit our website at pws.fullerton.edu, or call or e-mail us at:

Daniela Rubin
Research Office

(657) 278 4704
(657) 278-3671

drubin@fullerton.edu
pwstudy@exchange.fullerton.edu



CALIFORNIA STATE UNIVERSITY
FULLERTON

EXECUTIVE DIRECTOR'S COLUMN

by Lisa Graziano, M. A.



Here we are at the end of another action-packed year. And what a year 2016 has been! Because so many of you have asked, I'll begin by sharing that I continue to serve as PWCF's executive director while the Executive Search Committee continues to work diligently to find just the right match for this important position.

At the end of each year I have the distinct privilege to provide our readers with an overview of PWCF's activities and services throughout the year. An "overview" is really all I *can* provide because I could not possibly include in the short amount of space available all that PWCF accomplished or was involved with in 2016. If anyone wishes more detailed information about anything, please give me a call at the office so we can chat! As I look back at this year I am grateful for and inspired by the individuals who have given so much of their time and talents to improve the lives of others. This newsletter particularly highlights some of the people who have worked so hard during the year and are deserving of our thanks and gratitude.

PWCF has been serving families since 1979. The number of families and professionals has grown significantly since our founding. Today we are over 900 members strong and provide significant support to hundreds of families, as well as the professionals who serve them. PWCF's Board of Directors keeps me and **Emily Dame, M.Ed.**, Education and Training Coordinator, quite busy implementing services and providing supports that fall under one of four Program "pillars." What follows is an overview of the highlights of each of these Education, Support & Advocacy, Awareness, and Research Programs:

Education:

PWCF sponsored a Behavior Management parent conference, provided additional behavior training sessions for families either in their homes or remotely. We provided an IEP Parent Empowerment training seminar and gave each participant a 3-ring binder stuffed with great info. We brought in a special needs planning professional to teach parents what we need to do to plan for our child's future. We formed a Task Force to educate ourselves on the complexities of the new Home & Community-Based Services regulations so that we may better educate and advocate for families. We regularly collaborate with PWS specialists to keep up-to-date with current literature and research so that we can keep *you* up-to-date.

We educated neurodevelopmental professionals at Children's Hospital Los Angeles, and brought top-notch speakers to our Annual State Conference. Through our Annual Youth & Adult Program and our Walking for PWS events we educated over 80 university and nursing students about PWS. We taught hundreds of teachers and Regional Center case workers about PWS, and

took professional PWS training to group homes, supported living agencies, and into individual families' homes. We mailed over 60 educational DVDs, as well as books and brochures. We completed a large project translating into multiple languages critical documents on behavior; diet and exercise; and gastric and bowel issues, and will be distributing these documents to our members, PWSA (USA), and the International Prader-Willi Syndrome Organisation.

Support & Advocacy:

In addition to all of the requests we receive for assistance with Regional Center eligibility, group home placement, and family training, this year *exploded* with requests for support and advocacy with all things related to school.

We facilitated in-person support groups in three different parts of the State every quarter, and continue to maintain the only 24-hour PWS-related medical crisis line in the country.

We continue to support three PWS Clinics located at Rady Children's Hospital, Children's Hospital Orange County, and our newest PWS Clinic at UC Irvine serving adults with PWS.

We held our sixth annual PWS Camp session in Northern California and held a second camp session in Southern California. We served over 80 campers while their families enjoyed six days of respite.

Awareness:

PWCF believes that as public awareness increases, compassion and understanding will increase. We sent out Press Releases that reached hundreds of websites and a potential audience of over 11 million. We gave out thousands of awareness-raising products at various events, including the Long Beach Jet Blue Marathon and 5K where we were an Official Charity. Our 16th annual statewide walkathons saw over 750 people gather and play. Our active Facebook and Twitter pages are active and informative. The **Patay** family sponsored an amazing concert in their own backyard that not only raised awareness but funds for PWCF.

Research:

While our charter is not to conduct research, PWCF proudly advertised and supported local, national, and even international research. This year PWCF awarded our first Promising Researcher Travel Scholarship to help **Diobel Castner, M.A.** attend a conference at which she had a PWS research poster featured. We have come a long way in our treatment and management of the symptoms of PWS. And we have a long way to go to reach our vision of a full life without limits for every individual with PWS.

PWCF is fortunate to have a thoughtful, dedicated Board of Directors and an *extremely* hard working and devoted staff and consultants, namely **Emily Dame, M.Ed.**, Education and Training

Executive Director's Column continued on page 15

some 24 years after its first description, PWS was still virtually unknown by the public and doctors. PWSA (USA) hosted the first PWS conference and the first PWS scientific conference in 1980. Back then there were only about 60 published articles in the medical literature and very few researchers studying PWS. Resulting from the enormous work by dedicated PWS professionals, medical publications on PWS grew to more than 642 between 2010-2014. Dr. Cassidy shared improvements in knowledge about mortality issues, increased public awareness, and improved quality of life of patients and families, noting these changes have largely resulted from partnerships among clinicians, scientists, PWS associations, and families. Dr. Cassidy reflected upon what she's personally learned about PWS in her 35 year career: that early diagnosis and starting growth hormone early makes a big difference, that the genetic cause of PWS does not necessarily help predict the severity or manifestations in an individual; that the ability of families to set limits improves behavior; that education and support of families improves outcome; and that professional PWS associations like PWSA and PWCF are a great ally. She noted that the future of PWS promises to be better, and that we cannot judge the future by the present.



Harold van Bosse, M.D.

The final speaker of the day was PWS orthopaedic specialist **Harold van Bosse, M.D.** who provided information about orthopedic concerns. Because muscle tone is typically low, children typically benefit from ankle foot orthotic bracing (AFO's). Osteoporosis is typically a symptom of PWS which is treated using growth hormone,

increased activity, and care provider awareness of the potential for injury. More than likely also due to hypotonia, scoliosis is far more common in persons with PWS than the general population and can be diagnosed at all age ranges. Therapeutic interventions include physical therapy to improve trunk strength, sensory integration, keeping the young child on the tummy and crawling positions longer to improve gross motor skill development, and continuous monitoring for curve development. Dr. van Bosse addressed general scoliosis treatment issues including casting, bracing and surgery.

PWCF surprised **Dr. Suzanne Cassidy** with an award for *Lifetime of Excellence in Prader-Willi Syndrome* (see page 9). Two more outstanding women were honored as well: **Fran Moss**, PWCF's first Executive Director received a *Devoted Executive Director* award and **Renee Tarica**, one of PWCF's founders and long-time treasurer received an award for her *Lifetime Dedication to PWCF*.

Roger Goatcher presented his **2016 President's Awards** to well-deserving individuals:

- **Chris and Jessica Patay** – In recognition and appreciation of their work to produce the Tyrone Wells Benefit Concert which raised awareness of PWS and raised over \$14,000 to

support PWCF's programs and services

- **Donna Franco** – In recognition and appreciation of her nominating PWCF to receive a \$1,000 award from the Home Shopping Network
- **Maddy Fluhr** and **Eddie Resendes** – In recognition and appreciation of their sustained generous and playful support of PWCF's Walking for Prader-Willi Syndrome Northern California event
- **Patti and Tom McRae** – In recognition and appreciation of their sustained generous support of PWCF's Walking for Prader-Willi Syndrome Northern California event
- **Linda Ryan** – In recognition and appreciation of her leadership and service on PWCF's Residential Services Committee
- **Barbara Nguyen** – In recognition and appreciation of her sustained enthusiastic commitment to providing a fun and safe environment for children and adults with PWS at the Annual State Conference Youth & Adult Programs
- **Nanny Sanchez** – In recognition and appreciation of her sustained enthusiastic commitment to providing a fun and safe environment for children and adults with PWS at the Annual State Conference Youth & Adult Programs
- **Ben Romero** – In recognition and appreciation of his sustained enthusiastic commitment to providing a fun and safe environment for children and adults with PWS at the Annual State Conference Youth & Adult Programs



Keven Amarasekera, Nanny Sanchez, Barbara Nguyen, Ben Romero

Roger recognized the valuable work by outgoing Board members:

- **Tom McRae** – In recognition and appreciation of his valuable service on the PWCF Board of Directors from 2008 through 2016
- **Diane Kavrell** – In recognition and appreciation of her valuable service on the PWCF Board of Directors from 2014 through 2016
- **Daniela Rubin, Ph.D.** – In recognition and appreciation of her valuable service on the PWCF Board of Directors from 2014 through 2016
- **June-Anne Gold, M.D.** – In recognition and appreciation of her service on the PWCF Board of Directors from 2011 through 2016 and for her dedication to educating genetics students about Prader-Willi syndrome



While parents enjoyed their information-packed day, participants

in the **Youth and Adult Program** enjoyed their action-packed day. The Program was under the direction of PWCF's **Emily Dame, M.Ed.** who was assisted by an amazing team of Program Directors and Assistants **Barbara Nguyen, Nanny Sanchez, Kevin Amarasekera, Ben Romero, Jae Weller, Ethan Franco** and **Stephen Bellinder**.

Kids and adults with PWS and their siblings enjoyed a day filled with jungle boogie themed craft projects, games, a movie, a visit from the Sacramento Zoo's *Zoo Mobile*, a guitar session with Rodney Dong, a dance, and even a Zumba class led by the incredible **Rika** and **Haley Kavrell**. Over 40 volunteers recruited from Sacramento State University helped ensure a successful, safe and fun day for all.

love and understanding which helped us move forward."

"Thank you for putting [the youth program] together, it was amazingly fun and an awesome opportunity to learn about the PWS population!" ~Emily Jeffery, CSUS student volunteer

"I can't tell you how much the organization means to me! I look forward to the conferences and the Walks every year and I'll continue to help out for as long as you'll have me! If you all ever need a helping hand, don't hesitate to ask! I'll always be available for you guys!" ~ Kevin Amarasekera (sibling)



"[The Youth & Adult Program] was a magical day for me, too. Real stars are you, Emily, and all staff who prepared the conference and Haley who has been practicing dance for a long time. Thank you very much for your sharing your program. I am glad it was very successful because of your preparation, and volunteers cheering, and OMG!!!! Hayley [Kavrell] did an amazing job. Each individual was a super star and they expressed their smiles and energy. I just loved them all. Congratulations YAP 2016 "Jungle Boogie". ~ Rika Matsuda, PT and Zumba instructor"



Take a look at what attendees had to say about this year's incredible conference.

"Those of us who had the opportunity to attend left with our heads whirring with information, some new, some reiterated. Lots to think about, mull over, approach, consider, put into effect. BUT that is not only what the conference is about. It's also about one giant family reunion! Families from all over California seeing one another again, sharing good and not so good, beaming over our kids' successes, lending courage, strength and encouragement for concerns, surgeries and new endeavors approaching. Knowing that if our kid had a meltdown we were amongst those who UNDERSTOOD. We could exhale." Hasmukh Amarasekera

"As devastating as [the diagnosis] was and definitely life changing, once we hooked up with PWCF we had so much support, so much

Don't miss the 2017 Annual State Conference to be held in October in Southern California!

PWCF's PWS CAMP!

REGISTRATION OPENS JANUARY 2017



We are excited to announce that PWS Camp at Easter Seals Camp Harmon will be held from Thursday, July 13 through Tuesday, July 18, 2017.

We are actively working to create a Southern California PWS Camp. Stay tuned!

The cost of six glorious days at Camp Harmon is \$726 plus a \$75 registration fee.

As always, Lisa Graziano and Emily Dame will provide PWS Training prior to camp will remain at camp throughout the duration to provide any onsite

behavioral support needed.

Programming for Camp includes campfire fun, daily swimming, arts & crafts, hikes, basketball and tetherball, rap/share sessions, horseback riding, movie night, a dance, lots of time with the barn animals, and of course awesome camp counselors! Male and female nurses are onsite to administer all medications. Staff to camper ratio is 3:1, with 1:1 available. Access to food is strictly secured with daily menus that are healthy, low cal, and low carb.

PWCF's Board of Directors has not yet established the amount of scholarship funding we are able to provide to members for the 2017 season. Stay tuned!

PWCF's Camp is available only to PWCF members. Online registration for camp will open in January. Space will be limited. For more information about programming, menu, or if you need help registering contact PWCF at 310.372.5053.



See you at Camp!

Would you like to help a wonderful person with PWS make memories of a lifetime?
Would you like to give a PWS family a week of respite?

Sponsor a PWS Camper!

Any donation - large or small - will help make our campers' dreams come true! \$801 supports one camper.
Donate today to support PWCF's PWS Camp Scholarship Fund: www.PWCF.org

SPECIAL NEEDS PLANNING WORKSHOP FEATURED AT SOUTHERN CA SUPPORT GROUP MEETING



Support Groups offer not only valuable support and connection with other parents, they're also a place where you can learn a lot from professional guest speakers.

At its October meeting, the Southern California's Support Group featured a guest presenter from **SilverTree Special Needs Planning**. Attendees learned quite a bit about wills, special needs trusts, Letter of Intent (the specific "instructions" about day-to-day care of your child/adult when you're gone), the ABLE Act (savings plan), SSI, and why even when your adult lives at home with you, you need to charge them rent so that they receive the full amount of SSI benefits to which they're entitled.

SUZANNE CASSIDY, M.D. RECEIVES PWCF LIFETIME OF EXCELLENCE IN PRADER-WILLI SYNDROME AWARD



It was supposed to be a Panel Presentation featuring all of the conference speakers, or so thought **Dr. Suzanne Cassidy**. Weeks prior to the conference, she called to speak with conference chair **Lisa Graziano** about what potential panel topics to prep for and was told, “You really don’t need to

prepare *anything*. I’ve no doubt you’ll do just great without any preparation.”

Mid conference, Lisa called all speakers up to the stage for what Dr. Cassidy believed was to be the start of the Panel Presentation. As she readied herself to join the panel, looking a bit confused why everyone was standing at the podium instead of taking their seats at the panel table, Lisa explained to the audience, “Dr. Cassidy thinks this Panel Presentation is something other than what it actually is.” And when Tom McRae blasted the *Theme from Rocky*, Dr. Cassidy began to understand the secret that the Board, the Program Committee, and each of the other conference speakers knew: that the “Panel” was to honor her.

Below is an overview of the honoring Dr. Cassidy received:

Trying to craft an adequate summary of Dr. Suzanne Cassidy’s work in relation to Prader-Willi syndrome is a daunting task. Just her CV is 34 pages long! While it might be nice to know that she was American Health Magazine’s “Best Doctors in America” in 1996 and 1998;

...and that she was listed in Castle-Connelly’s “America’s Top Doctors” from 2001-2010;

...and that she was the founding Editor of the official Journal of the American College of Medical Genetics from 1997-2005;

...and that she was the Recipient of the “Excellence in Human Genetics Education Award” from the American Society of Human Genetics in 2014;

...and even that she was selected as the Stanley Wright Lecturer for the Western Society of Pediatric Research in 2015, these are but a small sampling of the highlights of her career.

Dr. Cassidy has been involved with the national Prader-Willi Syndrome Association for over 30 years. She chaired PWSA’s Scientific Advisory Board from 1994-2000. She organized the first meeting of the International Prader-Willi Syndrome Organisation’s (IPWSO) NATO Advanced Research Workshop on PWS in the Netherlands in 1991 and was elected President of IPWSO in 2010 and re-elected in 2013.

For many, many years she directed the PWS Clinic in Fresno, California until recently when, against PWCF’s and, no doubt, her patients’ protest, she resigned.

Dr. Cassidy has authored or co-authored hundreds and hundreds of research studies, peer-reviewed articles, books, chapters, and abstracts. She’s lectured in hospitals and medical centers, university and teaching institutions and conferences all over the world. Dr. Cassidy was instrumental in getting Prader-Willi syndrome included in medical schools’ curriculum.

But none of this adequately reflects Dr. Cassidy’s kindness, compassion, humor, and genuine interest in and care of her patients, our children with PWS. It was our great honor to award Dr. Cassidy with PWCF’s *Lifetime of Excellence in Prader-Willi Syndrome* as an expression of our tremendous appreciation and gratitude for all that Dr. Cassidy has done to advance the care of persons of all ages with PWS.



Dr. Cassidy Receives Standing Ovation

Each of Dr. Cassidy’s colleagues – Drs. Jennifer Miller, Harold van Bosse, June-Anne Gold, and Ken Smith – took the stage to share their thoughts and gratitude for her leadership and friendship.

As PWCF expresses our heartfelt appreciation to Dr. Cassidy for her lifetime of extraordinary contributions to PWS research, education and patient care, Dr. Cassidy expresses her thoughts to PWCF:



Dear PWCF Board and Lisa,

Please accept my deep gratitude for your kindness in honoring me during your excellent conference in Sacramento last weekend. I was completely surprised and really felt privileged by your recognition of my contribution to PWS. Having my colleagues make comments was an extra special touch and much appreciated, as well.

It has been my privilege to be part of the PWS community and to work with such wonderful people. Your recognition is icing on the cake. Thank you from my heart!

“Susie” Suzanne Cassidy, M.D.

GROWTH HORMONE RESEARCH UPDATES FOR CHILDREN AND ADULTS WITH PWS

Growth Hormone Treatment for the Child

Journal of Child Psychology and Psychiatry, *Cognitive and adaptive advantages of growth hormone treatment in children with Prader-Willi syndrome*, Elisabeth M. Dykens, Ph.D., Elizabeth Roof, Ph.D.

People with Prader-Willi syndrome (PWS) typically have mild to moderate intellectual deficits, compulsivity, hyperphagia, obesity, and growth hormone deficiencies. Growth hormone treatment (GHT) in PWS has well-established salutatory effects on linear growth and body composition, yet cognitive benefits of GHT, seen in other patient groups, have not been well studied in PWS.

Methods: Study I included 96 children and youth with PWS aged 4–21 years who naturalistically varied in their exposures to GHT. Controlling for socioeconomic status, analyses compared cognitive and adaptive behavior test scores across age-matched treatment naïve versus growth hormone treated children. Study II assessed if age of treatment initiation or treatment duration was associated with subsequent cognition or adaptive behavior in 127, 4- to 21-year olds with PWS. Study III longitudinally examined cognitive and adaptive behavior in 168 participants who were either consistently on versus off GHT for up to 4–5 years.

Results: Compared to the treatment naïve group, children receiving GHT had significantly higher Verbal and Composite IQs, and adaptive communication and daily living skills. Children who began treatment before 12 months of age had higher Nonverbal and Composite IQs than children who began treatment between 1 and 5 years of age. Longitudinally, the groups differed in their intercepts, but not slopes, with each group showing stable IQ and adaptive behavior scores over time.

Conclusions: Cognitive and adaptive advantages should be considered an ancillary benefit and additional justification for GHT in people with PWS. Future efforts need to target apparent socioeconomic inequities in accessing GHT in the PWS population.



Growth Hormone Treatment for the Adult

Journal of Clinical Endocrinology and Metabolism, *GH Therapy Continuation in Adults with PWS Beneficial*, Kuppens RJ, et al., 2016; doi:10.1210/jc.2016-2594

Continuation of growth hormone therapy (GHT) in adults with Prader-Willi syndrome who have reached adult height can help to reduce fat mass and increase lean body mass, study data show.

Renske J. Kuppens, M.D. of Erasmus University Medical Center in the Netherlands and colleagues conducted a 2-year, randomized, double blind, placebo-controlled crossover study in 27 young adults (mean age, 17.2 years; eight men) with PWS to determine the effects of GH therapy compared with placebo on body composition.

All participants were treated with GH during childhood and attained adult height. Participants were treated with daily subcutaneous injections of 0.67 mg/m² GH (Genotropin, Pfizer) or placebo for 1 year, and then were crossed over to the alternative treatment for another year. DXA was used to measure body composition.

Mean fat mass increased (4.1 kg; $P < .001$) and lean body mass decreased (–0.9 kg; $P = .069$) during placebo, whereas GH yielded lower mean fat mass (–2.9 kg; $P = .004$) and higher lean body mass (1.5 kg; $P = .005$). Fat mass percent of the limbs and trunk both increased ($P < .001$ for both) and limb lean body mass decreased ($P = .004$) during placebo. During GH, fat mass percent of limbs ($P < .001$) and trunk ($P = .007$) both decreased and lean body mass of limbs increased ($P < .001$).

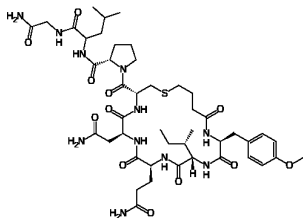
No serious adverse events were reported during the GH periods, whereas two serious adverse events and 12 adverse events occurred during the placebo periods.

“This crossover trial in young adults with PWS who were treated with GH during childhood shows that placebo treatment after adult height deteriorates the improved body composition with an increase of fat mass,” the researchers wrote. **“Compared to placebo, GH treatment results in a lower fat mass and higher lean body mass. This indicates that discontinuing GH treatment at adult height leads to deteriorated body composition, while GH maintains the improved fat mass and lean body mass without safety concerns.”** – by Amber Cox

Disclosure: Kuppens reports no relevant financial disclosures. One researcher reports receiving an independent research grant from Pfizer.

CARBETOCIN PROMISING

by Rob Lutz, PWSA (USA) Research Chair



PWSA (USA) recently announced that **Sara Cotter**, mom to a child with Prader-Willi syndrome, has formed a company dedicated to advancing treatments for PWS and related disorders. The company is called Levo Therapeutics (www.levotherapeutics.com). Sara has

years of experience in the pharmaceutical industry, most recently as an analyst with UBS. She recently left her job to pursue the leadership of Levo Therapeutics full time. Her commitment to PWS through Levo Therapeutics is a positive step for development of therapeutic options for the PWS community.

Levo Therapeutics announced that it has agreed to terms to obtain worldwide rights to Carbetocin from Ferring Pharmaceuticals. Carbetocin is closely related to oxytocin and was specifically designed to have the benefits of oxytocin while limiting its potential unwanted side effects.

Ferring has completed a successful Phase II study of Carbetocin in PWS. There are three phases in drug development and Carbetocin is ready to enter the third and final stage. Carbetocin is the fastest and best chance for a therapeutic option for an oxytocin-like drug. Levo Therapeutics plans to complete its transaction with Ferring Pharmaceuticals and build financial and human resources to perform a Phase III trial with PWS. If successful, they could then be in position to seek approval from the FDA for its use in PWS.

Reports Rob Lutz, PWSA (USA) Research Chair, "Exactly how the funds we raised to support the further development of oxytocin may be best used with Carbetocin/oxytocin is being evaluated. It is clear that through our raising of substantial funds as a PWS community, we have spurred increased activity on oxytocin/Carbetocin that led to this recent announcement."

The result of that activity -- having a talented PWS mom leading the development of Carbetocin-- is a very exciting step forward!



PWS RESEARCH ADVANCES

Identification of a Novel Paternally Expressed Gene in the Prader-Willi Syndrome Region

PWS researchers **Rachel Wevrick**, **Julie A Kerns Bletz**, and **Uta Francke** have isolated a novel gene from the Prader-Willi syndrome (PWS) smallest region of deletion overlap in proximal human chromosome 15q.

Their research abstract reads, "The imprinted gene in the Prader-Willi syndrome region was isolated using the direct selection method and yeast artificial chromosomes localized to the deletion region. IPW is spliced and polyadenylated but its longest open reading frame codes



for only 45 amino acids, suggesting that it functions as an RNA, similar to H19 and XIST. The RNA is widely expressed in adult and fetal tissues and is found in the cytoplasmic fraction of human cells, which is also the case for the H19 non-translated RNA, but differs from the XIST RNA which is found predominantly in the nucleus.



Using a sequence polymorphism, exclusive expression from the paternal allele in lymphoblasts and fibroblasts was demonstrated; monoallelic expression was found in fetal tissues. IPW is located about 150 kb distal to SNRPN, the only other known gene in the deletion interval, and about 50 kb proximal to the breakpoint of a translocation which defines the distal end of the PWS region and the proximal end of the Angelman syndrome (AS) region.

As is the case with SNRPN, PWS patients with 15q11-q13 deletions do not express IPW, whereas expression is normal in Angelman syndrome patients. Lack of expression of IPW may contribute to the PWS phenotype directly. Alternatively, the mRNA product of IPW may play a role in the imprinting process, acting either on genes located proximally in the PWS region or distally in the AS region.

PWCF RUNS 5K, HALF, AND MARATHON EVENTS!

by Julie Casey, Chair, Marathon Event

More than 20,000 participated in the JetBlue Long Beach Marathon & Half Marathon and Aquarium of the Pacific 5k Walk/Run events last October and another 20,000 were in attendance as observers. Among them were 40 TeamPWCF participants, including 4 who have Prader-Willi syndrome. In addition to awareness from the TeamPWCF shirts worn by our participants, the team has raised over \$11,000 to benefit Prader-Willi California Foundation.

PWCF hosted an information booth at the Health and Fitness Expo on race weekend as well as a Finish Line Festival booth on Sunday; thousands of people passed by both of these booths throughout the weekend. We talked with hundreds of people as we passed out brochures, wristbands, temporary tattoos, water bottles and information cards all containing our website so people can learn more. Runners passed by our banner as they crossed the finish line and saw our logo listed with the other official charities in the official program.

Everyone had a great time, ending the weekend on a high knowing that they contributed toward making our vision of *A Full Life Without Limits* a reality.

Thank you and congratulations to our TeamPWCF participants:

Our 5K Participants:

Hasmukh Amarasekera
Lauren Amarasekera
Amberly Bark
Ashley Bark
Whitney Bras
Dan Casey
Julie Casey
Ryan Casey
Gail Dong
Michelle Gannon
Paul Gannon
Terry Gannon
Mercedes Hernandez
Cyndie Kelly
Kieran Kelly
Brendan Loughnane
James Meade
Jennifer Meade
David Monaghan
Jeremy Ngugi
Maria Ngugi
Melenaie Ngugi
Mari Ota
Maria Ranirez
Maribel Rivera
David Spellman
Catalina Totaro
Lindsey Wang
Tony Wang
Chris Welker
Jennifer Wolkensdorfer

Our Half Marathon Participants:

Brian Bark
Carol Bark
Kimberlee Morgan
James Ngugi
Chris Patay
Jessica Patay
Suzanne Wildley

Our Full Marathon Participants:

Rodney Dong
Robert Harris

Thank you to the volunteers who helped at the Expo and Finish Line Booths:

Amberly Bark
Ashley Bark
Brian Bark
Kasen Bras
Keith Bras
Whitney Bras
Dan Casey
Julie Casey
Emily Dame
Rodney Dong
Eddie Gonzales
Emily Gonzales
Nathan Gonzales
Sabina Gonzales
Stephanie Gonzales
Linda Smith
Jenny Wolkensdorfer

Thank You to Supporters of PWCF's jetBlue Long Beach 5K and Long Beach Marathon:

General Support

Carol & Brian Bark
Helen Charles
Jacki Lindstrom
Tom McRae
Tania Ajam in honor of
Lauren Amarasekera
Joe Leong
Amy & Richard McGuire

Supporting Whitney Bras running for Team Ryan Ramirez

Katie Basterrechea
Eric Bergstrom
Bernadette & James Bras
Andrea Bras
Misty Collosi
Sally Johnson
Brittany Kean
Patrick Lynch
Tuan Le
Colby Matranga
Heather Meurs
Amy Perkins
Diane Paris
Karen Reynolds
Melissa Williams
Sarah Williams

Supporting Julie Casey

Parisa Amiri
Deborah Benedetto

Colleen Benn
April Bennett
Patricia Casey
Scott Casey
Patricia Chapin
Melinda Chen
Wayne Collett
Jamie DeBrosse
Gregory Ferland
Brian Edwards
Peggy Einnehmer
Amy Friedman
Craig Galante
Shelley Ginsburg
Christopher Harms
Denise Haro
Hillary Hoffman
Joan Hsai
Lisa Jean
June Jeong
Pamela Kesler
Keith Kincaid
Jennifer Klein
Jason Kramer
Marie-Claire Leon
Paige Lewis
Stephanie Lutjens
Ernie Mercer
Scott Noack
Daniel Nowicki
Aaron Paquette

Donors, continued on page 13

PWCF WELCOMES NEWLY ELECTED BOARD OF DIRECTORS

Four of the six candidates who ran for a seat on PWCF's Board of Directors were elected on November 5, 2016. Each will begin serving their three year term effective January 1, 2017.



Julie Casey



Diane Kavrell



Chris Patay, Esq.



Daniela Rubin, PhD

The remaining members of the 11-member Board include Whitney Bras, Rodney Dong, Roger Goatcher, Jacki Lindstrom, Kim Morgan, Nisha Mehta, and Jennifer Wolkensdorfer. At its November 4 meeting, the Board of Directors elected its 2017 officers: Roger Goatcher, President; Kim Morgan, Vice-President; Nisha Mehta, Secretary; and Renee Tarica, Treasurer. Congratulations to each of our newly-elected Board Members and Officers!

Marathon Donors, continued from page 12



Joseph Parra
Danielle Peretz
Susan Petoyan
Ginny Popovich
Judy Ray
Kim Rory
David Shin
Natalie Song
Emmeline St. Vaughn
Eileen Thiessen
Leslie Torbert
Vivan Tran
Sharon Willis
Evan Zarider

**Supporting Rodney Dong
running for Team Kiran**

Maynadine Avelino
Olivia Avelino
Joseph Cruz
Elizabeth & Marcos Da Silva
Kristen DeBenedetto

Gordon Dong
Angela Freeland
Misa Ito
Yujeo Kang
Karen Lee
Ann Norman
Candice Tejamo

**Supporting Cyndie Kelly
running for Team Samantha**

Karen Wade

**Supporting Ruby Maestro
running for Team Julianna
2016**

Karen Ghaly
Rosie Martinez

**Supporting Jennifer Meade
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2016**

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Wilfredo Cuadros
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James Meade
Joseph Mullahey
Marnie Nathanson
Shelly & Charlie Nathanson
Gordon Voelker

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running for Team Morgan**

Lynn Abess
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Brent Dyrness
Robert Figlin
Karen Frederiksen
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Cyndie Kelly
Wanda Kowalczyk
Joe Leung
Meredity McDonald
David Monaghan
Ariane Natale

Sumanta Pal
Howard Privette
Diane Juane
Alan Scop
Steven Vickers
Jillian & Chris Welker
Eric Ziegler

**Supporting Daniela Rubin,
PhD**

Veronica Jimenez

**Supporting Jennifer
Wolkensdorfer running for
Averie 2016**

Susan Hearon
Saba Hernandez
Ellen Hudspeth
Kathy Loney
Lynda Mlynar
Sean Pudney
Naomi Smith
Kelly Yurchick

WRITING IEP GOALS

by Ruth Heitin, Ph.D., Educational Consultant

Excerpted from www.wrightslaw.com/info/goals.lesson.heitin.htm

[PWCF Education and Training Coordinator, Emily Dame, recently attended an IEP meeting where the school district's IEP coordinator tried to convince the parent that, "Teacher goals don't have to be measurable. Only related service providers' (OT, PT and speech therapists) goals have to be measurable." PWCF wants all of our families to know that all IEP goals need to be measurable so that your child's progress can be accurately assessed, or a lack of progress can receive appropriate intervention and remedy.]

Creating an IEP with a team of people who are all there to design a good educational program for one unique child can be a pleasure. It can also be very productive. When the whole team has the same level of understanding about IEPs, it is even better. Sounds like crazy talk? Just ask those who have seen it happen. The big winner here is the child.

A Lesson in Writing IEP Goals

An IEP is good educational programming. Good IEPs set the standard for good education. Each part of the IEP addresses an important part of educational planning. The IEP team focuses on the unique educational needs of an individual student. The goals reflect the child's needs. Designing well-formed goals is an important part of writing an IEP.

"How do I find examples of good IEP goals?"

Marie, the mother who asked this question, had attended several IEP meetings for her child. She did not think the goals the IEP team proposed were good. Yet, she didn't know what good IEP goals look like. If you are a teacher, you may have the same questions. Good IEPs set the standard for good teaching. Each part of the IEP addresses an important part of educational planning.

IEP goals must be individualized. Rather than relying on sample goals, you need to learn how to write IEP goals that meet the unique needs of a particular child.

Goals

We all set goals for ourselves, whether we are aware of it or not. Our goals can be as simple as getting to work on time. They can be as complex as budgeting our expenses. We know what we need to do, and we set out to do it.

An IEP goal is not unlike a personal goal. With an IEP goal, we create an educational program for a child with special needs. An IEP goal describes what we hope the child will achieve, or the **intended outcome** of instruction. The outcome is stated as an action we expect to see. Goals must be **measured** in an objective way. We have to be able to see the action or count it or score it. When we state goals clearly as actions, measuring progress comes

EXPERIMENTAL THERAPY FOR PWS LOOKS PROMISING, SAYS STUDY

Excerpted from article written by Saranya Palanisamy, Tech Times, December 2016



Activating a set of silenced genes with the help of drugs helped to improve growth and the survival of a mice model with PWS, reports a recent study.

In the study supported by the NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development, researchers used two drugs –UNC0642 and UNC0638 – to activate the silenced PWS genes in the maternal chromosome in the cells obtained from an affected person.

The research team focused on the UNC0642 drug since it displayed better pharmacological results in the mice model with PWS. Similar to infants with PWS, the PWS mice show poor growth and don't survive beyond a certain stage.

When the drug was tested in the PWS mice model, the mice were observed to have gained weight [a desired outcome in baby mice] and displayed better growth than the untreated PWS mice. And about 15 percent of the mice survived into adulthood without serious side effects.

The drugs developed by the researchers work by blocking the functions of G9a protein, which along with other proteins, keeps the maternal genetic material intact in the chromosome.

"Overall, the study shows that this type of therapy may be beneficial for treating PWS, but researchers will need to evaluate the drugs' effects on other disease symptoms, such as compulsive overeating and obesity," the researchers reported in a press release.

The study is published in the journal Nature Medicine. For a link to the article in Tech Times: <http://www.techtimes.com/articles/190540/20161231/experimental-therapy-for-rare-incurable-disease-prader-willi-syndrome-looks-promising-says-study.htm>

naturally from the goal. A goal must establish a **criterion** for acceptable mastery.

In short, when we write instructional goals we have to know what the child needs to learn and what action we want to see. We have to measure progress toward the goal. Finally, we set a level of mastery that we expect. We use standardized tests and informal assessments to measure a child's progress toward the goals. We can do tallies or checklists or give tests specific to the action we seek. Anyone who looks at the measurement should be able to understand it. And, all those who review the measurement should be able to come to the same conclusion.

IEP, continued on page 16

PWS SPECIALIST MERLIN BUTLER, M.D. RECEIVES RESEARCH AWARD



Long-time PWS researcher **Merlin Butler, M.D.** received the 2016 Chancellors Club Research Award by the Kansas University Endowment's Chancellors Club. Dr. Butler is a leading researcher in Prader-Willi syndrome and long-time chair of PWSA (USA)'s Scientific Advisory Board. He has been a faculty member at KU Medical Center since

2008 in the departments of Psychiatry and Behavioral Sciences and Pediatrics, and is also the director of the Division of Research and Genetics for the clinical department and the medical director of the Genetics Clinic.

Dr. William Gabrielli Jr., chair of the psychiatry department and a professor of psychiatry and internal medicine notes that Dr. Butler is "well-respected for his research accomplishments and in this region of the country for the genetics evaluations he provides for patients. The Department of Psychiatry and Behavioral Sciences is privileged, honored and delighted to have Dr. Butler among our faculty." She continued, "We believe that more than half of the human genome codes for brain and behavior. Understanding the genetic, epigenetic and proteomic influences on mental illness and individualized medicine will help us move into the next generation of clinical brain science and mental health care. The presence of a world-class genetic scientist in the department can help us move in this direction."

Dr. Butler has invested much of his research career in the delineation of complex genomic mechanisms, specifically in PWS and in increasing awareness to improve care for those affected with this disorder of genomic imprinting.

"What I find to be the most rewarding part of my work, and in which I am the most proud as a researcher, is the positive changes made in translational research, in treating and caring for patients with rare genetic conditions, and in being a small part of improving their quality of life and outcome," Dr. Butler said. "What we have contributed to the study of PWS has led to the discovery of new genetic principles and concepts in the field of medical genetics by the characterization of a new class of genetic defects that play a role in development, cancer and aging."

Career Highlights

Dr. Butler's research in the 1980s led to an increase in knowledge and understanding in genetics, including the cause and diagnosis of PWS. He was the first to characterize differences in chromosome staining properties in families with PWS; he found that chromosome 15 donated by the father led to chromosome deletion in the child. A similar deletion was found when the chromosome came from the mother, though it resulted in Angelman syndrome. This research led to a new discovery in genetics referred to as genomic imprinting.

He received the Lifetime Achievement Award from the Prader-Willi Syndrome Association (USA) in 2008.

Dr. Butler is prolific in publishing about his research. He has published more than 400 research articles and multiple book chapters, and he has edited several journal issues and two textbooks. Among his published works is a standardized growth chart for PWS infants and children with and without growth hormone, published in 2015 in the journal *Pediatrics*, which serves as a guideline for growth hormone treatment in PWS.

PWCF congratulates Dr. Merlin Butler.

PWCF EDUCATES REGISTERED DIETITIANS

PWCF was a vendor at Children's Hospital Orange County's *Registered Dietitians in Practice: Advancing Practice in Pediatric Nutrition – Nutrition & Endocrine Disorders* on November 12. About 150 dietitians and Certified Diabetes Educators heard information about PWS presented by PWCF dietitian consultants **Jill Nowak, R.D., CDE**, and **Leah Blalock, R.D., CSP, CDE** in its own stand-alone presentation. Every attendee had the opportunity to visit PWCF's Education Booth and receive additional information about PWS and services and supports available from PWCF.

Jill will present key nutrition strategies and tips for managing PWS for PWCF on February 23, 2017 at the **Eat Right, Future Bright!** Parent conference.

For information and to register visit www.pwcf.org or call the PWCF Office 310-372-5053.

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ED Column, continued from page 5

Coordinator; **Katherine Crawford**, Graphic Designer, **Jill Nowak-Przgodzki, R.D., CDE**, dietitian consultant; **Leah Blalock, RD, CDE**, dietitian consultant; and **Julie Casey**, webmaster.

As a member of the Prader-Willi California Foundation, you have access to an extraordinary amount of information, support, and advocacy services. All of these supports and services cost a great deal, and our income is not what we want or need it to be to sustain the services our families and professional members need. So please, renew your membership when you receive your Membership Renewal Form and give an extra donation to the extent you can. Large or small, your gift helps improve the life of someone with PWS.

Learning how to write individualized IEP goals is an important first step in developing your child's IEP. IEP goals should also be SMART and based on good **educational** practice.

SMART IEP goals are:

- Specific
- Measurable
- Use Action words
- Realistic
- Time-limited

Educational research will help you identify essential skills in the core academic subjects of reading, writing, and math. When you know the **sequence of skills** for a subject, you will know how skills build on each other. You can identify gaps in skills – skills that your child hasn't mastered and needs to learn.

Think about how children learn math. A child learns how to add and subtract. Then he is ready to learn how to multiply and divide.

Before you can develop measurable IEP goals, the child's skills must be measured objectively. Objective data about a child's skills are the baselines for goals. This data also should show progress, or lack of it, when measured over time.

We tend to use the terms "goal" and "objective" to mean the same thing. In IEPs, there is a distinction between them. We write annual goals. Objectives are the short-term steps to reach goals.

Reading

In 2000, the report of experts on the National Reading Panel explained the research in reading. This included more than 10,000 research studies. All this information helped form a better understanding of reading and what works in teaching (see www.nationalreadingpanel.org/publications/researchread.htm). The findings from the research changed reading instruction forever. In 2001, Congress passed No Child Left Behind (see www.wrightslaw.com/nclb). The results of the research were included there, too.

Reading instruction requires explicit, intensive, and systematic instruction in the five necessary components of reading instruction:

- Phonemic Awareness - the ability to hear and sequence sounds in spoken words.
- Phonics - the relationship between the letters of written language and the sounds of spoken language.
- Fluency - the ability to read text accurately and quickly.
- Vocabulary - the words students must know to communicate effectively.
- Comprehension - the ability to understand and gain meaning from what has been read.

Learning to read requires a child to learn specific skills in sequence.

Children who have difficulty learning to read have deficiencies in phonemic awareness skills. A child with weak phonemic awareness skills will have difficulty learning phonics skills. This child will not be a fluent reader. If the child does not master phonics and fluency, he will not be able to master vocabulary and reading comprehension.

One young teacher made a banner to illustrate the sequence of reading skills. This came from the specialized program she was using. As students learned a skill, she would advance them down the banner. This made it easy for her to write specific reading goals.

Math

After children master math operations skills (adding, subtracting, multiplying and dividing), they learn how to use reasoning to solve word problems.

One of my clients, Jane, had this math goal in her IEP:

Jane will use problem solving strategies to solve 2 step word problems with + and - (0 - 999) and x and division (0 - 12) on 3/4 trials.

This is NOT a good IEP goal. Why not?

The intended outcome might have been for Jane to solve two-part word problems. But this goal says she needs to learn to use **problem-solving strategies**. The goal does not state whether she will be able to solve problems. Worse, this goal includes all math operations (adding, subtracting, multiplying and dividing), making the goal overly broad.

Jane's math goal is not SMART. It is not specific or measurable. It does not use action words, and is not realistic or time-limited.

How can we revise this goal to make it SMART?

According to Jane's IEP, using objects helps her to solve problems. A better goal for Jane might be:

Using real money, Jane will be able to show how much money she has after she receives two weeks of allowance, and how much money she will have left after she buys one object, with 75 percent accuracy measured twice weekly each quarter.

Now, the goal meets the five criteria for a **SMART** IEP goal.

Writing

Achievement in written language requires many skills. Mechanics help make thoughts clear. Word usage and sentence structure help make the writing interesting. Good thought expression sends the desired message.

EMPLOYMENT OF PERSONS WITH DEVELOPMENTAL DISABILITIES IN INTEGRATED AND COMPETITIVE JOBS A MAJOR FOCUS OF STATE AND ADVOCATES

As reported by Marty Omoto of CDCAN, the Brown Administration took new steps on the issue of employment of people with developmental disabilities, with the implementation of two programs that the State hopes will lead to increased numbers of people with developmental disabilities who are employed in jobs that are competitive and in job settings that are integrated - referred to as “competitive integrated employment”.

“Competitive integrated employment” or “CIE” is defined by the State as full or part-time work for which an individual - in this case a person with developmental disabilities - who is paid the State or local minimum wage or greater in a setting with others who do not have disabilities. “Competitive integrated employment” also includes definitions by the State related to persons who are self employed, and addresses issues regarding employee benefits and overall general definition of an integrated work setting.

Last August the Department of Developmental Services (DDS) released a letter to all 21 non-profit regional centers providing instructions and information on the implementation of incentive payments to providers who provide employment services to persons with developmental disabilities, that are outcome based under person centered planning, and in jobs that are competitive and in settings that are integrated. The incentive payment program would provide an incentive payment for each individual with developmental disabilities placed in a “competitive integrated employment” setting as follows:

- Payment of \$1,000 made to a regional center funded provider providing employment services [includes supported employment providers but also *other* providers who provide other employment services funded through the regional centers] who (on or after July 1, 2016) places an individual in a job under a “competitive integrated employment” setting, and who is still employed in that job after 30 consecutive days.
- Payment of an additional \$1,250 shall be made to that service provider if that same individual remains in that job under a “competitive integrated employment” setting for 6 consecutive months.
- Payment of an additional \$1,500 shall be made to that service provider if that same person remains in that job under a “competitive integrated employment” setting for 12 consecutive months.

This incentive payment program under the Department of Developmental Services is in addition to the paid internship program for persons with developmental disabilities.

The Department of Developmental Services, headed by director Nancy Bargmann, is the state agency under the California Health and Human Services Agency, that oversees community-based services funded through the 21 non-profit regional centers. Those

21 regional centers in turn contract with local community-based organizations and individuals to provide services and supports to over 290,000 eligible children and adults with developmental disabilities. Many of those individuals also receive supports and services from other sources including In-Home Supportive

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In Jane’s IEP, her writing goal read:

Jane needs to write a paragraph, with a topic sentence and at least 4 detail sentences, on one given topic using her editing checklist measured twice monthly.

So, if Jane writes that paragraph, has she achieved that goal?

By the way it was written, the intended outcome is that Jane only “needs” to write a paragraph to meet the goal.

A better writing goal for Jane is:

Jane will write and edit a five-sentence paragraph that addresses a given subject twice a month. Each paragraph will include a topic sentence, at least four details and a conclusion. She will earn a score of 75 percent or higher on a writing rubric for each writing assignment. There will be at least four writing assignments per quarter.

Tip: Rubrics are useful scoring tools that measure a child’s progress. A writing rubric includes the criteria and standards used to assess a child’s performance on writing assignments.

The revised goal is **specific** and **measurable**. It uses **action** words, is **realistic**, and **time-limited**. The revised goal is **SMART!**



Ruth Heitin Ph.D. is a [Special Education Consultant](#) serving students with special needs and their parents – evaluating needs, consulting with families and schools, and serving as an expert witness in legal proceedings. Dr. Heitin has served as an expert witness in mediations, court trials and more than 40 due process hearings. Dr.

Heitin’s doctoral degree is in Special Education Administration. She has been certified as a general education teacher, special education teacher and elementary school principal. Ruth has been a speaker with Pete Wright in [Wrightslaw training - All About IEPs](#). She is also a contributor to the Wrightslaw newsletter, the [Special Ed Advocate](#), as well as authoring articles in other educational publications. info@educationalconsultingva.com
www.educationalconsultingva.com/

WE GET MAIL



Dear PWCF: Here is a donation from the Tomelloso family. My son, Matthew Tomelloso, has Prader-Willi syndrome. He is 5 years old and thriving and doing great in part because of your executive director Lisa Graziano and all of her help, guidance, and overall general information. You guys are an awesome organization and we really appreciate everything you do. Keep up the good work. *Thanks again, from the Tomelloso Family*

Dear PWCF: I'm happy to report that all three of us implemented what we learned today with [Student] and it stopped several tantrums from escalating. Thank you for your great insight and advice. ~ *Mary Hensley, SDC K-3, Rail Ranch Elementary, Murrieta Unified School District*

We Get Mail about the Annual State Conference

Dear PWCF: This was my first conference but it definitely won't be my last! Thank you!!

Dear PWCF: I can't tell you how much the organization means to me! I look forward to the conferences and the walks every year and I'll continue to help out for as long as you'll have me! You're definitely welcome and if you all ever need a helping hand, don't hesitate to ask! I'll always be available for you guys! *Kevin Amarasekera, sibling*

Dear PWCF: I cannot tell you how much fun we have each year supporting the individuals in the Youth and Adult Program (YAP). Each year we get to see new faces and new volunteers, interns and university students. I love it! I love mentoring and coaching! This year I have to say was by far the most fun and most engaged group of folks of all the PWS State Conferences! Not to say each year isn't fun, fun, fun! People's Care is looking forward to being part of the PWS State Conference again next year - it will be our fifth (5th) year! Count us in! Our People's Care Team and residents...enjoyed the conference and we all had a fabulous time! Please send my warmest regards to Lisa [Graziano] and her amazing husband [TJ] and son Cam! We missed Cam this year! Lastly, I want you, Lisa and Roger [Goatcher] to know that I am humbled and so excited to have received the President's Award! That was awesome! ... Thank you Emily for being an inspiration to us and the PWS community and for all that you do for the California PWS Foundation! You are truly a gem! Keep shining bright! *Thank you and all my best, Barbara Nguyen, People's Care*

Dear PWCF: I am so proud to be a part of the Foundation and will continue to dedicate myself to the annual conferences! Looking forward to working with you again! *Best, Ben Romero*

Dear PWCF: Thank you very much for your sharing your program. I am glad it was very successful because of your preparation, and volunteers cheering, and OMG!!!! Hayley [Kavrell] did an amazing job [assisting with Zumba class]. Each individual was a super star and they expressed themselves and shared their smiles and energy. I just loved them all. Congratulations [on the] Youth & Adult Program 2016 "JUNGLE BOOGIE". *With a lot of loves, hubs, and xxxxxx, Rika Matsuda, PT and Zumba instructor*

Dear PWCF: I had such a fun time volunteering at the event and I hope in the future there will be more opportunities that students can participate in. It was such a wonderful learning opportunity. Many of the volunteers who also participated in the event gave me feedback about how much fun they had and that they too learned a lot. The team leaders who were directing all the volunteers were excellent and incredibly helpful. Thanks a million as well for all your hard work! *Sincerely, Amy Gore, student at CSU Sacramento*

Dear PWCF: I'm soooooo happy I had to opportunity to participate [in the Youth & Adult Program] again this year. I'll be more than happy to be there again next year! I want to thank you for being so awesome during the event! You are the REAL pro of the event...truly inspirational. Count me in for next year!! I can't imagine not being there. *Nanny Sanchez, People's Care*

Dear PWCF: Thank you for putting [the Youth & Adult Program] together; it was amazingly fun and an awesome opportunity to learn about the PWS population! *Emily Jeffery, CSU Sacramento student volunteer*

Employment, continued from page 17

Services (IHSS), Medi-Cal (for health benefits), Community-Based Adult Services, SSI/SSP grants (Supplemental Security Income/State Supplemental Payment), special education, mental health services and more. For more information, contact the Department of Developmental Services, Denyse Curtright at (916) 654-2208, or by email at denyse.curtright@dds.ca.gov

“Blueprint” for CIE to be released for Public Comment Soon

Though not specifically tied to either new employment program, the Brown Administration has been working on a “blueprint” that would outline how the State’s major agencies dealing with the employment of persons with developmental disabilities will coordinate efforts toward “competitive integrated employment”. The blueprint links three agencies – the Department of Developmental Services, the Department of Rehabilitation and the California Department of Education – in a process facilitated by the California Health and Human Services Agency in partnership with Disability Rights California (DRC). A draft final blueprint document is expected to be released for public review and comment possibly by the end of this month or by September. CDCAN will provide a full report on that blueprint when it is released. For a link to the webpage on the blueprint on the California Health and Human Services Agency website go to: [http://www.chhs.ca.gov/Pages/Competitive-Integrated-Employment-\(CIE\).aspx](http://www.chhs.ca.gov/Pages/Competitive-Integrated-Employment-(CIE).aspx)

Issue of “Competitive Integrated Employment” Strongly Supported by Many but Raises Concerns Among Some People

While the overall issue of employment of persons with developmental disabilities is strongly supported by most people, including policymakers of both parties, the specific ideas or proposals on how that is to be accomplished has exposed some fault lines between some people with developmental disabilities and families, providers and others who want to maintain current ways that provide employment including site-based settings and sub-minimum wage pay and volunteer work, and other persons with developmental disabilities and their families, providers and others who are pushing and have pushed for jobs and careers that are competitive and integrated work settings that pay minimum wage.

Employment Issue Linked to Larger Changes Federal Government is Requiring States to Implement

The overall and specific employment issue is also linked to larger changes under major new federal rules that requires all states to implement in order to continue receiving Medicaid Home and Community Based Services (HCBS) federal matching funds. In California those federal matching Medicaid dollars (called “Medi-Cal” in California) fund a wide range of programs, services and supports for children and adults with disabilities – including developmental, seniors and others including In-Home Supportive Services (IHSS), most regional center community-based services, Community-Based Adult Services and the Multi-purpose Senior Seniors Program (MSSP). States have until March 2019 to fully comply – though that date is sooner for any new programs that a state wants funded through those Medicaid dollars, such as California’s “Self Determination Program” that is still pending approval by the federal government.

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.

New Individual Members

Trisha Varriello

New Family Members

Julie Wong & Jeff Dolph

Renewed Individual Members

Cheryl Richmond

Renewed Family Members

Carol & Tom La Bossiere

Renewed Extended Family Members

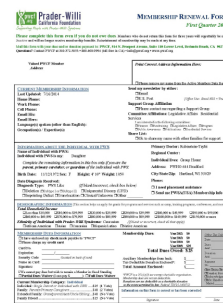
Linda & Stephen Hedstrom
Erin Phillips

Renewed Family Friend Members

Andrew Cantos

Renewed Professional Members

June-Anne Gold, M.D.
Ally Leonard, Rhythm Pharmaceuticals
Ashley Phelps-Leak, Lee Street Homes



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!

PWCF expresses our appreciation to:

• **Dominique Ginyard** for being a part of the panel, along with **Lisa Graziano** and **Emily Dame**, to educate over 30 neurodevelopmental professionals about PWS at Children’s Hospital Los Angeles

• **Angela Lucero** and **Cindy Bastidas** for volunteering to prepare the Annual State Conference packets and do a little office work too!

• For helping to review translations of articles into other languages, PWCF is grateful to:

- **Carina Chaij**
- **Charon Chen**
- **Giorgio Fornasier**
- **Marie-France Nausbaum**
- **Polly Tsai**
- **Diana Vega**

VOLUNTEERS
are **Priceless**

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

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Sirius (\$1000 or more)

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Willie Hinson in honor of Terry Hinson
Nancy & John Jenkins in honor of Cameron Graziano
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Peter Steinhart

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