The Gathered View
National Newsletter of the Prader-Willi Syndrome Association (USA)

Prader-Willi SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

An experience – much more than a meeting

The PWSA (USA) Biennial National Convention



Family fun at 2015 PWSA (USA) Conference

The world's largest assembling of people and information all focused on saving and transforming the lives of those affected by Prader-Willi syndrome is four months away. This year's "Caribbean Night… Together in Paradise" national convention is all about:

- Specific information that you need for your mind; and
- Supportive connections you'll appreciate for your heart.

Excitement is building steadily as key speakers are announced, program schedules are released, and all the opportunities for kids and families are finalized.

The schedule includes

Tuesday, November 14
PWS CTC Consortium

Wednesday, November 15
Chapter Leaders
Clinical Advisory Board Meeting
Scientific Advisory Board Meeting

Thursday, November 16
Medical & Scientific Conference
Professional Providers Conference
New Parent Mentor Meeting

Friday, November 17
General Conference
Rare Disease Meeting

Saturday, November 18
General Conference

Overall, the convention is an amazing array of activities. New information is being posted on the www.pwsausa.org website. Check out Facebook and other social media for "the latest and greatest" updates as we count down to the world's largest PWS convention. You'll find specifics about the Youth & Infant Program (YIP), the Youth & Adult Program (YAP), the Sibling Program, the Gala **and** YAP Gala, and much more.

For new attendees, these uniquely developed programs for our infants, youth and adults are staffed by compassionate care professionals. These professionals will provide your child with a safe environment, where they will have the opportunity to meet others like themselves, who are excited to make new friends and have two days of fun-filled activities. The website shows the schedule of General Conference sessions - ranging from:

- Therapeutic Interventions and Psychiatric Medications, to
- Improving Behavior and Preparing Your Child's Individual Education Plan, to
- Nutrition in Infancy, Clinical Trials, and Taking Care of the Caregiver, and – of course – more.

continued on page 2

Executive Director View

By Ken Smith, Executive Director

On May 29, 2017, PWSA (USA) lost a valued member of the PWS community.

Cindy Beles was a 10-year employee of PWSA (USA) with numerous duties. As Triage Advocate she was usually the first person people would talk to when they called the association. If it was a family with a new diagnosis, Cindy would spend some time listening to their concerns, answering questions and determining their needs before transferring the call to the most appropriate person, such as a crisis counselor.


Cindy Beles

Dubbed the *Voice with a Smile*, she retired in 2015 right after her 10th anniversary to care for her disabled son. Several months later she received the diagnosis of terminal cancer. She fought hard but lost her battle on Memorial Day.

We honor her memory and are grateful for her dedicated service to the organization and to our families.

continued on page 2

Volume 42, Number 4 ~ July-August 2017 ~ Our 42nd Year of Publication

Executive Director View, *continued from page 1*

Another item of great importance to our PWS community, the Amercian Health Care Act, is addressed below by board member and Advocacy Chair Tom Conway. Please read his memo addressed to the members of the PWSA (USA) Advocacy Network, which is a vital concern to all of us. Read and take action. Let's make our voices heard! Contact your representatives and senators. This is a chance to help make a difference. ■

Dear Members of the PWSA (USA) Advocacy Alert Network:

As you know, the U.S. House of Representatives recently approved a bill, known as the American Health Care Act (AHCA), which, if passed by the Senate and signed by the President, would repeal and replace the Affordable Care Act (Obamacare). The House bill would make drastic changes to current law that could have devastating effects on our community. In particular, the bill would reduce expenditures on Medicaid by $834 billion over ten years. The House bill would also dramatically impact the ability of less healthy individuals, including those with preexisting or newly acquired medical conditions, to obtain private insurance coverage. According to the nonpartisan Congressional Budget Office, if the House bill became law, such individuals would be unable to purchase comprehensive coverage with premiums close to those under current law and might not be able to purchase coverage at all.

In addition to the Medicaid cuts in the AHCA, the President's recently proposed budget calls for an additional reduction of up to $610 billion in Medicaid expenditures over ten years. The President's budget also proposes a combined $52.2 billion in cuts over ten years to the Social Security Disability Income (SSDI) and Supplemental Security Income (SSI) programs, both of which are important to our community.

If you oppose the above changes to current law, as well as the proposed budget cuts to Medicaid, SSDI and SSI, we urge you to contact your federal legislators as soon as possible to express your opposition. **Every contact helps!** Although the AHCA has passed the House and is currently before the Senate, contacting both your Senator and House member is important because the bill will most likely come back before the House in some form. All Senators and House members will vote on the budget.

The links below provide contact information for all legislators. If you have any questions, please feel free to contact me at: TConway@pwsausa.org

Thank you. ■

Tom Conway, Advocacy Committee Chair, PWSA (USA)

http://www.house.gov/representatives/

https://www.senate.gov/senators/contact/

Convention, *continued from page 1*



Three moms enjoying time at the 2015 conference

The convention has something for everyone, even including a grandparents session, and the programs are both extremely targeted to the PWS community and very high in quality. Just one example is the Friday opening speakers. Sisters and co-authors, Gina (Terrasi) Gallagher and Patricia Terrasi, share a love of wine, humor, and writing (excluding check writing). Gina and Patty are the co-authors of the best-selling, parenting book *Shut Up About Your Perfect Kid A Survival Guide for Ordinary Parents of Special Children,* and past recipients of the National Alliance on Mental Illness' Heroes in the Fight" Award for advocating for those with mental illness.

In the words of General Conference Chair, Kristi Rickenbach: *During the General Conference, you will have the opportunity to choose from multiple learning tracks that can be tailored to your individual preferences. It is a time to build relationships with other families, meet with top specialists and authorities on PWS, and just have fun. The conference is attended by not only family members, but also by professionals, who with us have a common goal to improve the lives of our children. Conference has been life changing for so many families and I hope this year to meet new friends along the way, and see those who I have come to cherish!*



Make your plans today to attend, as a 2015 participant said: *"Attending is an experience of a lifetime for a child, and attending is an experience of a lifetime for a family."*

The PWSA (USA) Caribbean Nights – Together in Paradise National Convention Has It All!

Find more information and register at *http://www.pwsausa.org/2017-pwsa-usa-national-convention-registration/* ■

"Thank you for helping my mom help me while I was in school." – Hayden

This is what Family Support can do - see page 6.

Pediatric Endocrinology Nursing Society (PENS) Conference, Minneapolis, MN, April 26-29, 2017

By Kathy Clark, RN, MSN, CS-BC, Coordinator of Medical Affairs, PWSA (USA)



Kathy Clark, Coordinator of Medical Affairs, PWSA (USA), with Lori Moline, New Parent Support Specialist, PWSA (USA), and Kristi Rickenbach, Parent Mentor and President of the Minnesota PWSA Chapter

PWSA (USA) sponsored an exhibit at this annual meeting which included pediatric endocrinology nurses from the USA, Canada and Australia. Over 180 nurses and health care professionals were in attendance. Our booth was busy - explaining our programs, distributing brochures, and providing the most up to date information about PWS. Our new logo was on display, and we now have a poster that describes the medical challenges found in PWS.

Lori Moline and Kristi Rickenbach's support helped make it possible for me to attend most of the lectures offered during the very busy exhibit day. I enjoyed spending time with them, and deeply appreciate their willingness to talk to nurses for over nine hours.

One of the nurse practitioners in attendance recently published an article about PWS in *Pediatric Nursing*, the journal for PENS; we presented her with a PWS tumbler as a thank you for her work. On the final day of this meeting, I presented the latest PWS research and treatment approaches in a general lecture. All of these efforts help spread the word about early diagnosis and treatment and the hopefulness that we feel today about the future. ■

Thyroid Issues in PWS

By Kathy Clark, RN, MSN, CS-BC, Coordinator of Medical Affairs, PWSA (USA)

One of the most commonly prescribed drugs in the USA is thyroid hormone (levothyroxine) to treat an underactive thyroid gland (hypothyroidism). That small gland, located on the neck, produces hormones that are essential to all parts of the body. Weight gain, tiredness, slow growth, and feeling cold are common complaints when the thyroid gland does not work. While these symptoms are common in PWS, thyroid deficiency is not the most likely explanation; but low thyroid hormone can still occur, and regular testing is important.

Primary hypothyroidism is the most common type of thyroid problem. When the gland itself does not work, thyroid deficiency is fairly easy to diagnose. There are symptoms such as weight gain, fatigue, slow reflexes, and low blood pressure and heart rate. Newborn babies are all tested for a severe type of hypothyroidism soon after birth. These problems are no more common in PWS than in the rest of the population. Primary hypothyroidism can be from an autoimmune process, which does run in families, so some people are just more likely to have this diagnosis.

In PWS, we are more likely to see a different type of low thyroid function – related to low thyroid stimulating hormone (TSH) which is from the pituitary. This is called **secondary hypothyroidism** or **TSH deficiency**. In this case, the thyroid gland itself is just fine – but it does not get the signal from the pituitary to make ideal amounts of thyroid hormone. This is an unusual reason for low thyroid hormones, but may be more common in PWS than in the general population. This type of "pituitary hypothyroidism" is easier to manage and is not as severe as primary hypothyroidism.

While most thyroid problems (primary and secondary hypothyroidism) are permanent lifelong conditions, there can be **mild TSH deficiency** when a child is taking growth hormone. It seems that sometimes the TSH production that was enough for slow growth and slow metabolism is simply not enough when growth hormone treatment kicks the body into a higher gear. Sometimes this condition returns to normal when the child is fully grown, and the thyroid supplement may not be needed when growth is completed.

Talk with your provider to understand which type of thyroid problem is being treated. Because **secondary hypothyroidism** is very rare, and primary hypothyroidism is very common, some healthcare providers may assume any patient taking thyroid pills has primary hypothyroidism. For example, emergency room doctors may want to draw a TSH, in case it is the thyroid dose that is causing symptoms – so be prepared to advocate by knowing which thyroid problem has been

continued on page 4

Too Darn Hot!

Pace, prepare, and plan your summer fun

By Kathy Clark, RN, MSN, CS-BC, Coordinator of Medical Affairs, PWSA (USA)

Body temperature regulation is a challenge for people with PWS. They can easily become overheated, especially during infancy and childhood. Here are some great ideas to help you be safe when the thermometer rises.

Outdoor activities should be planned for the cooler mornings, rather than sunny afternoons or the heat of early evenings.

Seek shade or create your own with an umbrella. Provide a wide brimmed hat for sun protection. Fair skin always needs good SPF protection, so avoiding direct sun because of the risk of overheating helps with two important health issues.

For schoolchildren, make sure the IEP includes practical plans for recess on hot days – shaded play area, wear a hat, provide low energy activities, and supervision by an adult watching for signs of an overheated child. We recommend outdoor time for all children and prevention and preparation can mean that your child will never suffer from a heat emergency.

Always **travel with a frozen water bottle**; metal bottles travel well. Keep one in your freezer and grab it whenever you go out, even for a short trip. It can serve as a drink and as a cold pack. Leave it on a car seat and let it defrost and cool the seat.

Cold drinks or frozen drinks (Slurpees) can help reduce body temperature internally. In a crisis, don't worry about the sugar content of an ice-cold beverage. Avoid caffeine if possible. However, don't overuse frozen treats during hot weather, or your child may come to expect these. Zoku slush makers will allow you to make your slushy treats out of preferred liquids.

Babies should sleep in an air-conditioned room with good air circulation. If you don't have central air conditioning, a window unit might be covered as a medical necessity – check with your insurance plan.

Don't expect any person with PWS to do well in a hot car – let the car cool off. Park in the shade, open the windows and maximize the A/C before loading in your most precious cargo.

Fans help cool the skin, which is a highly effective way to lower temperature rapidly. Invest in a small battery powered fan for travel, and a larger fan for at home. Wet skin plus **moving air is a very effective treatment for the heat.**

Travel with a small insulated cooler filled with thin wet towels, a water bottle, and blue ice packs. The cooler can be fully packed and kept in the freezer between trips.

Athletes use **technology** to keep cool, so check out the sporting goods aisles for the latest items – neck bandanas filled with gels that cool; Frogger towels, a shammy which stays cool when wet. Gauze blankets, commonly used for swaddling babies, are very thin cotton fabrics, perfect for draping over a stroller. Dip them in water first for an added cooling effect. Fold the blanket, dampen it, and store it frozen in a zip lock bag. Cooling gel pads are available – marketed for pet owners with hot furry pets – and are quite effective for short term use. These come in a variety of sizes. Most of these gel pads rely on pressure to active cooling, and some rely on water to be effective. There are also cooling gel pads made to fit into car seats. Duct tube devices can direct the front seat AC vents directly to the child in the back seat – such as The Noggle.

Construction workers need to stay cool too, so technology has been developed for the people who help get our roads repaired. Cooling vests can make extended time outdoors safer: polarproducts.com and ergodyne.com/cooling.html – available in child sizes. Many small battery-powered fans that include a spray water bottle, the ideal combination for cooling - air movement over damp skin.

What child doesn't enjoy a wading pool or a sprinkler? Keeping your hose in the sun will "warm" the water so that the pool isn't too cold – just make sure the pool is in the shade before filling it up.

What are serious heat problems?

HEAT EXHAUSTION is an **urgent** situation, often with heavy sweating, rapid pulse, dizziness, fatigue, cool moist skin

continued on page 5

Thyroid, *continued from page 3*

diagnosed. A very low TSH blood level in primary hypothyroidism would mean the person was taking TOO MUCH thyroid medication. In secondary hypothyroidism or TSH deficiency, a T4 or free T4 is a better test – because the TSH will always be low.

Ask your healthcare provider for advice about how and when to give the pills – usually on an empty stomach, which is hard to do with small children, and never in combination with any food that contains soy. These pills taste sweet, but should not be chewed. They can be crushed. Thyroid pills are slow acting and stay in the body longer than most medications. Sometimes a missed dose should not be doubled up the following day – ask your provider.

Interested in knowing more about hormones? The Endocrine Society has a superb patient education website filled with detailed hormone information and explanations – www.hormone.org. It does not currently include information about PWS or TSH deficiency, the type of thyroid problem which is more likely in PWS and others with pituitary dysfunction.

Reviewed by Jennifer Miller, MD ■

Too Darn Hot, *continued from page 4*

with goose bumps (despite the heat), muscle cramps, nausea and headache. This is most commonly seen after intense activity, such as sports. Many of these symptoms may not occur in persons with PWS – so look for red cheeks, exhaustion, and fatigue.

Rapidly cool an overheated person. Get into a cool place, at least into the shade, and make sure there is good air circulation or turn on a fan. Remove most clothing; wet the skin to bring down the body temperature. The largest blood vessels are on the sides of the neck, underarms, and the groin. Placing cold wet towels in these important locations will rapidly cool the blood. Be careful - ice must be wrapped to avoid damage to the skin. Encourage sips of the coldest beverage available – regardless of whether it has sugar – the goal when a person overheats is maximum hydration.

HEAT STROKE is an **emergency** – sweating stops and confusion or collapse can occur. Call 911 and continue all efforts to reduce body temperature as rapidly as possible.



Enjoy the summer!

Please don't let worrying about the heat limit your outdoor fun or keep you from time outdoors. Children with PWS should attend their sibling's soccer games, go to the beach, take a summer hike, and play in the back yard. Spending time in nature and being physically active are essential to physical and mental health, so don't let fear keep your family indoors. It is all about pacing, preparing, and planning. ■

CFC® Combined Federal Campaign *Approved Charity*

Federal Empoyees! The Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all."

Visit their Web site at http://www.opm.gov/cfc/index.asp to learn more. **PWSA (USA) CFC ID # is 10088**



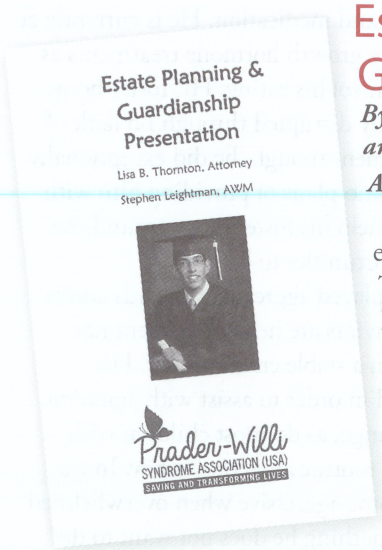
Want to be a part of the world's largest PWS advocacy community?

Become a member today! Go to: www.pwsausa.org and click on Membership

PWSA (USA) Member Benefits include:

- 20% discount on merchandise
- *Gathered View* newsletter
- Members only online access
- Free Webinar registration

Another great publication from PWSA (USA)



Estate and Guardianship CD

By Lisa B. Thornton, Attorney and Stephen Leightman, AWM

Ready to jumpstart your estate planning this summer? This CD contains the PowerPoint presentation plus great sample templates for a simple will, special needs trust and letter of intent from the PWSA (USA) National Conference. $30.00 (2013)

http://bit.ly/2tc8870pwsausacd

Family Support Campaign Around the Corner

Families across the country count on PWSA (USA)'s comprehensive support programs for resources and support for new diagnosis, school assistance, nutritional support, and much more. This summer, we'll be highlighting these services:

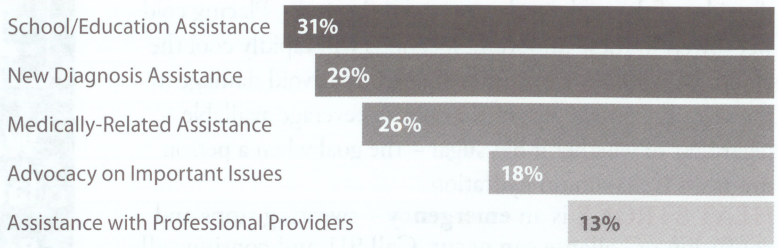
In just one quarter, nearly 600 Family Support activities were provided to families within the PWS community. That is a big number, but we have much more work to do. As demand for our services continues to grow, PWSA (USA) relies on the generosity of donors like you to help save and transform lives.

Regardless of size, your gift is important. Please visit us online and donate today. www.pwsausa.org

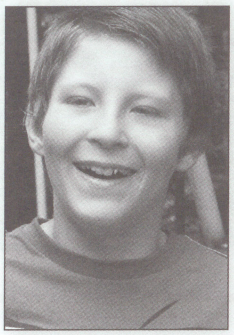
Reaching out to PWSA (USA) was one of the best decisions I have made, both for Kayleigh and us, her parents. We promptly were invited to join a support group and several people contacted me to introduce themselves and ask if I had any questions or needs. I did not realize how good it feels to have such support… Grateful does not even begin to cover the extent of my gratitude for such an amazing association and group of people. Thank you!

~ Erika, PWS Parent

Breakdown: Family Support Services Provided Last Quarter



Percentages shown represent distinct service types and therefore exceed 100.



Meet Ethan!

Ethan, age 12, is an absolute sweetheart!

He has been in foster care since January of 2012. Ethan has made tremendous progress since he first entered care until now in all aspects of his life.

Ethan longs to have permanency in a family that can provide the time and attention that he needs to be successful and for him to finally feel 'at home'.

Ethan was diagnosed with Prader-Willi syndrome as a young child. When he came into care, he was obese due to poor management of his diet and medication. He is currently at a healthy weight and receiving growth hormone treatments as well as medication to help control his eating. His foster home of nearly five years was recently disrupted through no fault of his own. While in that placement though, he did exceptionally well; however, that home had no plans of providing him with a forever family. He loved to help his foster mom around the house and he looked for opportunities to help her.

In the past, Ethan has displayed aggression towards adults (mostly); however, those behaviors are neither frequent nor typical of Ethan when he is in a stable environment. His medication has been adjusted in order to assist with agitation. Ethan does struggle with change, as do most children with Prader-Willi, and he requires routine and consistency. In the past, he would typically become aggressive when overwhelmed or forced/pressured to do something he does not want to do/feel comfortable doing. He also has a history of running from adults (while in the store, in the parking lot, he has ran out into the road before, etc.). Ethan has also struggled in the school setting because of these behaviors and was removed from the public school system for a time because of acting out towards school staff; however, in the fall of 2015, he began school full time and just successfully finished another school year! He now attends a transitional day program (very small classroom, lots of one-on-one attention). The school intends to transition him back to the local public school by the end of 2017.



Some of Ethan's interests are anything SPIDERMAN, coloring, playing video games, the Avengers, and different types of dolphins. He loves church and even sang in the church choir!

Ethan is a very precious young man. He is capable of completing small tasks, but does require supervision and direction. He's a very smart boy and very affectionate. He may need time to adjust, but with time and the correct supports he can certainly transition into another loving home successfully.

Consider helping Ethan find his forever family.

Contact Information:
Heather Looney, Foster Care Worker (276) 688-4111

Meet the Candidates - PWSA (USA) 2017-2020 Board of Directors



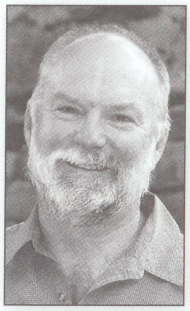
Mitchell H. Cohen
Weston, Connecticut

Mitch and his wife Francine have a daughter Ali, who has Prader-Willi syndrome. They have recently been working, successfully, on the first steps in her transition to a new supportive living environment. That change also required navigating the change to their home state of Connecticut for the proper funding mechanism.

Mitch currently serves on several boards for charitable organizations and has been honored for his charitable giving and fundraising efforts.

Professionally, Mitch Cohen leads Ernst & Young LLP's Global Life Sciences Tax practice. In this capacity, he has worked with many of the firm's largest pharmaceutical, biotechnology and medical device clients, and currently serves as tax coordinating partner for several of Ernst & Young's high-profile global clients.

Mitch received a BS in Accounting from Syracuse University and a JD from The State University of New York's University of Buffalo Law School. ■



Peter Girard
Townsend, Tennessee

Mr. Peter Girard has been married to his wonderful wife Gayle for 35 years.

They had two children born in 1987, twins, Amanda and Jeremy. Jeremy was diagnosed with PWS at the age of 9.

He has owned several successful businesses. In 1982 he started his first computer company and later sold it in 1990. In August 1990 he became an Air Traffic Control Specialist with the Federal Government and retired in 2012. During this time he also operated a computer consulting business that he still operates today. In 2008, along with family members, he purchased and renovated a motel in Townsend, and is currently the managing partner.

He has served on the Board of Directors of the Lake Conway Woods Homeowners Association as Vice President and is currently serving on the Board of Directors of Mountain Miatas of East TN, a 501(c)(7) organization, as Treasurer. While on the Board of Mountain Miatas, Pete has been instrumental in focusing the club on charitable giving.

Pete has served one year on the PWSA (USA) Board and has volunteered at the National Conferences since 2003, providing Audio Visual Support. ■



Tammie R. Penta
Tucson, Arizona

Tammie Penta is a retired police sergeant with over 27 years' experience. She is a recognized expert in elder and child abuse investigations, spending 10 years conducting criminal investigations from family crimes to organized crime. Additionally, she spent four years as a field training supervisor at the Southern Arizona Law Enforcement Training Academy, where she developed training programs as well as assisting in the Crisis Intervention Training where law enforcement, the Department of Developmental Disabilities and citizens with special needs or a family with special needs taught Southern Arizona Officers how to address crisis situations with people with developmental or mental health issues. Specific to this training was how to address the issues with several adult PWS homes that are located in Southern Arizona. This training has been taught in this area for nearly 14 years now and continues to be successful in educating local law enforcement. She has been on the PWSA (USA) Board of Directors, completing her first term this year. During her three years on the board, she has been the committee chair for the family support and leadership committees. Tammie has also served on the executive, chapter leaders and advocacy committees. Additionally she has sat on the Arizona chapter for Prader-Willi syndrome since 1996 and was certified through the (WSEAT) Wyatt Special Education Advocacy Training in 2013. Tammie and her husband Phil have been married for 24 years. Son Victor, age 23, was diagnosed with PWS at the age of two. Victor graduated high school in 2015 and is currently living at home. Son Nick, age 27, has completed his degree in health sciences and daughter Raquel, age 21, completed high school and is employed as a certified nursing assistant and respite provider while continuing her education in special education. This diverse background, along with her work ethic, dedication and motivation to improve the lives of those affected with PWS and their families will make her a desired candidate for this position. ■

e-News...

Reminder – stay informed and current with PWSA (USA)'s free e-News. Sign up by clicking on our Web site: www.pwsausa.org and watch for the next update!

Prader-Willi SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

PWSA (USA) 2017-2020 Board of Directors OFFICIAL BALLOT

Voting Instructions:

1. Review the candidates' statements printed on the Slate of Candidates.
2. Cast your vote on the Official Ballot, voting for three (3) candidates only. Insert the ballot into the Official Ballot Envelope.
3. Print and sign your name on the Official Ballot Envelope. Affix postage. Mail it to PWSA (USA) postmarked no later than August 19, 2017.
4. If you receive *The Gathered View* only in an electronic form and were not provided with an Official Ballot Envelope, please mail your ballot to: Julie Doherty, Secretary, PWSA (USA) 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471.

In the return address portion of the envelope, print your name and address and the following statement: I am/We are a PWSA (USA) Member in Good Standing Eligible to Vote. Place your signature below this statement.

Deadlines:

The deadline for voting is August 19, 2017. Ballots postmarked after August 19 will not be counted.

Confidentiality:

Your vote will be kept confidential. PWSA (USA) staff will verify voter eligibility and separate the Official Ballot from the Ballot Envelope before the Ballots are tallied.

Voting Criteria:

Voting members must be Members in Good Standing with PWSA (USA). Membership dues must be current and paid in full or a dues waiver granted.

Member Types Eligible to Vote: Each membership type, whether individual, family or professional, is entitled to one vote. ■

OFFICIAL BALLOT

Cast your vote for the 2017-2020 Board of Directors. Vote for three (3) of the candidates listed below.

☐ Mitchell Cohen ☐ Pete Girard ☐ Tammie Penta

Follow above directions to ensure your vote counts, then mail to:
Julie Doherty, Secretary, PWSA (USA) 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471.



Hunter Lens Event Successful Again...

Parents John and Lori Lens reported that: "overall, we had over 100 attendees participate in our eighth annual Prader-Willi awareness day. The event is held at a local par three executive golf course that allows women, children and men to play - bringing the community together, raising awareness and dollars for the association, while most importantly spending time with families and friends. To date, we have raised over $26,000 this year and we're still counting - with the help of company matching donations which are critical for us in raising the revenue we achieved."

Congratulations to the Lens family and many thanks to everyone who helped hold and who supported this fun event! ■

L to R: front row- Derek Barboza, Bruce Barboza, Lenny Barboza; back row- Hunter Lens, Brian Medieros

EMPLOYER MATCHING GIFT PROGRAMS

Many companies support their employee's charitable donations through MGP. In a couple easy steps, it's easier than ever to find out if your company participates and how to get started. If your employer doesn't currently participate in a MGP, PWSA (USA) can help you get set-up.

You Give + They Match = Double the Donation

1 Go online to **www.corporatematching.org** to see if your company is enrolled

Or

Ask your employer's HR department

2 If they are enrolled, print out or go online to complete form for your gift to be matched

If they are not yet set-up to match with PWSA (USA), *contact:* **Devon Young dyoung@pwsausa.org**

3 Celebrate! You just doubled your donation!

Employers often match 100% of your donation

QUESTIONS? CONTACT US : 1-800-926-4797

Current employees, retirees & spouses are often eligible!

FUNDS WILL ADVANCE AND ENHANCE

AWARENESS EDUCATION FAMILY SUPPORT RESEARCH ADVOCACY



Left to right: son Jake, mother Laura, dad John and sister, Katie.

$5,000 In Honor

A $5,000 donation was made to PWSA (USA), in honor of the Pawulak family, by a generous employer; shown in this holiday photo are son Jake, mom Laura, dad John, and daughter Katie. John Pawulak works at Clune Construction, which is a national general contractor with offices in Chicago, Los Angeles, McLean, VA, New York, San Francisco and Washington, D.C. Clune employs more than 450 professionals and manages $920 million in commercial and mission-critical projects annually. Clune believe the hallmark of their success is grounded in their dedication to consistently delivering clients' projects on time and under budget, with honesty, integrity, and a great deal of emphasis on client satisfaction.

Our deepest gratitude to Clune Construction Company, L.P., and heartfelt thanks for generously making a difference for children with PWS. ■

We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more good work(s) like this. Please see our web site, www.pwsausa.org

Casting for a Cause Catches Success









With some of the finest fishing in the world, South Florida was recently the site of the ninth annual ***Casting for a Cause*** tournament – a premiere PWSA (USA) event. Over $100,000 was raised through the tournament, funds that will be used to support the national convention and to enhance the organization's five key strategies of awareness, education, family support, research, and advocacy.

Congrats and kudos go out to the volunteers, led by PWSA (USA) Board of Directors chair Michelle Torbert, that put on the great event for both die-hard anglers and fun-loving supporters. Title sponsor 5 Brothers Produce was joined by dozens of other sponsors and supporters in making this ***On The Move*** (OTM) event so special.

PWSA (USA) leaders applauded the volunteers from the Sunshine State for their creativity and huge success, with Development Director Steve Queior saying "OTM events come in all shapes and sizes – from walks and golf outings to picnics and dinners, and supporters in one area putting on a Trivia Night. Simply let us know at the national office if you'd like to chat about putting your own fundraiser on, as the staff has information, templates, and tools to make it easy for you." ■



Watch for what's coming soon!

From the Home Front

Before and after





By Gage Haverfield, dad to Claudia

This journey started the day Claudia started high school. We've had our ups and downs at school but we saw her going into a funk that we had not seen in a long while. The people that were working with Claudia were trying but the environment in most high schools is the complete opposite of what we see as essential for PW success. Things that seem so insignificant in a typical child's school setting like a coffee shop with pastries and bagels can turn a student's day with PW into a living nightmare.

Things got really bad in our situation- to the point where Claudia had started to refuse to go to school. She cried almost every day about school and became very depressed. Claudia was involved in competitive cheerleading for kids with disabilities and Special Olympics swimming, but even that became super difficult because of all the frustrations culminating from school.

In September of 2015 we made a visit to Prader-Willi Homes of Oconomowoc, Wisconsin (PWHO). We had never really entertained leaving our baby with anyone. We received a tour of all the facilities. Many of the residents wanted to know if we were bringing our child here and they went on about how there is a true sense of community and friendship. One young man came up to me. He wanted to see a picture of Claudia so I showed him one on my phone. As we were parting he said that if she decided to come to PWHO she had a friend there waiting for her.

We knew it was the right place. Claudia has been at PWHO since February 11, 2016. PWHO has great medical resources in the area and dietician "magicians." You can see from the pictures the transformation into healthy individuals. Claudia came to PWHO at 267 pounds. As of April 14 as I'm writing this she is 167 pounds. A full 100 pounds lighter! She is off many of her medications or on reduced doses. The weight management is a huge success, but beyond her physical health, PWHO has made huge gains for her emotional health. She is surrounded by a community of individuals with PW and that makes her happy. It's definitely not an easy decision to have a child 500 miles from home. For us it was the best choice and I encourage you to at least explore the possibilities for your loved one. ■

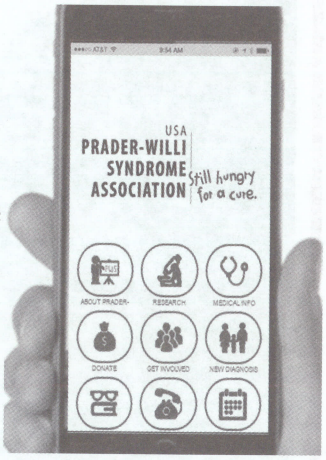
http://www.pwho.com
http://www.geneseelakeschool.com

Carry PWSA (USA) Wherever You Go!

By Evan Farrar, M.A., Research Coodinator and Family Support Counselor, PWSA (USA)

Are you carrying PWSA (USA) in your pocket? If not, why not? Because now you can by downloading the **FREE** PWSA (USA) app for your smart phone. With this app, you will have immediate access to all the important information you need on the PWSA (USA) Web site with a touch of your phone screen. Forget a handout you wanted to share with a teacher or doctor? No problem. It's all on your phone! Through this app you can:

- show your child's doctor important medical information during an appointment.
- watch a school video with your child's IEP Team.
- read the latest news on research and other topics of interest.
- provide ER staff with key medical alerts during emergencies.
- conveniently explore family support and other resources available to you.



You can also encourage all the family, friends, and professionals in your child's life to download the app so they can know what you want them to know about PWS and the support needs of your child.

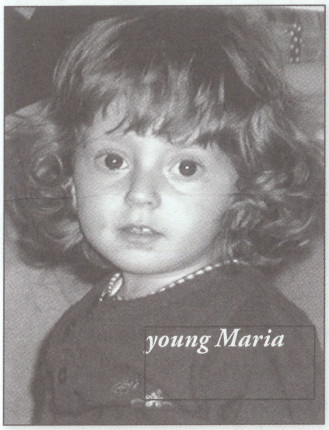
So what are you waiting for? Start carrying PWSA (USA) wherever you go by downloading today the PWSA (USA) app available for Android and iPhones. ■

A Special Time



Maria

Maria was listening to her mom Anne, in the kitchen, when this photo was taken. It was right before we started shooting photos before and during her high school prom, which she attended with a graduating senior as her date. The prom was fantastic; Maria will be a junior in the Fall. Her date graduated and will be attending college. Maria's still on growth hormone, helping to regulate her slow metabolism, keeping her weight down and preventing unhealthy obesity. Maria and I (her dad) regularly walk with her new "therapy dog" (Beau) about two miles per day. Beau is a natural therapy dog because of his natural instincts, which detects whenever Maria's about to have an anxiety attack or seizure. Beau, a "Goldendoodle" (English Retriever and American Poodle), doesn't shed and is devoted to the entire family. Beau has a special affinity to care for Maria, never seen before in the other three prior dogs we've had during her lifetime.



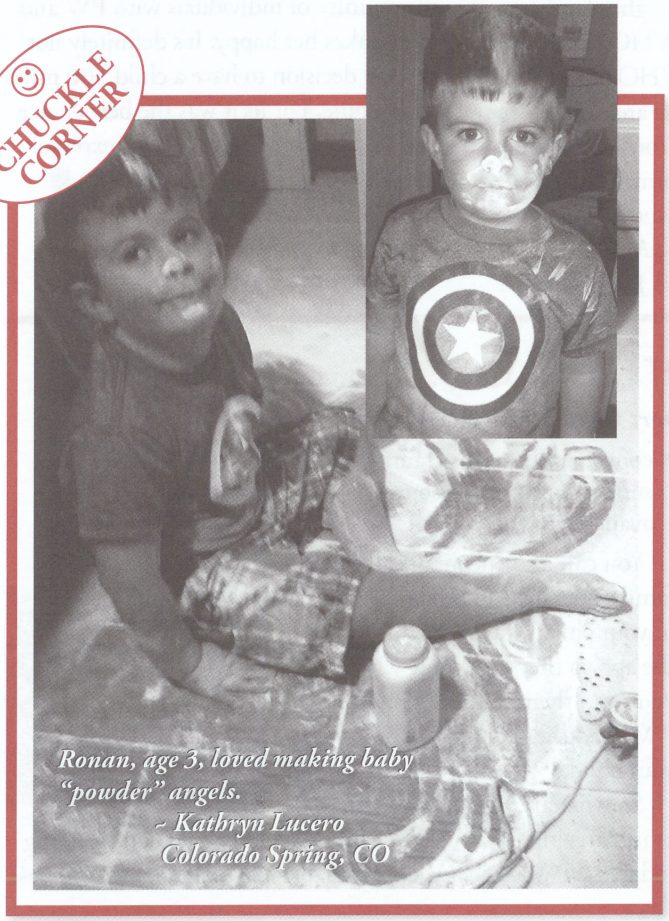
young Maria

Our family vacation will begin with a drive to Disney World. The girls enjoy the scenic journey riding through the states. Every other year, these trips create lasting memories for the entire family.

Oh yes, I've included photos of Maria. She had a great time, both with her "makeover" and special date for this magical night. Between the hair salon and her cousin doing her makeup, the whole experience was a very big deal. Maria will always remember this. We found when we make positive "big deals" of her teenage experiences, it makes Maria feel like the beautiful young woman she has become and that's priceless for her self-confidence. ■

Her proud dad,
Bill Vucci

CHUCKLE CORNER



Ronan, age 3, loved making baby "powder" angels.
~ Kathryn Lucero
Colorado Spring, CO

WE REMEMBER
Dr. Andree Walczak

Late Spring 2017, we were notified of the death of Dr. Andree Walczak, one of the early pioneers on Prader-Willi syndrome. She was a PWSA board member from 1980-1983. Dr. Walczak had a PWS clinic at Michael Reese Hospital in Chicago in 1981 when we (Janalee and Al) visited her. That was at a time when we were contemplating starting a Missouri support group for PWS, but only knew of two other families in the St. Louis area. Dr. Walczak told us that she began her program with two children who had PWS, and by the time we met her, she had 26 in the program. She told us that there were approximately 2,000 people with the syndrome known to PWSA (the USA was added later) and she was a great encouragement for us starting what became the Missouri state chapter. There are now over 8,000 with the syndrome known to PWSA (USA). We lost track of Dr. Walczak when she left Chicago, but did hear that she retired to Arizona. We remember her as a very kind and wise physician.

~ Janalee & Al Heinemann

Pennsylvania and Sheltered Workshops

By Lota Mitchell, mother to Julie, with PWS

On January 25, 2017, I received a phone call which would change my life for many weeks to come.

Our daughter with PWS, Julie, 47, has lived in a group home at Keystone Community Resources (KCR) for 23 years. KCR, a large provider of residential and workshop programs, is in Scranton, far east Pennsylvania. My husband and I live in Pittsburgh, far west Pennsylvania. KCR has an excellent program for 24 individuals with PWS, a small piece of its total pie, and several sheltered workshops and day programs.

The phone call from KCR warned of a serious threat to the sheltered workshops and day programs of Pennsylvania – and every state in the nation. Driven by the Federal Home and Services Based Rule of January 2014 and the Workplace Initiatives and Opportunities Act (WIOA) signed into law by then-President Obama in March 2014, states were to have their policies in compliance by this year. The goal was to bring adults with Intellectual Disabilities (ID) and autism more into the community and avoid segregation. States were given some flexibility, but several simply shut down their sheltered workshops and day programs.

Pennsylvania's proposed policies went beyond the mandate. In January 2018, consumers (the ID and autistic population) were to spend 75% of their time in workshops and day programs and 25% in the community. Six months later this changed to 50% in workshops and day programs and 50% in the community. Another six months later they could spend only 25% of their time in workshop and day programs and 75% in the community.

The state said it was not shutting down these programs. Actually, it wouldn't need to. At 25% utilization, financial survival would not be possible, forcing closure.

The KCR call was followed by a letter informing me and another parent from the Pittsburgh area, Larry Emark, about parent meetings and a conference call number for those too far away to attend.

Parents on the western side of the state knew nothing about this. In fact, providers had been told not to tell their families. Ten state representatives from the eastern side had signed a letter expressing their concern over these policies. My state representative had no knowledge of it. So the #1 goal was to get the word out.

I called the national office about sending an e-blast to all our Pennsylvania email addresses, and the next two weeks were spent with the Pennsylvania chapter president, Maria Silva, and I struggling over the wording. At last it went out. Did it help? We'll never know, but the capital in Harrisburg was deluged with a flood of phone calls, emails and letters. The damaging 75/50/25% policy was removed.

A hearing was held in Harrisburg on March 13, with a rally preceding it with an estimated attendance of 750. KRC sent three busloads of people plus a van with staff and a few residents. Larry and I drove from Pittsburgh the night before. A microphone was set up with press photographers in the lower level of the Rotunda of the Capitol Building. Julie and I both had a chance to speak briefly, along with many others, about how important workshops and choice are.

During the hearing the committee of state representatives and the rest of the audience listened to "testimony" from Ted Dallas, State Secretary of Human Services, and Nancy Thaler, Deputy Secretary of the Office of Developmental Programs, which had issued the policy. Other speakers were mainly high level people responsible for providing workshop/day program services in different organizations.

The hearing continued for a full two hours. The committee seemed to be in sympathy, expressed concern for adequate funding, and later issued a very favorable resolution supporting sheltered workshops/day programs. The bill has not been voted on yet, and work on funding questions is ongoing. Secretary Price has sent a letter to all states delaying compliance until 2022.

The situation appears better than on January 25. Government is far more complicated and layered than I ever dreamed; yet sometimes ordinary people can make a difference. ■

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

~Margaret Mead

Update on PWSA (USA) School Initiatives

By Evan Farrar, Family Support Counselor

Over the past 5 years, PWSA (USA) has developed a special education advocacy program for parents that is unmatched in the rare genetic disease community. The program goals are:

- To equip parents to act as effective school advocates for their child.
- To equip school professionals to appropriately and effectively serve students with PWS.
- To facilitate the creation of a positive working relationship between parents and school professionals.

We are advancing these goals through two primary initiatives.

The Wyatt Special Education Advocacy Training (WSEAT)

Named in memory of our first family support counselor, David Wyatt, the WSEAT consists of 6 online training modules. Parents and school professionals can view one or all the modules depending on their needs. Each module includes recommended reading and downloadable resources.

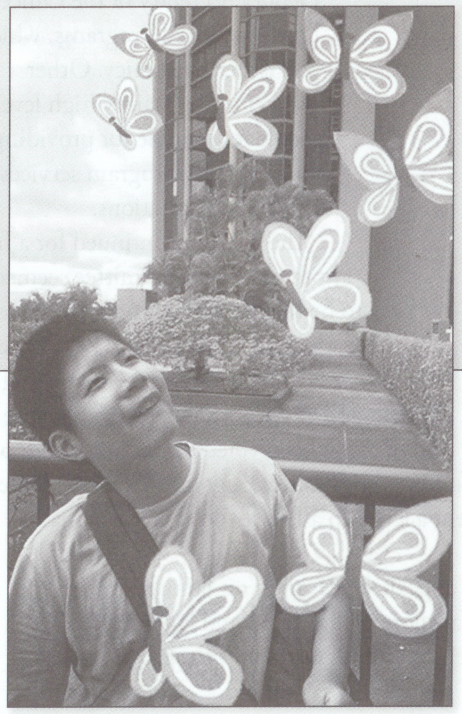
Module 1 and 2: The Power of Inclusion and Responding to Behavioral Challenges: In these modules parents will learn about the importance of inclusion and how schools should respond to behavioral challenges.

Module 3 and 4: Effective Advocacy: In these modules, parents will learn about school advocacy and practical advocacy tips and strategies.

Modules 5 and 6: PWS Specific School Challenges and Solutions: In these modules parents **and** school professionals will learn how to address common PWS-specific school issues such as food security. These modules are also great resources for school professionals.

Parents can also order a **free** copy of the book *From Emotions to Advocacy* published by Wrightslaw. The book is a comprehensive overview of special education advocacy for parents and should be on every parent's bookshelf.

If you have a school aged child, and have not visited the WSEAT page on the PWSA (USA) website, then check it out today. It is the single most important school advocacy program PWSA (USA) has ever created and it is all free! ■



Corbin Soo - May Day

School Times E-Letter

School Times is a **free** e-letter that focuses exclusively on PWS related school issues. It is written for parents and school professionals, with over 1,000 subscribers. Past issues are on the PWSA (USA) website. ***School Times*** covers topics like: effective advocacy, resources for school professionals, parent/teacher perspectives and breaking hot topics. New sections include: early childhood education, home schooling, and resources for Spanish speaking parents. To subscribe, simply visit this link: http://bit.ly/2s2mPpBSchoolTimes and fill in the form for your free ***School Times*** ! ■

Register PWSA (USA) as your charity of choice when shopping on Amazon and they will donate a portion of the price of your eligible **AmazonSmile** purchases to Prader-Willi Syndrome Association (USA) when you shop on **AmazonSmile.** To get started: https://smile.amazon.com/ch/41-1306908 ■

Prader-Willi SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

Our Mission: Prader-Willi Syndrome Association (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

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The Members Only section requires a password: member20

E-mail Support Groups: We sponsor nine groups to share information. Go to: www.pwsausa.org/egroups

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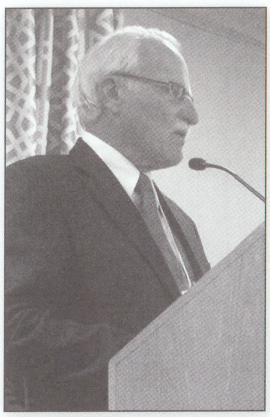
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Board Member Koerber Honored Chevron Retirees Award Dinner

On May 22, 2017 Jim Koerber, Vice-Chair of the PWSA (USA) Board of Directors, was honored and recognized by the Chevron Retirees Association for his work with PWSA (USA) State Chapters (Indiana and California) and our National Chapter. He was also instrumental in achieving on a political level, of adding PWS to the California State definition of developmental disability, as defined in the Lanterman Developmental Disabilities Service Act. This addition ensures all those diagnosed with PWS automatically qualify for services in California.

Jim has drawn from his many years of experience at Chevron to lead a committee to develop a strategic plan for our association. The Prader-Willi Syndrome Association (USA) annual business plan incorporates the use of our vision, mission and strategic plan, into a plan detailing the time, attention and labor of people for organizational and financial improvement. This plan ensures we are all working together for that common good. Jim draws off all his life experiences through his professional work at Chevron, and raising a daughter with PWS. He and his wife Rita made it their mission to learn as much as possible about PWS to help enrich the life of their daughter and all others with the syndrome. Jim is nearing the end of his three-year term on the Board and hopes to continue his contributions and leadership of PWSA (USA). Congratulations, Jim! ■

In this Issue

Cindy Beles ..... Front Cover
Advocacy Network 2
Thyroid Issue 3
Family Support 6
Meet the Candidates 7
Development/Communications 9-10
From The Home Front 11-12
Making a Difference in Pennsylvania 13
School Initiatives 14