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A Magical Night with Tyrone Wells



Past Board members **Jessica and Chris Patay** are big fans of **Tyrone Wells**. So after attending one of his concerts earlier in the year they thought how wonderful it would be for Tyrone to be a part of a PWCF event. So Jessica sent Tyrone an email, not *really* expecting him to answer but thinking it would be a good place to start. Tyrone being the kind of amazing man he is, sent Jessica an email reply straight away saying he'd be *quite* interested in doing a benefit concert and put the couple in touch with his manager.

A few months later, with stately trees and greenery that is the Patay's beautiful backyard as his backdrop, Tyrone treated fifty fortunate people to the most intimate and magical concert each had probably *ever* previously experienced. It truly was a magical night.

The concert raised over \$14,000 to support PWCF! Jessica and Chris remind us how much just *one* family can do to raise awareness of PWS and funds to support PWCF's critical programs and services. **Thank you, Jessica and Chris, for all of your support of persons with PWS!**



See page 3 for Tyrone Wells Benefit Concert Donors

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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
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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
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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 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: 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: 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 EXPERT

Dear PWS Expert: "We just currently had to do surgery to remove a very large cyst on our daughter's ovary (7"). It looks benign so that's good. But at age 15, it seems unusual. Ever heard of other girls having this?"

Kathy Clark, PWSA (USA)'s Medical Affairs Coordinator, responds: Many young women with PWS do not have normal pituitary release of LH and FSH (gonadotropins) which are responsible for developing an egg with a follicle (which can turn into a cyst). These aren't unusual in any teen girl. Since so many girls with PWS have spontaneous puberty, and some periods, many doctors assume the system is working but perhaps sluggish. Taking an oral contraceptive pill would shut off LH and FSH and prevent cyst formation. It would be wise to see an OBGYN if the endo is uncertain.

Pills can be given so there are no periods – periods are not "necessary" – but estrogen is needed. Taking estrogen stops the natural production of LH and FSH – so no egg, no cyst. If the LH and FSH balance is off, the poor follicle just grows bigger.

For more information you can go to:
www.healthline.com/health/follicular-cyst#Causes3

THANK-YOU TO TYRONE WELLS BENEFIT CONCERT DONORS!

Jacqueline Cameron	Jessica & Chris Patay
Annette Castagna	Joyce & Gabriel Patay
Cathleen Daniel	Tracy Patay
Sheri Eaton	Danielle Peretz
Melissa Fry	Jim Porter
Beverly & Dominic Ginyard	Linda & Mark Ryan
Stefani Goldenberg	Julie Sampras
Lisa & TJ Graziano	Jen Smith
Hansen Family Foundation	Jocelyn & Patrick Stuart
Kirsten Hanson	Krista Thorrington
Leah Hutchison	Monique & Peter Thorrington
Estelle Iuno	Lorrie Tom
Karen Klabouch	Kathleen & Lee Tomlinson
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Bonnie & Justin McCarthy	Jeannette Wagner
Nisha & Minesh Mehta	Arnold Wensinger
Tanya Monaghan	Suzanne Wildey
Adrienne & Steven Patay	



UNDERSTANDING COENZYME Q-10: UBIQUINONE VS. UBIQUINOL

by Meghan Lyons, MS



[Coenzyme Q10 \(CoQ10\)](#) is a fat-soluble, vitamin-like compound produced naturally by our bodies. Found in nearly every cell in the body, CoQ10 is concentrated in organs that require the most energy — such as the heart, liver, muscles and kidneys. CoQ10 is concentrated in these organs because it is essential to the process of producing cellular energy from the food you eat.

Ubiquinone vs. Ubiquinol

In the body, CoQ10 exists either in its oxidized form, ubiquinone, or in its reduced form, [ubiquinol](#). When oxidized CoQ10 (ubiquinone) is used by the body, it transforms and becomes ubiquinol. In the same way, reduced CoQ10 (ubiquinol) becomes ubiquinone when it carries out its role in the body.

To better understand how this works, let's take a look at CoQ10 and cellular energy production. CoQ10 is found inside the powerhouses of cells called the mitochondria, the site where energy production occurs. It acts as an electron acceptor or donor in the chain of reactions that lead to energy production. When oxidized CoQ10

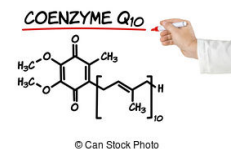
(ubiquinone) accepts an electron from another molecule in the chain, it becomes reduced (ubiquinol) and when reduced CoQ10 (ubiquinol) donates an electron, it becomes oxidized (ubiquinone). Maintaining this state of equilibrium is how the body benefits from CoQ10.

CoQ10 Supplements

Regardless of what form of CoQ10 you take as a supplement, the body is able to convert the consumed form to the other form as needed. In other words, if you take a reduced CoQ10 supplement (ubiquinol), the body can convert the reduced CoQ10 (ubiquinol) to the oxidized CoQ10 (ubiquinone) and vice versa. This conversion takes place to maintain a state of equilibrium between reduced CoQ10 (ubiquinol) and oxidized CoQ10 (ubiquinone).

The Bottom Line

Unquestionably, both forms — ubiquinone and ubiquinol — are effective and essential to important pathways in the body, and in states of need, either form can be reduced or oxidized to form the other.



FOOD TIP: GG SCANDINAVIAN BRAN CRISPBREAD

Shared by June-Anne Gold, M.D. and submitted by Beverly Ginyard



- Excellent source of fiber - 4g of fiber per serving
- 2g net carbs per serving
- 2 crackers is 50 calories
- Fat free, low sodium

GG Scandinavian Bran Crispbread is a low carb, high fiber appetite control cracker that quickly absorbs more moisture and satisfies you more completely than any other bran product. Prepared from 85% unprocessed bran, with rye flour and water added, the batter is slowly baked over a twelve-hour period. The moisture is evaporated, leaving a crisp, flavorful, thick cracker containing 85% bran. GG Scandinavian Bran Crispbread are delicious with any topping and can be used in place of regular bread in sandwiches or snacks. Available at GG Products at 855-507-7442, at Smile.Amazon.co, and soon at retail stores.

GADGET TIP: BED BUDDY MICROWAVE HEAT-PACK

Submitted by Katherine Crawford



This gadget tip goes out to all the parents out there who could use a bit of relaxation on the go. Microwavable heat packs all follow the same basic premise: fabric surrounding some microwavable contents, such as rice or lentils. There are many microwavable heat packs available, but I like this Bed Buddy's in particular. Bed Buddy's design is small enough to fit into any style microwave, big enough to do the job, and has a nice distribution of weight - and weight can also be calming.

If you're feeling crafty, microwavable neck wraps are simple to make, feel great, and are inexpensive too. I've made several, and they work just as well as Bed Buddy's. A basic version can be made by sewing together two rectangles of fabric (or one rectangle folded over) in the size neck warmer you want. Then, fill with desired filling. Lentils are great if you like a smooth, bead-like consistency. Rice smells lovely. Corn (not popcorn, mind you!) has a unique texture worth trying as well. For a cold pack, place in freezer.

PWCF AWARDED \$1000 AFTER NOMINATION BY PWCF MEMBER



Thanks to PWCF Extended Family Member **Donna Franco**, PWCF was awarded \$1,000 in the Home Shopping Network Cares \$1,000 A Day Giveaway!

Wrote Andrea Masterson of HSN Cares, "At HSN we believe that, to achieve great things, you must be courageous, curious and open to collaboration. **Dedication to your mission and collaboration among those you serve was beautifully highlighted in [Donna Franco's] submission.** Courage and curiosity are about willingness [to] learn and take action for something that you believe in – something that comes from the heart."

**Thank you, Donna Franco,
for your nomination and support of PWCF!**



EXECUTIVE DIRECTOR'S COLUMN

by Lisa Graziano, M. A.



The first order of business is to apologize to all of our members and readers for the tardiness of this edition of the *PWCF News*. Due to circumstances of the klutziness kind, I injured myself early in July and lost total use of my left arm for many weeks. Only recently have I been able to type with any degree of speed, and so newsletter articles have languished in my brain or remained unedited in the computer without benefit

of having our newsletter graphic designer (Katherine Crawford) morph them into our wonderful newsletter format.

As every one of you whose ever been seriously injured or ‘down’ for any period of time knows, neither time nor the deluge of daily responsibilities slows just because *we’re* down. As the accumulated demands of family, home and work escalate, so does the experience of stress. In a serendipitous stroke of good fortune, I recently attended a conference that featured psychologist Gregory Lester, PhD who announced, “traditional stress management methods don’t work for mental health providers, but here’s something that does.” Now *that* got my attention! And as I listened, a significant portion of what he presented began to resonate with the kind of stressors that parents and care providers of someone with PWS experience. If your past quarter of the year has been as action-packed with stressors as PWCF’s has with our huge awareness, support, and educational activities and events, and as *we’re all* heading into the homestretch of the year and all the holiday stressors *that* usually brings, I thought it appropriate to devote this issue’s column on sharing new ways of thinking about stress and managing it.

As a backdrop: the term “stress” as it’s currently used was first coined by endocrinologist Hans Selye in 1936, whose stress model was based on physiology and psychobiology. He defined stress as “the non-specific response of the body to any demand for change.” In its original meaning, stress was never a *bad* thing. Indeed, wrote Dr. Selye, “*Man should not try to avoid stress any more than he would shun food, love or exercise.*” So it appears it’s not stress we should avoid, the real culprit is *distress*; distress being defined as extreme anxiety, sorrow, or pain.

Everything biological is wired to survive first and foremost. All objectives and all other goals take a back seat to survival. All biological things are driven to survive in the physical world. Human beings are driven to survive in both the physical world *and* the conceptual world.

In the primitive conceptual world, “right” means survival and “wrong” means loss of life. Survival in the conceptual world means we are “right” not “wrong”. (Ever notice that most people with PWS simply cannot admit to being wrong or to making a

mistake? To someone with PWS, “right” and “wrong” are tantamount to their literal “life” or “death” which is probably why saying “You might be right” is such an effective de-escalation.) Like effective psychotherapists who must unrelentingly generate positive behavior in the face of things always being “wrong” with our patients, PWS requires us as parents and care providers to unrelentingly generate positive behaviors in the face of things always being on the verge of “wrong” in the mind of our loved one. Similar to keeping going in battle, purports Dr. Lester, this psychologically and neurologically depletes one.

Add to this the experience of having no control but shouldering all the responsibility for our patient - or our loved one with PWS – we are left feeling helpless, and chronic helplessness depletes us and results in our feeling exhausted, hollowed out, empty.

Finally, where there is no resolution or closure, which is frequently the case for professional care providers whose patients terminate before our work is “done”, we eventually become literally depleted of emotional energy. For parents and providers, where there is frequently a never-ending closure of needs, we end up being depleted of emotional energy.

The problem with stress/distress is that it depletes us of energy, morale, and enthusiasm. Traditional stress management strategies are ineffective, asserts Dr. Lester, because they don’t *replenish depleted energy*. But how can we replenish our energy?

Our frontal lobes expend energy when we plan, think, organize, try to manage or fix what’s “wrong”. At the end of a day, we need to rest our frontal lobes! Resting one’s frontal lobes lowers cortisol levels. **Here’s how we rest our frontal lobes:**

Stop thinking! Anything that doesn’t require a lot of thought is good. Engage in activity that is mindless, repetitive, and doesn’t require a whole lot of thinking. Do anything that uses your hands: knit, crochet, do a puzzle, cook (if you enjoy cooking). And my personal favorite mindless lobe-resting activity: watch tv!

Get things off your mind. Talk with someone who will just listen. It’s important to be able to vent with someone. No problem solving! Put into language what you’re experiencing, struggling with. If you can’t *talk* it out of your brain, *write* it out of your brain. Simply putting our thoughts and feelings onto paper gets them out of our brain, diminishes neuronal activity, and reduces distress.

Sleep. The brain takes the energy we’d normally use during consciousness and turns it into reparative activities when we sleep. So the old adage that things become clearer when we “sleep on it” is absolutely true!

Executive Director’s Column continued on page 17

SOCIAL SECURITY DISABILITY BENEFITS & PRADER-WILLI SYNDROME

by Deanna Power

Adults and children living with PWS typically require extensive therapy and constant supervision. Individuals with PWS and their family may be eligible to receive financial assistance in the form of Supplemental Security Administration (SSA) benefits, which can help manage the expenses associated with managing the syndrome.

What Disability Benefits Are Available?

The Social Security Administration defines disability as a severe impairment that is expected to last at least a year or end in death. It has two disability programs that provide financial assistance to people with recognized physical or mental impairments. The required medical criteria are the same in both cases, but each program addresses the needs of a different applicant profile.

- **Social Security Disability Insurance (SSDI):** This program pays monthly benefits to disabled workers. To qualify, you must have worked for a specified period of time and paid Social Security taxes. For this reason, SSDI is often referred to as the “worker’s disability” program. If your loved one’s PWS is a result of brain surgery or trauma, you’d likely qualify for SSDI.
- **Supplemental Security Income (SSI):** SSI is designed to help those with limited assets and financial resources, such as children and the elderly. In order to qualify for SSI, your monthly income must be under a certain amount established by the SSA. With child applicants, the SSA will evaluate their parents’ income to determine eligibility. Once the child turns 18, he or she may apply to continue receiving benefits on their own. Most people born with PWS will need to apply for SSI.

Medically Qualifying for Disability Benefits with PWS

The SSA’s listing of disabling impairments is also known as the Social Security “Blue Book.” To be considered disabled, you must meet one of its listings. Because the Blue Book does not specifically reference Prader-Willi syndrome, applicants will have to meet a listing associated with their symptoms. For example, children could qualify under one of the following:

- [100.00](#)-Low Birth Weight and Failure to Thrive
- [102.00](#)-Special Senses and Speech
- [110.08](#)-Catastrophic Congenital Disorder
- [112.02](#)-Organic Mental Disorder
- [112.05](#)-Intellectual Disabilities
- [112.08](#)-Personality Disorders

The application must be accompanied by medical documentation confirming that you (or your child) have been diagnosed with the condition in question. For example, if the application was being made under listing 112.08-Personality Disorders, the SSA will want to see evidence that the symptoms are being experienced to a debilitating extent.

Examples of required documentation include:

- Psychological or developmental test results
- Medical evidence of specific psychological impairments, such as abnormalities of behavior, thought, mood or development

Your doctor will complete a residual functional capacity (RFC) form, which the SSA will use to determine how Prader-Willi syndrome has impacted your ability to function. For adults, the SSA requires evidence that the condition has left you unable to work full-time (without the need for frequent rest breaks) at jobs that you are trained and qualified for.

Adults with Prader-Willi syndrome may have difficulty walking or accomplishing daily tasks such as dressing, bathing, cleaning their house, etc. and require intense supervision during preparation and clean up of meals. Their RFC will likely indicate that holding down a full-time job would be impossible for them. With children, the RFC is used to evaluate the extent that PWS has impaired their ability to do age-appropriate activities, such as go to school and play.

For more information about SSA disability benefits and how to apply when your loved one has Prader-Willi syndrome, go to the Social Security Administration’s website, visit your nearest SSA office, or call the SSA toll-free at 1-800-772-1213. Contact the PWCF Office for documentation about Prader-Willi syndrome that you can submit with your application and physician’s letter(s). It is highly recommended that you mail your application and accompanying documents to the SSA instead of applying online. Documentation about what PWS is and why it keeps your loved one from being able to maintain gainful employment is absolutely critical and difficult to impossible to do online.

Living with Prader-Willi syndrome is challenging. Regular cash benefits and access to affordable medical care can help improve the quality of life of everyone in your family.



The best way out is always
through.

~ Robert Frost

PWCF BOARD MEMBERS RAISE AWARENESS IN THE MEDIA

PWCF Board members **Daniela Rubin, Ph.D.** and **Diane Kavrell** have been busy raising the public's awareness of PWS.

In July Dr. Rubin was interviewed for an article that appeared in



the Orange County Register about the importance of a physically active lifestyle. She provided readers with important information about PWS. Dr. Rubin is an associate professor of kinesiology at CSUF and has been leading a federally funded research program on PWS and childhood obesity at CSUF since 2008.

<http://www.ocregister.com/articles/children-722979-rubin-parents.html>

Diane Kavrell was interviewed for an article that appeared in the Sacramento Bee in which she shares her family's story.

<http://www.sacbee.com/news/local/health-and-medicine/article94382222.html>

"No one gives you a parenting book that tells you do this, this and this," Kavrell said. "It's the same thing with special needs: No one gives you a book that tells you how to be a special-needs parent." Having recently started a support group in the Sacramento area, Diane knows that being a part of a PWS Support group means, "You don't feel alone and isolated." She added, "It's invaluable because you can look and see how other people are managing. Sometimes it's good and sometimes you just need to cry with someone."

Kavrell said she hopes that by continuing to spread awareness, children never before diagnosed will come forward and be correctly diagnosed. She and the other families will be there to help.

"It's a really good feeling to know that I can help somebody," Kavrell said. Helping one "somebody" at a time is what Diane and Dr. Rubin are doing every day, and PWCF is grateful for their work to educate the public about PWS.



HEALTHBRIDGE CLOSES PRADER-WILLI SYNDROME PROGRAM

Sadly, the PWS Program at HealthBridge Children's Hospital in Houston closed its doors. An announcement came in August from John W. Cassidy, MD and Erin Cassidy, MSN, "For the past 5 years HealthBridge Children's Hospital in Houston PWS Inpatient Unit has helped children with Prader-Willi syndrome (PWS) and their families reach goals that have improved their health and overall quality of life. HealthBridge has served numerous children over this period of time, and has made a positive and lasting impact on the lives of patients and their families.

"Current pressures in today's health care environment now preclude us from maintaining a program of excellence. Thereby, we have been forced to make the difficult decision to close the program rather than compromise care. Nevertheless, we will

continue to meet the needs of the community and the children who need specialty hospital care in our Brain Injury and other post-acute care programs, which are the core competencies of Nexus Health Systems.

"The program will complete the care of our current patients and prepare them to transition to home or to the family's placement of choice. When that mission is complete and the last patient is discharged the program will formally close. However, during this final phase of closure we cannot accept any new admissions. Yet, even though the program will no longer be part of HealthBridge Children's Hospital, the legacy of the program will live in the hearts of all whose lives were enriched over the years."

10 THINGS YOU SHOULD KNOW ABOUT ABLE



In December 2014 the Stephen Beck, Jr., Achieving a Better Life Experience Act (ABLE Act) won final congressional approval and was signed into law by President Obama. The enactment of the ABLE Act culminated an eight-year campaign to gain approval for tax-free savings accounts to help individuals and families finance disability needs.

The ABLE Act is built on the foundation of the current 529 education savings plans that help families save for college. In the case of ABLE, families now have a tax-deferred savings vehicle to save for the care of people with disabilities.

1. What is an ABLE account? ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families, will be created as a result of the passage of the Stephen Beck Jr., Achieving a Better Life Experience Act of 2014 or better known as the ABLE Act. The beneficiary of the account is the account owner, and income earned by the accounts will not be taxed. Contributions to the account made by any person (the account beneficiary, family and friends) will be made using post-taxed dollars and will not be tax deductible, although some states may allow for state income tax deductions for contribution made to an ABLE account.

2. Why the need for ABLE accounts? Millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care and food and housing assistance. Eligibility for these public benefits (SSI, SNAP, Medicaid/Medi-Cal) require meeting a means or resource test that limits eligibility to individuals to report more than \$2,000 in cash savings, retirement funds and other items of significant value. To remain eligible for these public benefits, an individual must remain poor. For the first time in public policy, the ABLE Act recognizes the extra and significant costs of living with a disability. These include costs, related to raising a child with significant disabilities or a working age adult with disabilities, for accessible housing and transportation, personal assistance services, assistive technology and health care not covered by insurance, Medicaid/Medi-Cal or Medicare.

For the first time, eligible individuals and their families will be allowed to establish ABLE savings accounts that will not affect their eligibility for SSI, Medicaid/Medi-Cal and other public benefits. The legislation explains further that an ABLE account will, with private savings, “secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Medicaid [Medi-Cal], SSI, the beneficiary’s employment and other sources.”

3. Am I eligible for an ABLE account? The ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If you meet this age criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI, but still meet the age of onset disability requirement, you could still be eligible to open an ABLE account if you meet Social Security’s definition and criteria regarding significant functional limitations and receive a letter of certification from a licensed physician. You need not be under the age of 26 to be eligible for an ABLE account. You could be over the age of 26, but must have had an age of onset before the individual’s 26th birthday.

4. Are there limits to how much money can be put in an ABLE account? The total annual contributions by all participating individuals, including family and friends, for a single tax year is \$14,000. The amount may be adjusted periodically to account for inflation. Under current tax law, \$14,000 is the maximum amount that individuals can make as a gift to someone else and not report the gift to the IRS (gift tax exclusion). The total limit over time that could be made to an ABLE account will be subject to the individual state and their limit for education-related 529 savings accounts. Many states have set this limit at more than \$300,000 per plan. However, for individuals with disabilities who are recipients of SSI, the ABLE Act sets some further limitations. The first \$100,000 in ABLE accounts would be exempted from the SSI \$2,000 individual resource limit. If and when an ABLE account exceeds \$100,000, the beneficiary’s SSI cash benefit would be suspended until such time as the account falls back below \$100,000. It is important to note that while the beneficiary’s eligibility for the SSI cash benefit is suspended, this has no effect on their ability to receive or be eligible to receive medical assistance through Medicaid.

Additionally, upon the death of the beneficiary the state in which the beneficiary lived may file a claim to all or a portion of the funds in the account equal to the amount in which the state spent on the beneficiary through their state Medicaid/Medi-Cal program. This is commonly known as the “Medicaid Pay-Back” provision and the claim could recoup Medicaid/Medi-Cal related expenses from the time the account was open.

5. Which expenses are allowed by ABLE accounts? A “qualified disability expense” means any expense related to the designated beneficiary as a result of living a life with disabilities. These may include education, housing,

10 THINGS YOU SHOULD KNOW ABOUT ABLE, CONTINUED

transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative services and other expenses which help improve health, independence, and/or quality of life.

- 6. Can I have more than one ABLE account?** No. The ABLE Act limits the opportunity to one ABLE account per eligible individual.
- 7. Do I have to wait for my state to establish a program before opening an account?** No. While the original law passed in 2014 did stipulate that an individual had to open an account in their state of residency, this provision was eliminated by Congress in 2015. This means that regardless of where you might live and whether or not your state has decided to establish an ABLE program, you are free to enroll in any state's program provided that the program is accepting out of state residents.

To determine which state ABLE programs are accepting out of state programs, please refer to the individual state pages. Examples of state ABLE programs accepting enrollment nationwide include: Ohio, Nebraska, and Tennessee. An example of a state ABLE program only accepting in-state residents would include the Florida ABLE United program.

- 8. Will states offer options to invest the savings contributed to an ABLE account?** Like state 529 college savings plans, states are likely to offer qualified individuals and families multiple options to establish ABLE accounts with varied investment strategies. Each individual and family will need to project possible future needs and costs over time, and to assess their risk tolerance for possible future investment strategies to grow their savings. Account contributors or designated beneficiaries are limited, by the ABLE Act, to change the way their money is invested in the account up to two times per year.
- 9. How is an ABLE account different than a special needs or pooled trust?** An ABLE Account will provide more choice and control for the beneficiary and family. Cost of establishing an account will likely be considerably less than either a Special Needs Trust (SNT) or Pooled Income Trust. With an ABLE account, account owners will have the ability to control their funds and, if circumstances change, still have other options available to them. Determining which option is the most appropriate will depend upon individual circumstances. For many families, the ABLE account will be a significant and viable option in addition to, rather than instead of, a Trust program. For more information, the webinar on

[ABLE Accounts, Trusts, Financial and Benefits Planning](#) is archived on our website along with its slides and transcript.

- 10. How Will I know Which State ABLE Program is Right for Me?** By the Summer of 2016, we expect that several states will have opened ABLE programs and be inviting eligible individuals nationwide to open an ABLE account regardless of their state of residence. When comparing State ABLE programs you may want to consider the following questions in order to find a program that best meets your needs:

Opening an Account

- What proof will the ABLE program require for you to document in order to open an account or show that your disbursements are qualified expenses?
- Is there a minimum contribution to open an ABLE account?
- Is there a fee to open an account and, if so, how much is that fee?

Maintaining the Account and Fees

- Is there a required minimum contribution to your account? If so, what is the amount?
- Are the fees front end loaded or are they reduced if you leave your funds invested for several years?
- Are there restrictions on how often you can withdraw funds from your account?

Investment Opportunities

- What are the investment options the state ABLE program offers?
- Are the options likely to meet your needs for limiting risk with the growth of your contributed dollars to the ABLE account?
- Does the program offer any unique or value added program elements to help you save, contribute to your account, grow the account, and manage your invested dollars?
- Does the state program offer any unique or value added program elements (such as a match or rewards program, financial literacy info or program for beneficiaries) to help you save, contribute to your account, grow the account, and manage your invested dollars? If so, what is it?

Unique to Your State

- Does your state have a program and, if so, do they offer a state income tax for contributions to their account?
- Is there a "debit card/purchasing card" available with the program? Are there added costs to this?

For a more detailed understanding of how you can begin to comparing programs and things to think about when preparing to opening an ABLE account, go to <http://ablenrc.org/about/becoming-able-ready>

INDICES OF ADIPOSITY BY WEIGHT STATUS IN CHILDREN WITH AND WITHOUT PWS

Diobel M. Castner¹, Daniel A. Judelson, FACSMI, Jessica G. McGarrah²,

Marilyn C. Dumont-Driscoll², Daniela A. Rubin, FACSM¹

Weight management is critical in PWS. Tracking an individual's body mass index (BMI) is one method used to ensure one maintains a desirable weight. How exactly does BMI do this? In children, $BMI = \text{weight in kg} / [(\text{height in cm})^2]$. In children, growth charts are used to identify BMI percentile for age and sex based on the calculated BMI. The BMI percentile is then used to classify the child into one of four weight statuses: underweight, healthy weight, overweight and obese. Therefore, the focus is often on making shifts from the overweight and obese weight status categories to achieving a healthy weight! While useful, BMI does not tell the entire story.

BMI tracking is frequently used to help people maintain a healthy weight, but is it a good measure for individuals with Prader-Willi syndrome?

BMI is not particularly sensitive to changes in body composition (i.e., fat mass versus lean mass [muscle]). This is especially tricky in children with PWS, who typically present with increased fat mass and decreased lean mass. So, a child with high fat mass and low lean mass can be the same weight as a child with low fat mass and high lean mass. To remember is that a pound is still a pound, but the composition may differ.

While BMI tracking is practical and feasible in the clinical practice, BMI may not be a good estimate of body fat in PWS. The underlying question here is "Does a child with PWS, who is classified as being healthy weight based on their calculated BMI, still have high amounts of body fat? What about with regards to waist circumference?"

We thus compared how other tools, like waist circumference (WC), and body fat (BF%) measurements compared to weight status charts using BMI. We studied 35 children with PWS and 120 children without PWS, ages 8 to 12 years old, and classified them into BMI weight status categories (i.e., healthy, overweight or obese). For each BMI weight status category, children with and without PWS had a similar waist circumference. However, body fat was always higher in children with PWS compared to controls, regardless of the BMI weight status.

When looking at the weight status charts, BMI underestimated body fat levels compared to the WC and BF% charts. This occurred in children with PWS who were classified as being healthy weight and overweight for BMI. Specifically, in those who presented with a healthy BMI, 29% were actually considered overweight when using the WC chart and 75% were classified as overweight/obese

when using the BF% chart. Moreover, in PWS children with an overweight BMI, 17% were identified as being obese based on the WC chart and 100% actually were classified as obese using the BF% chart.

Children without PWS also showed disagreement between the BMI weight status chart and the WC and BF% charts, particularly in the overweight BMI weight status. Of those who were overweight for BMI, 50% were identified as obese using the WC chart and all overweight BMI children were classified as obese based on the BF% chart.

In summary, the BMI weight status chart underestimated body fat levels in children with PWS who were classified as being healthy weight or overweight for BMI. More research needs to be done to identify other surrogates of body fat that may better fit the body fat in children with PWS. Based on these findings, it is important to not accept changes in BMI at face value. It is critical to maintain a strict diet and regular physical activity participation to maintain a healthy weight and improve body composition.

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Diobel Castner won PWCF's 2016 Promising Scholar Travel Scholarship.



PWS CAMPS: FEATURING CAMP PAIVIKA'S DEBUT!

Having Fun and Making Friends, California Style

EASTER SEALS CAMP HARMON

This summer, for the first time ever, Prader-Willi California Foundation provided *two* PWS exclusive summer camps!

The first camp session was held in July at **Easter Seals Camp Harmon**, located in the beautiful Santa Cruz Mountains. About fifty six campers enjoyed six sunny days as they swam in the heated pool, made in arts and craft projects, ran hard during sports and games, dressed up for the talent show, played with the menagerie of farm animals, putt putt golfed, and rode a horse, just to name a few of the fun-filled activities. Wrote one parent on her evaluation form about her 19 year old son's experience, *"He came home extremely happy, joyful, and fulfilled. He showed a new air of confidence (this was his first time away from home). He had matured some. He was more relaxed. He was proud."* In another 10 year old camper's own words, *"I made great friends. We had things in common. We had an awesome time."* Equally as important as our campers' experience at camp is our families' experience of some rejuvenating respite. Wrote one mom, *"It was a nice vacation/break for the entire family. My husband and I had a chance to reflect, relax, and reconnect with each other. You could say it was 'refreshing'... In the end, we all had a renewed appreciation for one another. I feel that camp gave us the opportunity to grow even closer as a family."*



ABILITY FIRST CAMP PAIVIKA

The second camp session was held in August at **Ability First Camp Paivika**, nestled in the beautiful San Bernardino Mountains. Thirty campers participated in horseback riding, sports and games, drama, arts and crafts, talent show, a luau dance, and a daily dip in the pool. Though there were considerable bumps throughout the six day stay, most campers had lots of fun. Wrote one camper on his evaluation form, *"It was a lot of fun!"* while his parents shared, *"It did benefit us. [My husband] and I had four full days to relax and do some fun things... we had opportunity to spend significant time together [which] does not happen often."*



We are working to develop our 2017 camp session(s). PWCF remains committed to ensuring our PWS Camps always provide a food-safe, low-anxiety environment, with compassionate PWS-trained counselors so that all of our campers enjoy their camp experience and families enjoy some worry-free respite.

WALKING FOR PWS IN NORTHERN CALIFORNIA



The morning fog dissolved early on June 26 to reveal clear blue skies and a warm, welcoming sun just in time to commence PWCF's *Walking for PWS* event under the Golden Gate Bridge.

Families and friends traveled from all over Northern California to celebrate together and honor each other. The morning kicked off with participants walking under the balloon archway and proceeding along the picturesque Walk path that was dotted with PWS Information signs designed to educate the public about this rare disorder. With a beautiful blue ocean as our backdrop, it was another beautiful day for a Walk!

As the throngs of 250+ walkers rounded the bend from their effortless walk, our beloved PWS Noisemakers band rocked out while kids and adults alike enjoyed their picnic lunch, relay games, water balloon toss, tug of war, sack races, face painting, and arts and crafts. This year's raffle featured some amazing prizes generously donated by the **Patti and Tom McRae**. Each prize came with a corresponding joke or clever tag-line delivered by their son, **Duncan**, who served as the raffle MC. New families met and connected with the larger "PWCF family." Several park visitors stopped by PWCF's Education Booth to see what our event was all about and a couple even made donations.

This year Northern California was the clear fund-raising winner, raising more money than Southern California; \$42,700 and \$32,700 respectively. **A total of \$77,211 was raised at this year's 16th Annual Walking for PWS events to support PWCF's vital programs and services.** Congratulations go to to Lisa and Nate Miller, parents of 5 year old Levi, who raised over \$10,000 for PWCF at Northern California's WALK and won the BEATS wireless headphones!

Shared Lisa, "*We've been participating in the Walk since Levi was an infant. It's not only a great opportunity to meet other families*

in our area but it gives us a greater purpose to raise awareness within our personal network of family and friends, and fundraise for a cause that's near and dear to our heart. It takes a village to raise any child and having an organization like PWCF as a part of that village is essential! So fundraising to support the organization that supports us is important. And receiving donations from family and friends in our personal village is both touching and humbling. Thank you to PWCF and thank you to our donors! Winning the headphones was great, but what's even better is knowing our fundraising is going to make a difference to so many families living with PWS!"

A huge "Thank you!" to more of our top fundraisers:
Shannon & Stephen Hunt honoring **Jaylon Hunt**
Julia & Jeremy Rutledge honoring **Maddox Rutledge**
Sally & Mark George honoring **Luke George**
Stephanie & Bill Bartlett honoring **Gianna Bartlett**

The prize for raising *awareness* however is priceless, and *everyone* who supported this year's Walk events is a winner in our book!



PWCF extends our special thanks and appreciation to everyone who helped make this event fun and successful, especially:

- Patti & Tom McRae – Planning Committee, Set Up Registration, signs
- Maddy & Eddie Resendes – Planning Committee, Set Up, Games
- Emily Dame, PWCF's Education & Training Coordinator
- Richard Swartwout and Todd Landwehr of Pfizer Endocrine Care
- Diane Kavrell & Julia Rutledge – Planning Committee, New Family Welcome Committee
- Sara Formslag – Planning Committee, Set up, Registration
- Mike Moore – Planning Committee
- Diana Vega – Planning Committee, Set up
- Lisa & Neil Vitro – Planning Committee
- Ivette Ramos – Planning Committee
- Austin & Lesley de Lone – Planning Committee
- Kim Cain – Planning Committee
- Jamie Burns – Planning Committee
- Roger Goatcher – Planning Committee
- PWS Noisemakers Band Members:

- Austin de Lone (in absentia)
- Adam Gabriel (guitar, vocals)
- Lisa Kindred (vocals)
- Dick McDonough (drummer)
- Eric McCann (bass)
- Kevin Zuffi (keyboard)



SUPREME COURT TO WEIGH FAPE MANDATE

by Michelle Diamant | September 29, 2016



The U.S. Supreme Court will hear arguments in a case centering on what level of educational benefit public schools must provide children with disabilities under the IDEA.

trivial educational benefit, while others hold that the act requires a heightened educational benefit,” the parents said in their petition to the Supreme Court. “Resolving the conflict among the circuits will ensure that millions of children with disabilities receive a consistent level of education, while providing parents and educators much-needed guidance regarding their rights and obligations.”

For the first time in more than three decades, the U.S. Supreme Court says it will consider how much educational benefit schools must provide students receiving services under the Individuals with Disabilities Education Act.

The Douglas County School District argued that it would be up to lawmakers to impose a higher standard in asking the high court to decline the case.

The nation’s high court said Thursday that it will hear arguments in a matter known as *Endrew F. v. Douglas County School District*.

The Supreme Court’s decision to take up the matter comes at the urging of the Obama administration. In a brief issued last month, the U.S. solicitor general agreed with the parents that the IDEA requires schools to provide more than minimal benefit to students with disabilities.

At issue is the IDEA’s mandate that public schools provide children with disabilities a free appropriate public education, or FAPE.

“This court should hold that states must provide children with disabilities educational benefits that are meaningful in light of the child’s potential and the IDEA’s stated purposes. Merely aiming for non-trivial progress is not sufficient,” the solicitor general indicated.

The case was brought by parents known in court papers as Joseph F. and Jennifer F. who pulled their son with autism out of his Colorado school district and sent him to a private school. They then sought reimbursement from the Douglas County School District arguing that the boy, Drew, was not provided FAPE.

The case will mark the first time since 1982 that the Supreme Court has addressed the FAPE mandate. However, it’s not the only special education matter the high court plans to weigh.

Both a hearing officer and the U.S. District Court for the District of Colorado found in favor of the school district, saying that FAPE was provided because the boy received “some” educational benefit.

The Supreme Court said this summer that it will hear the case of a Michigan girl with cerebral palsy who sought to bring her service dog to school, which centers on whether families must exhaust their options under the IDEA when they have a dispute with schools before seeking remedies under the Americans with Disabilities Act.

The U.S. Court of Appeals for the Tenth Circuit agreed prompting the parents to appeal to the Supreme Court, citing differing standards from courts across the country.

“Some courts, including the Tenth Circuit ... hold that an IEP satisfies the (IDEA) if it provides a child with a just-above-

CALIFORNIA’S ONLY PWS ADULT CLINIC AT UC IRVINE



Under the direction of PWCF Professional Member and member of the Board of Directors **June-Anne Gold, M.D.**, the PWS Adult Clinic at UC Irvine is up and running and seeing a growing number of patients. Dr. Gold, a geneticist and specialist in PWS, serves as the Clinic Coordinator, with **Virginia Kimonis, M.D.** serving as a geneticist and **Steven Chessler, M.D.** serving as the treating endocrinologist. The Clinic Coordinator is **Kathy Hall, MSBT**. The Clinic is located at 101 The City Drive, Pavilion 1 in the city of Orange. If your loved one or patient is an adult with PWS and you want to be seen at the PWS Adult Clinic, contact Kathy Hall at 714-456-5792.

LESSONS LEARNED ABOUT INTELLECTUAL DISABILITIES THROUGH ANIMATED FILMS

by *Ihab Shahawi, President/CEO of The SAILS Group*

This post was originally featured on HuffingtonPost.com



The way a culture responds to those with intellectual and developmental disabilities is shaped, in large part, by how disabilities and illnesses are portrayed in popular culture. Books and movies that feature characters grappling with their humanity through the lens of intellectual challenges and mental illness are uniquely positioned

to help battle lingering stigmas.

By focusing on the exceptional abilities of their characters, pop culture is helping to recast those challenges not as a weakness, but as a source of strength. With the CDC estimating that upwards of 1 in 68 children identify as autistic, it's important that we have accurate cultural representations of this large segment of the population.

As this recent viral comic depicting the autism spectrum goes to show, sometimes effective education about learning differences comes not through dense medical texts, but through simple narratives that affect us on the emotional level. Greater understanding around disabilities leads to greater empathy. Empathy, in turn, fosters better care.

So it's encouraging to see the world of animated films delving into storytelling that celebrates our differences. The four films below took a lighthearted and imaginative approach and reached a huge audience in the process. For a better understanding of what it's like to live with a disability, plan a movie night with these instant classics.

Finding Nemo & Finding Dory

Beyond the huge audience of children who relate to the lovable characters in the "Finding Nemo" franchise, Pixar has received high praise from disability support groups for its portrayal of characters who are propelled forward—rather than being held back—by their differences. In 2003, the world fell in love with a spunky fish named Nemo, who learns to think of his undersized fin as his "lucky fin." In this summer's blockbuster hit "Finding Dory," we follow along on the journey of a fish with short-term memory loss. In both films, these characters are not portrayed as different in a sea of normal; instead, they are just two more fish playing to their own unique strengths. There are also whales with echolocation issues and nearsighted sharks. The point is, everyone deals with their own unique limitations, and we don't live in a world where differences should be isolated from so-called "normal" characters.

While memory loss is not a common symptom of autism, many moviegoers who either have autism or care for a child with autism found strength and relatability in Dory. She feels the need to

constantly apologize for her forgetfulness, although she can't help it. As we at [The SAILS Group](#) and other advocates for mental health awareness work to remove the stigma around autism, a good first step is realizing that there is no apology necessary. Throughout Finding Nemo and Finding Dory, Pixar beautifully illustrates why it's actually good to be different. Parents and caregivers have also related to the role of Dory's parents in caring for their own children on the spectrum, which requires a balancing act of fostering a supportive environment while also letting children thrive on their own. For an animated children's movie and sequel, these aquatic hits address disability with a deft touch that encourages awareness, acceptance, and a celebration of the differences that make each of us unique.

Inside Out

While Disney Pixar's "[Inside Out](#)" isn't about a learning disability per se, its unique portrayal of the wide spectrum of human emotions is a helpful way to think about how emotional experiences can be extremely nuanced, especially for children on the autism spectrum. In the film, an 11-year-old girl named Riley is adjusting to a cross country move. Her emotions are represented by the animated characters of Joy, Sadness, Anger, Fear, and Disgust, and they operate out of headquarters in her brain. This original spin on a film about emotions takes the question Joy asks near the beginning of the movie quite literally:

"Do you ever look at someone and wonder what is going on inside their head?"

What this film does in such a groundbreaking way is portray how emotions play a huge factor in how we all develop different coping strategies for life's daily challenges. Emotions are incredibly complex and interwoven for everyone, and that effect can be amplified in those with ASD. "Inside Out" signals a rising cultural awareness of the complex dance that emotions play in every moment, and consequently we're starting to see more considerate responses to autism and other disabilities in real world settings. From companies hiring more autistic individuals to airports and theme parks creating sensory calming rooms for autistic visitors, it's a great step forward that the world is becoming a more navigable place for those who have difficulty processing emotions.

The Present

This short and sweet animated film had an incredibly successful debut on the festival circuit last year, winning more than 50 awards and running in over 180 festivals. The secret to its success? Clocking in at under five minutes, you'll be hard pressed to find someone who isn't affected on an emotional level after watching this film. It's relatable, imaginative, and all around a great little story. Similar to the viral success of the autism spectrum comic

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SKIN PICKING INFORMATION FOR PWS

Excerpted from PWCF's New Member Handbook



Picking of the skin is a common behavior in persons with PWS. This behavior ranges in degree from person to person and within the same person over time. Occasional picking at the skin is normal; who among us hasn't picked at a bug bite or scab? But in persons with PWS where the signals of touch and pain are often weaker and where there can be an obsessive quality attached to the picking, picking may be prolonged and become problematic. Picking can occur spontaneously, can become a habit, can occur when the individual is feeling more anxious or stressed, or occur when the individual is feeling bored.

As with many PWS symptoms, work to proactively reduce the potential for skin picking. Use bug spray when you may be exposed to biting insects. Keep fingernails short and the skin "slick" with lotion. Immediately cover bug bites or bumps on the skin with a band-aid. Do your best to eliminate or reduce stressors that may increase anxiety. Try not to draw attention to the picking because telling someone to "stop picking" often increases picking behavior rather than reduce it. Instead, keep the hands busy with squishy balls, stickers, coloring, and any other fine motor activity, or simply ask them to carry something for you. Get your child or adult up and active and doing something to reduce boredom-related picking.



A sensory integration strategy described by PWS specialist B.J. Goff, M.Ed. has been found very helpful to reduce picking behavior. This technique uses a wooden hand-held massager. At bedtime, after pajamas are on and firmly rub the wooden massager up and down the back for five minutes (avoid direct massage over the spinal column). Repeat this procedure 10-14 consecutive days. If/when picking behavior recurs, simply massage again, following the five minute massage protocol for another ten to fourteen consecutive days.

A supplement found to be helpful to reduce skin picking behavior is N-Acetyl Cysteine (NAC) which comes from the amino acid L-cysteine, one of the building blocks of proteins within the body. NAC can help decrease compulsive behaviors such as skin-picking and hair pulling. NAC capsules can be purchased without a prescription, usually at health food stores. It should not be started without first consulting with your child's doctor to make sure there are no interactions with any other supplements or medications.



Medication, such as Topiramate (Topomax) may be helpful for more difficult cases.

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.

Join the registry by going to: <https://pwsregistry.org/>

.....
Films, continued from page 14

mentioned above, this short film was actually based upon a comic strip by the talented artist Fabio Coala and adapted for the screen by Jacob Frey.

I don't want to spoil it for anyone who hasn't seen it yet, but I think the real gift of "The Present" is how it lets us celebrate our similarities at the same time that we learn to respect each other's differences.

Movies have the power to change cultural perception around social issues such as intellectual disabilities. Changing how disabilities are perceived is the first step to changing our care models. So it's encouraging to see animated films stepping up to the plate to celebrate the amazing diversity in our shared humanity.

BOARD CORNER

Summary of Board of Directors Meeting on July 26, 2016

Submitted by Tom McRae

Your PWCF Board met via telephone conference on Tuesday, July 26th. Present at the meeting was our Executive Director, **Lisa Graziano**, and the following Board members:

Whitney Bras, Rodney Dong, Roger Goatcher, June-Anne Gold, M.D., Jacki Lindstrom, Tom McRae, Nisha Mehta, Kimberlee Morgan, Daniela Rubin, Ph.D., Renee Tarica, Jenny Wolkensdorfer

Here are some of the highlights of that meeting:

HCBS (Home-Based Community Services) & Person Centered Planning

- **What is HCBS?** The federal government helps pay for most of the services regional centers provide to individuals with developmental disabilities. In March 2014 new federal rules became effective describing how home and community-based services (HCBS) are provided. The HCBS rules affect licensed community care facilities, residential settings (group homes), work activity programs, and day programs. The new rules explain what these settings should be like. All services in every state must follow the new rules by March 2019.
- **Main Concern of the PWCF Board:** We want to ensure that the people with PWS in group homes and work programs do not have unrestricted access to food. Currently, the new HCBS rules do not ensure this.
- **What is the PWCF Board's plan?** A PWCF committee has been created. We will be educating ourselves on the new HCBS rules and will meet as needed to develop and implement a plan of action. We anticipate that this plan may include reaching out to other PWS organizations to form a coalition, working with policy makers to amend rules for our people, and developing a guide for parents with explicit language to include in IPPs to ensure our folks access to food is restricted and supervised as needed.

Residential Services Committee Update

- **Linda Ryan** has had to resign as Chair of the Residential Services Committee due to time constraints.
- **Lisa Graziano** is following up with 2 of the current Committee members who have expressed an interest in possibly taking on this key role.

Executive Director Candidate Interviews

- **Roger Goatcher** reported that the Executive Committee is conducting phone interviews with three new Candidates on July 27th.
- Roger will report back at the next meeting on the status.

Camps Update

Camp Harmon

- 54 campers attended this year!
- **Lisa Graziano** and **Emily Dame** arrive at camp early to provide another brief staff training and then stay at the camp to assist with issues as they arise. They reported that although there were some isolated, tough issues, by and large the camp went great!

Camp Paivika

- PWCF committed to Camp Paivika to pay for 45 campers.
- Currently, only 30 campers are confirmed to attend due to 12 campers backing out at the last minute.
- Emails were sent out to eligible campers letting them know of the available spots
- PWCF will have to pay from its coffers for any shortfall in committed campers.

PWSA (USA) Chapter Leader's Meeting Update

Roger Goatcher, PWCF Board President, and **Julie Casey** attended the PWSA (USA) (www.pwsausa.org/) meeting in Milwaukee, Wisconsin in early July. They met with other state chapters as well as PWSA representatives. Some items of note were:

- **Parent mentors:** PWSA has a number of parent mentors across the country. In California, **Julie Casey** is one, and **Jenny Wolkensdorfer** is in the process of becoming one.
- **Home and Community-Based Services (HCBS):** PWSA does not intend to become actively involved. State chapters are asking for more help, but PWSA is hoping issues can be resolved at the state chapter level.
- **Compliments for PWCF:** Several state chapter attendees approached both Roger and Julie with compliments on PWCF's website and social media efforts.

Fund Development Committee

Golf Tournament

- Board member **Rodney Dong** has been working on setting up a golf tournament fund-raiser.
- Rodney reported that the golf tournament will have to be deferred until next year (maybe February) as the recent Sand fire has damaged the course.
- Stay tuned! Keep your head down! Don't bend your arms so much!

Donation Box at Bianchini Market

- **Jacki Lindstrom** is working with her contacts at a Bianchini Market to set up a Donation Box for PWCF.
- Just waiting for materials to arrive (Jacki expects sometime in September or October)

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We can actually get back some of the energy we've expended and create *new* energy. Here's how:

Complete things you've been avoiding. Energy attaches to things that we tell ourselves we need to do or take care of but never do. When you tell yourself you need to clean out that drawer that keeps getting stuck because there's too much stuff in it and you don't, time and time again, you've "attached" a bit of your energy to it and that energy just sits there. As soon as you finally clean out that drawer, you reclaim some of your energy. So complete one of those "I need to do that; I should do that" projects and get some of your energy back. Or, decide you're *not* going to clean out that drawer and take back the energy that's been attached to it.

Lose yourself in something. Do something where you lose track of time, where you lose your sense of self. Be loving with your

spouse, your pet. Make silly faces and noises with a baby. Have fun with a hobby.

Have fun. Having fun gives us energy! Most adults stop having fun because all fun is essentially stupid! Do what makes you smile, laugh. Go fishing. Dance. Ride your bike. Do something, *anything*, that you experience as fun!

So if you're already eating healthy, exercising and meditating, good for you and keep it up! For the rest of us, consider some of the above strategies and see how much distress you can rid yourself of and how much energy you can create. We've got nothing to lose and everything to gain, especially as we head into the holidays. As for me, I already feel a resurgence of energy as I complete this newsletter!

Tyrone Wells Benefit Concert Update

- **Chris and Jessica Patay** are hosting this fund-raiser at their home.
- PWCF helped set up the website for the event.
- So far, \$8,600 of their goal of \$10,000 has been raised!

IPWSO (International Prader-Willi Syndrome Organization) Conference Update

Dr. June-Anne Gold reported on the IPWSO conference:

- IPWSO (<http://www.ipwso.org/>) Conference took place in Toronto last week over 2 days.
- Productive two days of various panels regarding self-determination, disabilities, and inspirational talks.
- Cuba putting in a bid for next year to hold the conference.

Public Awareness Committee Discussion Items

Walking for PWS Northern CA Event

- Approximately 255 people attended! Together the Southern CA and Northern CA walks grossed \$76,800 in revenue.
- **Google Grants Update:**
- Google Grants provides qualifying non-profits \$10,000 in free ads per month. Google Grants requires that each non-profit actively manages their ads. PWCF pays \$99/month to Elevate Clicks, a Google Ad Grant company, to actively manage our ads and consult and advise us.
- Currently, PWCF is employing our ads to increase awareness of both PWS as a genetic disorder and PWCF as the non-profit, California organization serving people with PWS.
- Our longer term plan is to work with Elevate Clicks to learn how to leverage this social media technology to develop relationships with people who show an interest in PWS by clicking on our ads. This involves employing software packages that allow us to automate:
 - The capturing of email contacts of people who agree to provide their email.

- At regular intervals, sending emails of engagement/stories to these people.

- How we automate all this will require investment in a tool for capturing, storing, and contacting emails automagically. The board okayed the purchase of the "Active Campaign" tool (\$237/year), but further review was needed to see if this was the right tool and the right time to move to it from the current "Constant Contact" tool.

Marathon/5K promotional giveaways

- The board passed a motion to spend up to \$1000 on items containing info about PWS/PWCF to be given away to the public attending PWCF's Exhibit Booth during the Aquarium of the Pacific 5K and JetBlue Long Beach Marathon and Half Marathon events October 8-9, 2016.

PWCF Video Update

- PWCF is creating a 2-minute video that describes who PWCF is and what we provide. We need a short, impactful, engaging video to accompany our grant requests.
- **Lisa Graziano** reported that in addition to **Jessica Patay**, **Danielle Peretz** will also help edit the script.

Closing

There were many more updates, reports, hijinks and hilarity during the meeting, but, luckily for you, I'm only given so much space in this column.

Please allow me to bug you again that in order for us to make our vision -- "**A Full Life Without Limits**" -- a reality, we need your continued support. Contact us (send an email to info@pwcf.org) and ask how you can help!

Also, if you shop online via Amazon, an easy way to help PWCF that costs you nothing is to shop using the "Amazon Smile" program. Check it out at: <http://smile.amazon.com/ch/95-3480752>.

WE GET MAIL

Dear PWCF: It was good to meet you finally at what looked to be a very successful PWCF walk. Well done.... Keep up the distinguished work – we always appreciate collaborating with you. Regards and thank you, *Claudia Shambaugh MRP, RM493 Study Coordinator, University of California, Irvine*

Dear PWCF: Thanks to your organization for all that you do for people with PW! Have a great weekend, *Jeffery Darling, Manager, Resource Department, San Andreas Regional Center*

Dear PWCF: So many informative articles in this [April-June 2016] newsletter! Great job! A keeper! *xoxo, Linda Ryan*

Dear PWCF: I am the parent of a 24mo girl with PWS. Although we live in Pennsylvania, I have found your organization to be the most helpful, reassuring, and user-friendly resource for those learning to navigate life as the primary advocate of an individual with PWS. I particularly loved the facts posted daily during PWS Awareness Month! Thank you for demystifying and clarifying this unique syndrome in a concise and passionate manner.... *Kimberly Griffin*

Dear PWCF: I was [at the Northern CA WALK event] supporting my cousin, Nolan Bonk. I appreciate the support that the organization and PWCF community provides my family and those with this unique and difficult challenge. Thank you so very much! *Michael Denatale*

Dear PWCF: Thank you so much for providing the training to our team. I know that everyone found the information extremely valuable!!! Again, thank you for working with us over the last few months!! *Athena Zografos, Critical Intervention Clinician Specialist, Creating Behavioral and Educational Momentum*

YOU SHOP, PWCF RECEIVES A DONATION!

Just by shopping at your local Ralphs grocery store, you can support PWCF!

Simply register or re-register for the new term with the Ralphs Community Contribution Program and **every time you shop, PWCF will earn a donation.**

Participants are required to register for the new term online at www.ralphs.com or by calling Ralphs at 800-443-4438 starting September 1, 2016. Even if you registered as recently as June, July or August 2016, you need to register again beginning in September.

For your convenience, step-by-step website registration instructions can be found at www.ralphs.com, click on Community, click on Community Contributions, click on 'Enroll Now'. If you don't have computer access, please call Ralphs at 800-443-4438 for assistance.



Dear PWCF: I wanted to thank [Emily] for the effective and beautiful management of Aiden while at camp. It's so comforting knowing you are a part of the care of the PWS community! Sincerely, *Petra Martinez-Ali*

Dear PWCF: Thank you for coming up and presenting. Your lecture was great and you left the staff hungry for more information. *Sean Manchester, Director of Special Education Services, Nevada Joint Union High School District*

IEP TRAINING EMPOWERS PARENTS



In September PWCF's President, **Roger Goatcher**, provided a training session on the Individual Education Plan. Not only is Roger a Deputy Superintendent of Special Education and really knows his educational stuff, he's a great down-to-earth teacher.

Every participant in this workshop training received a three-inch three-ring binder packed with helpful information and articles, forms, sample letters, etc.

One of the most critical concepts Roger wanted all participants to understand is "Education Benefit will be one of the most important concepts to keep in mind throughout the IEP process. Schools will refer to their practices and how they are providing educational benefit for your child. The more you understand about what educational benefit is and is not, will help you in working with the school district on services and programs."

If you've not yet attended one of these great educational seminars, you're missing out! Stay tuned for upcoming seminars offered through PWCF.

VOLUNTEERS are *Priceless*

PWCF expresses our appreciation to:

Cameron Graziano for his help with 3rd Quarter Member Renewal Forms

Jack Hale and his girlfriend **Eva Free** for providing childcare support at the Support Group meeting and the Parent Empowerment Training, both held in September.

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

Alexandria Brown

New Family Members

Patricia & Craig Diamond

Eva & James Moresco

Mari & Tye Simpson

Bonnie Whitney

New Extended Family Members

Marie France Nusbaum

Renewed Extended Family Members

Rima & Robert Buch

Nick & Judy Cropper

Dawn & Jeff Fijman

Pat Grey

Ashok Gujral

Susan LaChance

Nancy & Christopher Rohan

Joyce & Norman Smith

Renewed Family Friend Members

Linda & Jack Gross

Irene & Kyle Kaiser

Renewed Professional Members

Amy Beals, MSCD, CCC-SLP, Speech & Language Therapy Services

Jowella Chico, Jowella Chico's Care Home

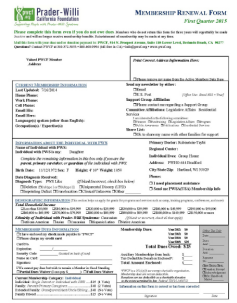
Tony Keuter, People's Care, Inc.

Cynthia Pollock, Law Offices of Cynthia R. Pollock

Luz Rasco, Talia Vi Homes, Carfax

Sterling Ross, Esq., Robb & Ross, Special Needs Trusts & Conservatorship

Melissa Sweet, PRIDE Industries



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

*Renew your
membership today!*

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@pwc.org

DONATIONS

July - September 2016

Shining Star Donations

Canopus (\$500 - \$999)

Suzanne Privette in honor of Samantha Morgan
(monthly donation)
Tom McRae in honor of Duncan McRae
(monthly and company-matched donation)

General Donations

Darcy Alexander
Kyra Allen via PG&E Corporation Foundation
(recurring donation)
Marie & Kenneth Babcock
in memory of Joseph Melchin of Duxbury, MA
Yasuko & Ira Bloom
Rima & Robert Buch
Carina Chaij
Lesley & Austin deLone
Cherise Dunham-Bennett
Gobbell Revocable Living Trust
in honor of Madison Gobbell
Pat Grey in honor of Chase Grey
Linda & Jack Gross
Susan & Daniel Hedstrom
Anita and Ira Hermann, The Hermann Family Trust
Karla & Clint Hurdle
Irene & Kyle Kaiser
Mary & Alan Kisaka
Kroger Stores
Jacki & Jeff Lindstrom
Georgene & Ralph Lowe
Patti & Tom McRae (monthly donation)
Kathleen & Stephen Meeker
Steve Mercieca thru Johnson & Johnson
Mamta Patel
Reiko Nakamura
Terry Regan
Joyce & Norman Smith
Renee & Brent Snyder
Kathleen Stets in memory of Clara Belle Hartwick
Target Stores
Anita & George Tapia, Jr.
Walter Clark Legal Group

Donations to Support the Annual State

Conference

Mary & Pat Williams

Donations to Support PWS Camps

Kathy Dignan
Diane Kavrell
Mayuri & Venkat Paruchuru
Suzanne Privette in honor of Samantha Morgan
(monthly donation)
Lisa & Neil Vitro

Magnanimous Donations to Support Walking for PWS Events

Angel Lance in honor of Levi Miller
Elaine, Larry, Nicole & Alex Barden
in honor of Gianna Bartlett
William Koenig in honor of Haley Kavrell

Generous Donations to Support Walking for PWS Events

Steven Bacich in honor of Gianna Bartlett
Stephanie Bartlett in honor of Gianna Bartlett
Malea & Rich Bonk in honor of Nolan Bonk
Linda Faber, PhD & Arnold Brickman, M.D.
in honor of Luke George
Dave Capper in honor of Haley Kavrell
Sharon Chen in honor of Kyle Baker
Jill Barnes & Paul Colin in honor of Duncan McRae
Deborah Cookson
Edward Court McDonald Jr. Mary Michele
McDonald Family Trust in honor of Duncan McRae
Bob Eshleman in honor of Haley Kavrell
Anthony Estrada in honor of Alexander Phan
Toby Flax in honor of Haley Kavrell
Maddy & Eddie Fluhr-Resendes
in honor of Emma Fluhr-Resendes
Charlene & Brian Hopkins
in honor of Adam Hopkins, Jr.
Margaret Hunt in honor of Jaylon Hunt
Carolyn & Gordon Jones
in honor of Duncan McRae
Diane & Brandon Kavrell in honor of Haley McRae
Jacki and Jeff Lindstrom in honor of Julia Lindstrom
Lindstrom Inc. in honor of Julia Lindstrom
Edward Mann in honor of Maddox Rutledge
Kyle Marks in honor of Gianna Bartlett
Joseph Martinez
Annette, Kate & Dan McCormick
in honor of Isable Hays
Donald McRae in honor of Duncan McRae
John Mickelson in honor of Haley Kavrell
James Montero in honor of Jaylon Hunt
Karen Murad in honor of Julia Lindstrom
Patricia Noland in honor of Brent Noland

John Navarro & Susan Ojeda
in honor of Eric Ojeda
The Philly Family
in honor of Emma Fluhr-Resendes
Terri Grass & Robert Priest
in honor of Duncan McRae
Kim & Pierre Russell in honor of Oliver Young
Julia & Jeremy Rutledge
in honor of Maddox Rutledge
Michael Rutledge in honor of Maddox Rutledge
David Sim in honor of Ahlyjah Blessin Latu
Jennifer Soibelman in honor of Jaylon Hunt
Reena Spurrier in honor of Jaylon Hunt
Mauri Staker in honor of Jaylon Hunt
Nicholas Vincent in honor of Maddox Rutledge
Jason Viscarra in honor of Jaylon Hunt
Jordan Vitro in honor of Justin Vitro
Vicki Wasson in honor of Maddox Rutledge

Donations in Honor of Josie Meade's 1st

Birthday

Ella & Stephen Fischbein
Marnie & Yeda Fish, Jordan Lee Fish
Foundation Inc.

Donations in Memory of John Michael Evans

Dallas Ann H. Erwood
Janet Evancik
Karen & Manny De Jesus
Guralnick & Gilliland, LLP
Nancy & Bryan Foster
John Goodloe
Deboer & Keane Kramer
Emilie L. Lamar
Michael & Jeanette Bidart Family Foundation
Hortense & James Packer
Sue Radoff
Riverside County Judges Association
Judy & John Sansone
Patricia and Richard Scott
Eleanor Segall
Alicia & Dennis Stout
Douglas Welebir
Jennie & Leroy Wenstrom II
Wescom Credit Union Employees
and the We Care Foundation

Donations to Support Research

Canyon Verde

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)