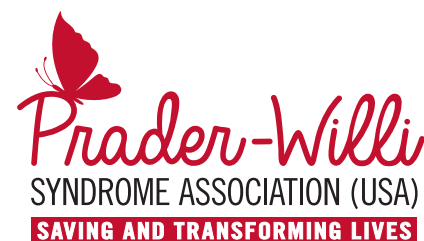


The Gathered View

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



CEO View By Steve Queior, PWSA (USA)

Together We're Strong – Because of Volunteerism

Volunteerism is alive and well in the United States. In fact, the phenomenon of literally millions of Americans sharing their time, talents, energy, and resources supporting thousands of great causes is key in protecting and improving our quality of life in this country.

Saving and Transforming Lives of those affected by Prader-Willi syndrome is one of those great causes. On behalf of our entire organization and the PWS community, let me thank you for what you do to help those affected by the syndrome. This issue of *The Gathered View* has profiles of six volunteers willing to make a difference by committing the extensive time and effort required to be a member of our Board of Directors. The board, of course, is extremely important to the ability of PWSA (USA) to deliver our Five Pillars of Support: Awareness, Family Support, Research, Education, and Advocacy.

That said, the focus of the book *Servant Leadership* is that the most important role of volunteers “at the top” of the organizational chart is really to serve those making positive impacts “in the trenches” - supporting those serving on committees, organizing grassroots fundraisers, and helping with the good work of chapters around the country.

This book's author, Robert Greenleaf, said “*Nothing in this world happens except at the initiative of a single person.*” Bill Gates added that “*Leaders are those who*

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Be an Advocate for Change

The actions of Congress, states, and rule-making bodies such as the Centers for Medicare and Medicaid Services have a direct affect on individuals with Prader-Willi syndrome and their families.

PWSA (USA) receives daily inquiries about public policies that control access to health care and insurance claims. Our office is also regularly asked about rights to educational and vocational opportunities and about residential placement, including whether certain funding streams can meet specialized housing needs. PWSA (USA) supports increasing funding for treatments and drugs that will help those with PWS. Together, the PWS commUNITY can ensure our collective voice is heard by decision-makers creating policies affecting our lives.

Recognizing the impact of effective advocacy in ensuring improved health, safety, and enhanced quality of life for those affected by Prader-Willi syndrome, the PWSA (USA) national board recently approved the creation of a **Public Policy Action Center** (PPAC). The action center is a true “game-changer” that will strengthen our influence on public policies to ensure maximum benefit for the PWS community. In addition to the creation of the PPAC, the PWSA (USA) Advocacy Committee has doubled in size and has recommitted itself to informing the PWS community of critical public policy issues and leveraging the power of grassroots supporters.

Why It Matters

Because Prader-Willi syndrome is considered a “rare disease,” extra effort is needed to raise awareness of elected officials to help pass legislation and regulations that help our community, and to defeat those that do not.

While the PWS community might not have the resources of larger groups, positive change is possible. More education, effective communication, and strategic alliances with partners in the PWS and rare disease communities will help ensure:

- ✓ “Pre-existing condition” insurance status is maintained, and that health care remains affordable
- ✓ Access to appropriate residential and day programs to learn job skills
- ✓ Education and training is available
- ✓ Communities and schools are aware of and are equipped to work with individuals with PWS and their families
- ✓ New medicines and treatments are more readily available

These are just a few of the many critical issues the PWS community is being asked to support.

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Together, the PWS commUNITY can ensure our collective voice is heard by decision-makers creating policies affecting our lives.

Volume 43, Number 4 ~ July-August 2018 ~ Our 43rd Year of Publication

The 2018 RARE Act

The Rare Disease, Advancement Research, and Education Act of 2018 (H.R. 5115) or RARE Act of 2018 was sponsored by Andre Carson (D-IN) and co-sponsored by Ryan Costello (R-PA), Elanor Holmes Norton (D-DC), Mark Pocan (D-WI) and Peter Visclosky (D-IN). Congressman Carson introduced bill H.R. 5115 to the House on Rare Disease Day, February 27, 2018. The bill was then referred to the House Committee on Energy and Commerce on 2/27/18 and the Subcommittee on Health on 3/2/18.

PWSA (USA), along with other patient organizations representing the millions of men, women, and children living in the United States with rare diseases, support the “RARE Act of 2018.” This legislation, if enacted, has the potential to improve the lives and well-being of the thousands of Americans living with Prader-Willi syndrome.

The RARE Act would provide much-needed investment in rare disease research; direct the Centers for Disease Control and Prevention (CDC) to increase its efforts in tracking and quantifying rare diseases; require the Agency for Healthcare Research and Quality (AHRQ) to implement rare disease outreach and awareness campaigns for physicians; and commission additional analysis and recommendations from the National Academy of Sciences on how to accelerate rare disease therapeutic development.

Each of the provisions within the bill would be of substantial benefit to the PWS community. **First**, this legislation would greatly *increase the funding* authorization for the Rare Disease Clinical Research Network (RDCRN). This network is administered by the National Center for Advancing

Translational Sciences (NCATS) within the National Institutes of Health (NIH). The RDCRN

represents one of the most robust and collaborative research networks dedicated to rare diseases in the world. However, the program is only open to a small number of diseases due to funding limitations. This bill would help address this problem by authorizing sorely-needed additional funding.

Second, this legislation would *increase the understanding* of rare diseases by requiring CDC to create the “National Rare Disease or Condition Surveillance System.” This system would track and quantify rare diseases in the U.S. in order to facilitate research, development, and treatment for rare disease patients.

Third, this legislation would require AHRQ to *expand its efforts in educating* our nation’s physicians on rare diseases, including PWS. The physician community is generally unaware of rare diseases, and significant additional outreach is needed to better equip our physicians to treat the rare disease patient population.

Finally, this bill would require the National Academy of Sciences to update its 2010 report, “Rare Diseases and Orphan Products: Accelerating Research and Development” outlining the state of rare disease therapeutic development and put forward new recommendations within the next several years. Given that 95 percent of rare disease patients are still awaiting their first treatment approved by the Food and Drug Administration (FDA), these recommendations are desperately needed. ■

This legislation, if enacted, has the potential to improve the lives and well-being of the thousands of Americans living with Prader-Willi syndrome.

CEO View, continued from page 1

empower others.” Throughout PWSA (USA), we are working to develop new ways to empower you to create positive changes. For example, a major opportunity to leverage your support is making your voice heard in public policy advocacy, as described in the adjoining article “*Be an Advocate for Change*”.

Volunteers involved in the Prader-Willi Alliance of New York and the Prader-Willi Syndrome Association of Colorado recently hit home runs through their advocacy, each convincing their state legislatures to recognize – in law – that PWS is a qualifying disability when determining eligibility for disability-related supports and services. Let’s work

together to replicate these great successes in many more states.

While joining our Advocacy Committee is one way to volunteer, there are many others. These include participating in other committees focused on programs ranging from chapter relations to our national convention, and from fund development to publications to family support. We also have experts serving on multiple advisory boards, including the Scientific Advisory Board and the Clinical Advisory Board. And I do want to come back to the board of directors, as they also drive the work of the finance, executive, leadership development, and audit committees.

Grassroots activities offer great ways

to be involved in forwarding our cause. These include helping out your state or regional chapter, setting up peer fundraising sites on the web, and/or having a local event. This type of activity provides satisfaction, connects you with other fine folks, and increases awareness about PWS. Rikka Bos of our staff team (rbos@pwsausa.org) would love to chat if you want to explore these opportunities.

It has been said that “*We are all faced with a series of great opportunities brilliantly described as insoluble problems.*” So, while individually we are faced with many challenges, together we are strong. Please consider volunteering for the cause, and join me in sincerely thanking those involved in helping *Save and Transform Lives*. ■

Organization View

Advocate for Change, continued from page 1

The New PWSA (USA) Public Policy Action Center (PPAC)

In June, this easy-to-use resource was put on the website for the entire PWS community to make their voice count on multiple key issues. Accessible via the link <https://p2a.co/KglyyNs> this powerful software platform provides information about key legislative and regulatory issues. The issues are grouped in four areas:

- Residential placement and housing issues
- Access to health care and insurance coverages
- Research, treatments, and drug development
- Education, school, and vocational issues

The first *Call To Action* stakeholders are being asked to support is passage of the **Rare Disease Advancement, Research, and Education Act**, often called the RARE Act of 2018. If passed, this bill will:

- Increase rare disease research funding
- Create new efforts to track and combat rare diseases
- Educate physicians on rare diseases
- Commission additional research

It Only Takes Two Clicks to Impact Elected/Appointed Officials

Once you initially enter your name and address in the PPAC, you'll never have to do that again. The PPAC software will know, by your zip code, who your elected representatives are and address your message to them.

The PWSA (USA) office has pre-loaded a supportive message about the RARE Act, which you can personalize however you'd like. Then, one just clicks how they'd like their message sent: by email, Twitter, Facebook, and/or patch-through telephone call; anyone can use one or up to all four of these methods of communicating their support.

If a member of the PWS community would like to be notified about future critical issues, they just need to mark a single box. Everyone is encouraged to not only check out the new PPAC and support the RARE Act, but also to sign up to receive information on upcoming policy issues.

Lastly, please let the PWSA (USA) office know of laws, rules, and regulations our Advocacy Committee might review and analyze. Your input and questions can be emailed to Advocacy@pwsausa.org. ■

PWSA (USA) 2018-2021 Board of Directors Approval of 2017 Annual Membership Meeting Minutes OFFICIAL BALLOT Voting Instructions:

1. Review the candidates' statements printed on the Slate of Candidates on pages 5-6. Read the 2017 Annual Membership Meeting Minutes on page 4.

2. Cast your vote on the Official Ballot, voting for six (6) candidates only. Note any corrections necessary to the Annual Membership Meeting Minutes. 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 17, 2018.

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 17, 2018. Ballots postmarked after August 17 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.

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PWSA (USA) General Membership Meeting

Caribe Royale Hotel, Orlando, Florida

Saturday, November 18, 2017

The meeting was called to order at 11:53 a.m. by PWSA (USA) Board of Directors member Jim Kane.

IPWSO: Dr. Tony Holland, IPWSO President, thanked us for the opportunity to speak on behalf of the organization and thanked PWSA (USA) for their many years of support of their mission and work. IPWSO has 34 member countries and 100 additional countries that have been contacted in various degrees. They have subgroups of an SAB, CAB, PPCB and FamCare, which supports families supporting adults with PWS. They support countries where there is no PWS organization, through the IPWSO Web site and printed materials. They also offer free diagnostic testing, which is very important for countries with no test sites and for countries where the testing is very expensive. Workshops are held worldwide. A conference is held every three years, with 2019 to be in Cuba. "Friends of IPWSO" is now a registered charity in the United States to raise funds for IPWSO. Deanna Wells was the winner of the backpack drawing.

Executive Director: Ken Smith thanked convention program chairs, as well as Michelle Torbert and Jackie Mallow, for making this our largest convention with the largest number of new families in attendance.

Fund Development: Steve Queior noted that Sara Dwyer, editor of *The Gathered View*, is here and encouraged attendees to share their great stories with her. Convention sponsors were thanked, as their support lowers the registration price for everyone. The exhibitors were thanked, and attendees were reminded to turn in their stamped cards to be eligible for tonight's drawing for a free iPad and free 2019 convention registration. The state chapters were recognized for providing

assistance to families to attend. A convention scholarship committee was formed and those sponsors were recognized. The Five Pillars of Support were shared with attendees, noting that we are a full-service organization that provides Awareness, Family Support, Research, Education and Advocacy. This allows us to *Save and Transform Lives*. The Clint Hurdle Hot Stove Dinner, held in Sarasota, will take place in March. Since we don't charge for all the great services our families receive, fundraisers like our annual Angel Drive campaign is what helps the five pillars grow. The mailing for that will go out in early December.

Jim Kane closed by sharing a personal story of how PWSA (USA) literally saved his daughter's life. Of the 6,000 rare diseases, our organization is the **ONLY** one in the world that supports our families and provides the services we do. We should take pride in the fact that our counselors help families through the first years, through the IEP process, and through group home placement. He presented "**three asks**" to the attendees: **1. Use us.** Use the other families in these rooms. Reach out and

allow us to help you. In doing so, it helps us *Save and Transform Lives*. **2. Get involved** at the state or national level. It will help the person you're helping, but will transform you as well. **3. Convention registration** covered about half of the actual cost of the convention. **Your help is needed** to generate that money – on a small or large scale. **We need everyone to help us** because we're here to help you.

Meeting adjourned at 12:21 p.m.

Respectfully submitted,
Julie L. Doherty, Secretary

*Of the 6,000
rare diseases, our
organization is the
ONLY one in the world
that supports our
families and provides
the services we do.*



2018-2021 Board of Directors 2017 Annual Membership Meeting Minutes

OFFICIAL BALLOT

Cast your vote for the 2018-2021 Board of Directors. Vote for six (6) of the candidates listed below.

☐ Crystal Boser

☐ Dan Driscoll, M.D.

☐ Christine Geraci

☐ Kristi Rickenbach

☐ Paige Rivard

☐ Marguerite Rupnow

☐ Corrections to the 2017 Annual Membership Meeting Minutes: _____

☐ No Corrections Necessary (if neither box is checked, we will assume you have no corrections to the minutes)

Meet the Slate of Candidates



Boser



Driscoll



Geraci



Rickenbach



Rivard



Rupnow

Crystal Boser, M.B.A., Glendale, Wisconsin – Before becoming the co-owner of Root Connections Consultative Services, Crystal was the Director of Operations for an independently owned pediatric clinic for over 12 years. During her tenure, she helped the practice grow significantly by assisting in the expansion of services to include occupational therapy, speech and language therapy, as well as lipidology services. Crystal and her husband, Clint, have been married for 16 years and are the parents of Kyle, 23 years old and Kameron, 15 years old. Kyle was diagnosed with Prader-Willi syndrome (UPD) when he was four years old, and Crystal attended her first PWSA (USA) National Conference the month after receiving the diagnosis. In 2000, Crystal became an active member of the Prader-Willi Syndrome Association of Wisconsin, Inc. and is currently the organization's President. In addition, Crystal is the Chapter Relations Committee Co-Chairperson for PWSA (USA) and is a Parent Mentor for both organizations. In addition to hosting fundraisers and events, Crystal has also chaired the PWSA (USA) Chapter Leaders Meeting for several years and has assisted for many years in the YAP program offered during the National Conventions. In her free time, Crystal likes to watch Kameron compete in F.E.A.R., read, watch football, camp, and spend time with friends/family. ■

Dan Driscoll, M.D., Ph.D., Gainesville, Florida – Dr. Driscoll is a Professor of Pediatrics and Genetics, as well as the Hayward Professor of Genetics Research, at the University of Florida College of Medicine. He has been conducting clinical and laboratory research on Prader-Willi syndrome since the late 1980s. He has been a major contributor to the understanding of the genetics of Prader-Willi syndrome (PWS) and genomic imprinting in the PWS region as well as to the elucidation of the natural history of PWS. His group devised the technique (DNA methylation analysis) that is used around the world to diagnose PWS.

Dr. Driscoll is widely published on PWS and is a major spokesperson on PWS in the U.S. and internationally. He has had an active PWS clinic for the last 30 years and was the principal investigator for the PWS component of an NIH funded 11 year national Rare Disease Center grant. He has served in the past on the PWSA (USA) Board of Directors and is currently the Chair of the Clinical Advisory Board for PWSA (USA), as well as the Chair of the Clinical and Scientific Advisory Board for the International Prader-Willi Syndrome Organisation (IPWSO). He would, therefore, contribute valuable clinical and scientific expertise to the Board of Directors. ■

Christine Geraci, M.B.A., Durham, Connecticut – Christine is currently the Director of Finance for a large nonprofit located in New Haven, Connecticut that serves children and families affected by mental illness. She earned her M.B.A. in business management from SUNY Stony Brook, along with a B.A. in political science. She is currently set to achieve a graduate certificate in Nonprofit Leadership from University of New Haven in June 2019. During her spare time, she was elected to her Board of Education and was chairwoman of the Yale New Haven NNICU Family Committee. Christine and her husband, Andrew, have twin girls, Cameron and Mackenzie (PWS). The girls are currently five years old going on 25. When Christine and Andrew received Mackenzie's diagnosis, they immediately jumped in and wanted to raise awareness and educate people. They are often called to local NNICU's when new infants are diagnosed. Given Christine's expert financial background in nonprofits, she feels she would be a valuable asset to PWSA (USA). ■

Kristi Rickenbach, Minneapolis, Minnesota – Kristi and her husband, John, run Centershot Ministries (CsM) a nonprofit organization. Over the last eleven years, CsM has touched the lives of children in 48 states and 23 countries worldwide. Working with the youth in South Africa has become a yearly trip for the Rickenbachs and has changed the way they view the world. Kristi and John have been married for 29 years and have five amazing children and three beautiful grandbabies. Their youngest child, Justice Faith (14), was diagnosed with PWS (UPD) when she was one month old. Justice is currently in the 8th grade and loves helping other kids that are also dealing with PWS. Three of Kristi's passions in life are her faith, family and helping families and children that are affected by Prader-Willi syndrome. Kristi is the President of the PWSA Minnesota chapter, a parent mentor and is a committee member at PWSA (USA). ■

Paige Rivard, Omaha, Nebraska – Paige holds a B.S. degree in business administration from Kansas State University, Manhattan, Kansas. Paige is recently retired from 20 years in the credit card processing industry where she was Director of Relationship Management for National Accounts. She is currently working toward her M.B.A. in healthcare management at Creighton University. Paige and her husband, Dr. Matt Rivard, have been married for 30 years. They have a daughter, Jordan (19), a freshman at Creighton University and a son, Jake (8), diagnosed with Prader-

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Meet the Candidates, continued from page 5

Willi syndrome (UPD) and Neurofibromatosis (NF-1) at birth. Paige and Matt travel across the U.S. to see multiple specialists for both of Jake's genetic disorders. Paige and Matt are also licensed foster parents. Paige became a parent mentor with PWSA (USA) two years ago and is in the process of starting a Nebraska chapter. Paige is active in her community serving on the board of directors for Munroe Meyer Institute whose mission is "to be world leaders in transforming the lives of individuals with intellectual and developmental disabilities, their families and communities through outreach, engagement, premier educational programs, innovative research and extraordinary patient care." She is also serving on the Quality and Patient Safety Team for Children's Hospital in Omaha. Paige is active in the Omaha Public School District serving on the Superintendent's Special Education Advisory Council (SEAC). If elected to the board, Paige will bring her passion for advocating for newly diagnosed families and increasing awareness of resources to families affected by PWS. ■

Marguerite Rupnow, M.B.A., Watertown, Wisconsin

– Marguerite has been working with children and adults with Prader-Willi syndrome since 1987 and became the Director of Operations for Prader-Willi Homes of Oconomowoc in 2002. In March 2018, she became the National Director of Admissions and Advocacy for Prader-Willi Homes of Oconomowoc. Marguerite has been actively involved in PWSA (USA) and IPWSO conferences by conducting numerous presentations to other caregivers. In 2009 she had the distinct privilege to participate in the first international caregivers' conference in Herne, Germany, which was focused on developing the book the "Best Practices in Standard of Care in PWS". Marguerite has been the program leader for the PWSA (USA) national convention Youth Adult Program (YAP) program since 2009.

Marguerite has over 33 years of leadership experience and has been involved in the development of program, group home, management, and employee trainings. In 2015, she was elected to the Board of Directors of PWSA (USA). She is the past president of Respite Care Association of Wisconsin, and is on the Project Search Steering Committee for the Watertown Regional Medical Center/Watertown High School. In her free time, she is also an adjunct professor at Wisconsin Lutheran College, teaching Business Ethics and Leadership Capstone courses.

"After so many years in the field, I am always amazed at the capacity of our people to overcome an obstacle, have a view on life that is admirable and demonstrates to me how insignificant my current challenges are and to see the sunshine in the small things."

Marguerite holds a Master of Business Administration degree with concentration in health care administration/management from Concordia University of Wisconsin. She lives in Watertown, Wisconsin with her husband John, and two sons, Jabin and Jonah. Marguerite enjoys crafting, gardening, traveling, and being a "football" mom.

I am extremely honored to have served my first term on the Board of Directors and to be part of this invaluable organization in "Saving and Transforming Lives". That honor and dedication will continue if I am re-elected. ■



In Remembrance

Well Done, My Good and Faithful Servant

John Butler 9/19/30-4/22/18

We opened the PWSA (USA) office in Sarasota, Florida in the fall of 1997, and as executive director, I was working with a very lean staff of two (myself included). Among other needs, there were a lot of repairs that were needed in the aging office we were renting. Just as I was mulling over how we were going to do the repairs needed with such a limited budget, I walked John Butler offering his services as a volunteer. John, the grandfather of two girls who have Prader-Willi syndrome, (Note: It is very rare to have two from one family.) worked in maintenance at a steel company for 34 years before his retirement. **I told him it was like an angel walked in my door at the very moment I needed him!** John volunteered for us for the next 19 years – until he was no longer physically able. In the early years, John helped with everything from remodeling to small repair and maintenance jobs. When he was no longer able to get on a ladder, John was not too proud to help fold brochures and stuff envelopes.

John and Mary, his loving wife of 63 years, are the proud parents of four children, twelve grandchildren, and seven great-grandchildren. Like all of his grandchildren, John was very proud of Meghan and Lindsay, the two granddaughters who have PWS, and their accomplishments, John would be beaming when he brought them to our office for a visit when they were in town. Talking to his children and grandchildren at this memorial service, I can see that John's gift of service to others was passed down to the family. They all have a beautiful heart for helping others. You taught them well, John. ■

– Submitted by Janalee Heinemann



We can do no
great things ~
Only small things
with great love

– Mother Teresa

Central Adrenal Insufficiency in PWS - Update 2018

By Kathy Clark, R.N., M.S.N. CS-BC, Coordinator of Medical Affairs, PWSA (USA)

Central Adrenal Insufficiency (CAI) was identified as a possible risk in PWS in 2009 by a team of researchers in the Netherlands. At that time, PWSA (USA) recommended testing all individuals with PWS for this potentially life-threatening deficiency. Since 2009, other researchers have published studies which did not find the high levels of deficiency found in the original paper. These studies, done around the world, did not support this and did not find a significant risk of CAI. A review paper, summarizing all such studies, was published in 2016; it recommends that physicians continue to test for this deficiency, but that CAI may not be common in the PWS population noted that it appears less likely in adults. These authors encouraged more research in this area.

Central Adrenal Insufficiency is caused by the lack of pituitary ACTH (Adrenocorticotrophin Hormone), which acts upon the adrenal gland hormones. The adrenal glands make three hormones – cortisol (for energy and sugar balance), androgens (male-like hormones, which stimulate underarm and pubic hair growth) and aldosterone (controls salt balance). The adrenal glands also make adrenaline, which is not affected by ACTH or the pituitary gland.

Cortisol hormone levels vary during the day, with a strong burst before morning, and variations as needed for body stresses. CAI is a very rare condition and a difficult diagnosis to make. The testing is complicated, and the most accurate tests are potentially dangerous or unavailable in the USA. When an individual has a tumor of the pituitary gland or is born without a pituitary gland, the diagnosis is clear; these are the typical reasons for having CAI.

Individuals who take cortisol pills daily must wear medical alert bracelets and be provided with an emergency injection to carry, in case of a serious injury or illness such as becoming unconscious. There may be some individuals who produce normal daily quantities of cortisol but who need that “stress dose” whenever they undergo surgery or have a significant illness or injury.

If your child is currently on cortisol, you should continue this medication, and discuss these new findings at your next appointment. It is dangerous to suddenly stop taking cortisol. There are people with PWS who clearly have inadequate cortisol production and who benefit from this medication. ■

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Applied Behavior Analysis (ABA) and Prader-Willi Syndrome: Dispelling Myths and Improving Behavior

Presentation by Cindy Szapacs, M.Ed., BCBA

Reviewed by Denise Servais

I had the pleasure of attending Cindy Szapacs' presentation on behavior during the PWSA (USA) convention last November. At the outset of her presentation, Cindy, a board-certified Behavior Analyst who has a master's degree in Education from the University of Virginia, stated there were common misconceptions about ABA. I have to admit, I thought I knew all about Applied Behavior Analysis (ABA) as it was tried with my daughter. But after listening to Cindy's presentation, I found out there were very important factors that must be considered when using ABA. ABA is a set of principles and procedures that all follow the same guidelines. While Cindy gave a lot of great in-depth information, it is too much to include in this article, but some of the highlights are presented below.

ABA is a scientific problem-solving approach that is aimed at producing significant behavior changes. It can be applied to all ages, those with and without a diagnosis. A quality program contains a mix of structured teacher-led activities, and structured student-led activities both at the table/desk and in the natural environment. The main objective is to teach people socially significant behaviors. Decisions as to how to teach and change behavior are made based on what we see; the interventions chosen are scientifically validated.

Cindy gave seven key dimensions of ABA. Here are a few that stood out to me: While behaviors can be positive or negative, the behaviors that are selected need to be socially significant behaviors (pick your battles). The interventions are monitored and evaluated, and decisions are data based. The behavior must be observable and measurable. This means that using emotions as a reason for

behavior (i.e., anger) is not satisfactory.

Consistency is an important aspect of any behavior strategy. Behaviors are likely to get worse than better and typically take three weeks for target behaviors to decrease. **Recognizing the motivation behind the behavior is the first step in successfully changing behavior.**

“...after listening to Cindy's presentation, I found out there were very important factors that must be considered when using ABA.”

Cindy discussed how to look at behavior and emotions: **Setting event** (provides information about the person that might influence behavior (i.e., anxiety/hunger), **Antecedent** (what happened just before the behavior occurred), the behavior, and **Consequence** (i.e. attention, escape, reinforcement). We all demonstrate behaviors for four different reasons: social attention, escape or avoid demand, desire for an item or activity, and sensory stimulation.

Using positive reinforcement immediately after desired behavior is more effective than punishment. A positive reinforcer is any stimulus presented after a behavior that increases the likelihood that the individual will display the behavior again.

Cindy reported that people with PWS typically respond best to antecedent interventions. Examples include:

- Embed a sense of control throughout the day
- Offer access to calming breaks – puzzles, paper tearing, coloring
- Use specific, concrete language
- Establish consistent, clear rules and expectations
- Provide positive reinforcement systems – tokens, self-monitoring
- Express low emotion in response to problem behavior
- Show no social attention in response to problem behavior – ANY attention is good attention
- Maintain distance when agitated

Here are some other examples I found helpful for negative behavior:

■ **If for attention-** minimize/withdraw attention

■ **If for preferred items-** first/then statements, teach communication

■ **If for escape-** keep demands on them, chunk work, behavior momentum (start with easy tasks)

■ **If for automatic reinforcement (i.e sensory stimulation)-** teach time/place, teach leisure skills, teach alternative/incompatible behavior

Lastly, Cindy discussed another behavior intervention called the Functional Behavior Assessment (FBA) which is commonly used in schools. The FBA is conducted to identify the function(s) of the problem behavior, create a plan, and teach alternative appropriate behaviors. Positive Behavior Support plans should be created based on the results of the FBA.

For further information on this presentation, please contact Cindy. szapacs@gmail.com ■

Elisabeth Dykens, Ph.D., Honored with NORD 2018 Rare Impact Award

Posted by Christina Jensen, Submitted by Lisa Graziano, M.A.

On Thursday, May 17, 2018, at NORD's 35th Anniversary Celebration, Dr. Dykens was honored by NORD* with other recipients, a Rare Impact Award, at Andrew W. Mellon Auditorium in Washington, D.C.

Elisabeth Dykens, Ph.D., a clinical psychologist and researcher studying rare genetic syndromes, has long been a leader in the field of intellectual and developmental disabilities. Since she began her research in the late 1980s, she has come to be regarded nationally and internationally as an authority on behavioral characteristics.

Elisabeth has focused her career on the behavioral studies of Prader-Willi syndrome (PWS) and Williams syndrome and was the first researcher to describe cognitive profiles and compulsivity in PWS patients. In addition, her research on both PWS and Williams has led to the development of numerous clinical trials and a library of over 150 peer-reviewed publications. She has received various honors including the Association of University Centers on Disabilities Outstanding Achievement Award in 2011.

As important as her scientific achievements are for the advancement of rare disease research, she has also had an invaluable role in improving the lives of patients and families outside of research by serving as a friend to the community.

"The real heroes are the families and individuals themselves. It has been nothing but a pleasure to share their struggles and strengths with them. I feel honored to do that."

As the Director of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, one of her first research projects with the team was establishing the Academy of Country Music (ACM) Lifting Lives Music Camp for People with Williams syndrome, a week-long residential camp studying the connection between Williams syndrome patients and their love for music. Now in its twelfth year,

while serving to study Williams syndrome, the camp also provides music enrichment, education, and opportunities for independence and flexibility advancements for campers. In the years since the camp started, 40 peer-reviewed articles have been published and campers have learned valuable life skills that have led to



employment opportunities. For Elisabeth, this is especially gratifying, and the camp has become her passion.

Outside of her work with the research team, she has served as a board member on the Special Olympics and on the Scientific Advisory Board of the Prader-Willi Syndrome Association (USA).

As more trials come to fruition,

Elisabeth has high hopes for the future and looks forward to sharing more resources with the rare disease community to fill the gap while cures for genetic syndromes are still being sought.

Congratulations to Elisabeth. ■

"I am deeply honored to receive the NORD's Rare Impact Award and I am very grateful to individuals with rare syndromes and their families for all the gifts and lessons they have taught me."

~ Elisabeth Dykens

"I feel especially privileged to have learned from the families who are the life long caregivers for people who have Prader-Willi syndrome, Williams syndrome, and other intellectual disabilities."

~ Elisabeth Dykens

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 visit our website, www.pwsausa.org

*NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 280 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

"Let Him Show You Who HE Is."

In 2017, Dorothea and her husband Randall's lives changed. They were expecting their firstborn – a son. Like many new parents they waited with anticipation and love of their little miracle, being told it was very unlikely she would ever conceive. This poignant time was also occurring when Dorothea had recently lost her father. Naturally the couple and both of their families were very excited



Hunter as a newborn

about this new addition to their family.

At the birth of their son Hunter at 39 weeks, they knew something was

wrong. "I was terrified," said Dorothea. And the tests began: neuro, cardio, genetics, the works, etc. One by one the tests came back negative. "I wanted to hear there was nothing wrong with my child." Being able to feed Hunter was challenging as he was having a hard time staying awake to feed and had esophageal reflux.

And then came the genetics diagnosis: Prader-Willi syndrome. At the South Miami Hospital, under the professional and nurturing care of Hunter's geneticist, Dr. Mislen Bauer, plans were being put into place for the issues with which Hunter was born in addition to others besides PWS. "We were discharged from the NICU the day after receiving his diagnosis, and we were completely numb." With a reassuring voice and hope in her eyes, Dr. Bauer told them to take their sweet baby home. "Love him, nurture him and let him show you who HE is," said Bauer. Immediately their research into learning more about the syndrome pointed them



Dorothea and Hunter, age 10 months

"Hunter has shown us the true meaning of love."

- Dorothea

to PWSA (USA) with its outstanding family support and counseling for newly

diagnosed families, and also to the Florida Chapter.

Quickly, Dorothea learned she was not alone. PWSA (USA) staff Lori Moline and Diane Seely, as well as PWS mom Michelle Torbert "threw me a lifeline," and guided the family through the journey of discovering resources,

counseling, and the reward of bringing to light this darling boy named Hunter.

Hunter is love personified. Dorothea shared a bit of the purpose and heart in raising their son. Of Greek heritage, Dorothea (meaning "gift of God") shared she is the granddaughter of the founder of the National Hellenic Society. Through Hunter, they saw his little personality shine – an acutely empathic soul, and love personified. "Hunter has shown us the true meaning of love." He continues to show them how hard he can work and does not give up during his therapies and interventions.

Through it all, Hunter smiles and has told them in HIS way, to "keep the good stuff", let go of the negative, and find the joy and happy in the good moments.

Dorothea also shared how VERY helpful it was to have a three-ring binder (or something similar) to keep all his notes, records, reports, appointments, etc., with his various caregivers organized and readily available. What a lifesaver!

Hunter will turn one on July 25. He is a thriving, happy baby who is beating the odds, showing the world who HE is and reminding us all to "keep the good stuff." ■

Do you enjoy and use social media?
Did you know there are special group pages
for FAMILIES ONLY, on Facebook?
To become a member of these closed pages,
please visit <https://www.pwsausa.org/new-diagnosis/>
and complete and submit the new diagnosis form.
~ Thank you!

Access PWSA (USA) via App

<http://bit.ly/2CsjHsnPWSAmobileapp>

Thanks to the Settles family, enjoy freedom to browse information on our website via the ease of a free app available (link above) on all mobile devices via iTunes or Google Play. ■



Going Back to School? Keep it Simple!

It's that time of the year again and school is back in session! As a parent of a child with Prader-Willi syndrome, you are probably feeling nervous or a little scared about the changes that the new school year brings: new teachers, a new aide, and maybe even a new school. You may even be apprehensive about the level of understanding that the school team has about PWS. By keeping these simple best practices in mind, the worries you have about supporting your child with PWS in the school setting will alleviate quickly.

1. Prepare your child for the start of the school year

It is important to prepare your child that the summer schedule they have learned and become accustomed to will change. Provide a visual to show details of how the schedule will change. This visual may include: a sequential depiction (in words and/or pictures as appropriate) classes and activities, including any breaks and lunch period for each school day. This schedule could take the form of a Velcro schedule where the student could make changes and remove classes/activities as the day goes on. It could be in a format that allows the student to check off completed activities, whatever works best for the student. It is best not to write in specific times that events will occur as the student will be clock watching rather than focusing on the task at hand. The schedule should be reviewed each morning with the student, including an explanation of any changes with particular attention to the snack or lunch routine.

2. Request training on PWS for the entire school team

It is often necessary for school teams to engage in training to understand the complexity of PWS and supporting a student with PWS in the school environment. This is especially important when there is a school transition (e.g., elementary to middle school or middle to high school).

3. Introduce your child to the new environment and the new school team

If this is a new school for your child, it is helpful to introduce your child to the school and the new staff in advance when possible. This introduction may include a walk through the school building to familiarize the student with the school and where their classroom(s) will be located. If the child can meet any of the teachers, staff, clinicians, or aides before the start of the school year, this can set the stage for a good relationship. A more formal meeting can also be requested to meet the IEP team members and review

educational documents such as the IEP, Behavior Plan, or Health Care Plans. This more formal meeting will give you the opportunity to revise documents and add specially designed instruction that may benefit your child during the upcoming school year.

4. Establish a communication system

The family and teacher need to establish an agreed-upon communication routine and format. Based on your child's needs, you may want to suggest daily or weekly communication. It is also helpful to discuss the form in which the communication will be delivered (e.g., email, phone calls, communication log, etc.) It is important to highlight positive aspects of the child's day as well as behavior concerns and areas where increased supports may be necessary to promote positive behaviors and participation throughout the day.

5. Identify a "Go To" person

If your child will be changing classes and having different teachers for different subjects, identify one teacher who would serve as the "go to" person. This is the person who would be the final arbitrator on any issues that may arise throughout the school year. Your child needs to have someone to go to with a concern- someone who can provide reassurance, answer any questions, and resolve any conflicts. This teacher would also be the "go to" person for the parents when they have questions about managing food issues, academic concerns, or just verifying stories their child brings home.

For a child with PWS, transitioning back into the school routine is tough after the lazy days of summer! By following the simple tips above when your child is going back to school, you will have a smoother transition and will start the school year out on a positive note.

PWS Training Resources

PWSA (USA) is available to assist with trainings and can provide informational handouts on various PWS topics for school staff. Other resources are available for purchase on the website. (1-800-926-4797/ www.pwsausa.org) ■

Amy McTighe, Ph.D. PWS Program Manager, The Children's Institute of Pittsburgh. Video conferencing, on-site training, and phone conferencing. Contact Dr. McTighe at 412-420-2436 or amt@the-institute.org.

BJ Goff, Ed.D. PWS Specialist and Professor of Special Education. On-site training and consultation, phone conferencing, and mediation. Contact Dr. Goff at 413-782-7830 or bjgoff13@gmail.com.

28th Annual Prader-Willi Alliance of New York Conference a Success

For nearly 30 years, Linda LeTendre and her conference committee have been coordinating the very successful annual Prader-Willi Alliance of New York (PWANY) conference. As in years past, their deep understanding of topics most important to the Prader-Willi community and their ongoing commitment to supporting professional providers was evident. A robust agenda kept attendees engaged throughout the two-day event, providing countless educational and support opportunities.

Keynote speakers Rachel Johnson (PWANY Administrative Coordinator) and Lisa Pesante (Office for People with

Developmental Disabilities [OPWDD] PWS liaison) shared information about changes to legislation to include Prader-Willi syndrome and impacts on OPWDD's eligibility. PWSA (USA)'s Family Support Counselor, Stacy Ward, facilitated a breakout session wherein professional providers had an opportunity to idea share and learn from one another. Other topics included: Pitolasant and its potential therapeutic benefits; Applied Behavior Analysis therapy*; financial planning for families with special needs children; care coordination; health and nutrition; psychiatric, dental, and orthopedic

concerns; relationships and dating; and educational advocacy.

In attendance at the conference was PWSA (USA)'s Chief Executive Officer, Steve Queior. While there, Steve was able to connect face to face with PWANY's Board of Directors to better understand the issues unique to New York's families, and learn more about the challenges and successes they have had. Steve also presented on the "State of the National Association," highlighting PWSA (USA)'s Five Pillars of Support, and the new Public Policy Action Center (PPAC) that will empower greater advocacy for the PWS community at both the Federal and State level.

*See ABA article on page 8 of this issue ■

A Beginning Over a Cup of Coffee

By **Linda LeTendre**

My 30-year journey with PWS in New York began with the passionate letters Harry Persanis wrote to Assemblyman Steve Saunders when the Rhinebeck Country School was closing. The school had an expertise in working with people with Prader-Willi syndrome and the people with PWS had nowhere to go. I was an intern working on my M.S.W. and the New York State Assembly was a field placement.

What is interesting is that many years before, back in the '70s, I had read about PWS in an article in *Good Housekeeping* and remembered not only the name of the syndrome but the salient features of it as well. Turns out there was a whole generation of people with PWS who were diagnosed through that article by their parents! Harry was impressed that I knew what PWS was.

I actually met him in person months later when I became the Executive Director of the Alliance for the Neurologically Impaired (ANI). The Prader-Willi Association of NY was one

of the seven-member associations. He came to my office and offered to take me out for coffee (I am your friend for life if you buy me coffee) and talk about PWS and policies that affect it. ANI closed six months later and I was unemployed. It was discouraging looking for work, and I got a call one day from Harry asking where I was and that they needed me. I can still hear his voice on that call, and it meant so much to me. We began to work together to plan the first-ever New York conference devoted entirely to PWS. Thirty years later, I was still helping to plan and run the Prader-Willi Alliance of NY conference.

My faith calls me to to work on behalf of the people who are marginalized and not served as they should be by this wealthy nation, to speak on their behalf and to work for justice so I always felt like my work for PWANY was a mission from the Holy Spirit. I had found a home and a family with PWANY, and the people and families with PWS touched my heart; I grew to love them all. Christine Persanis, Harry's daughter, has

*"I can still hear his voice
on that call and it
meant so much to me.
We began to work
together to plan the
first ever NY conference
devoted entirely to PWS."*

been a friend for 30+ years. Her kindness and thoughtfulness has made me a better person. When my mom was hospitalized during one of the conferences, Christine had a card made and sent to her before I did! The "apple does not fall too far from the tree."

While PWANY paid me for my conference work, I believe it important to give back so I did some projects as a volunteer. I helped to develop and put together a tool for parents to not only organize information about their child, (medical, educational, legal, etc.) but be able to provide information to the professionals working with their

continued on page 13

Chapter View

Coffee continued from page 12

children. Any parent of a child with PWS will tell you that they have to educate the professionals working with or treating their child. I also helped to arrange a “Grand Rounds” teaching day



Linda left, with Christine Persanis, age 46, at the 2018 New York Conference

at Albany Medical Center to begin to develop some PWS medical experts in the Capital District.

The biggest change I have seen is in the treatment of PWS. It used to be that there was little to no medical treatment for PWS. Now there is the growth hormone that has made an enormous difference in the lives of people with PWS. It is gratifying to look back over 30 years and see this success. I will miss the conference and the people (it was like an annual family reunion), but I will not miss the bad dreams before the conference- like when it would be the day of the conference and I did not have one folder, meal ticket, or registration and everyone is standing in line waiting to get in! (Organizing conferences sometimes has stressful moments!)

What stands out most for me in these 30 years is what I learned about loyalty, honor, and character from Harry. He was one of the most powerful influences in my life. ■

Chapter Events and Happenings

What is going on in your area?

Summer and Fall are perfect times to spread awareness with others during vacations, holidays and the return of the school year. Make time to attend or plan an event in your state and help spread awareness of the PWS COMMUNITY.

July

29th: Los Angeles County Support Group Meeting

29th: Sacramento Area PWS Support Group Meeting

August

18th: PWSA-WI, Inc. 18th Annual Golf Benefit

September

15th: San Francisco Bay Area PWS Support Group Meeting

22nd: PWSA-WI, Inc. Strike Out PWS

23rd: PWSA-PA Family Day with the Pittsburgh Pirates at PNC Park

October

6th: 2018 Aquarium of the Pacific 5K Run/Walk (California)

7th: 2018 JetBlue Long Beach Marathon and Half Marathon (California)

27th: PWCF Annual Conference

November

4th: Los Angeles County Support Group Meeting

4th: Sacramento Area PWS Support Group Meeting

9th: PWSA-PA Annual Conference

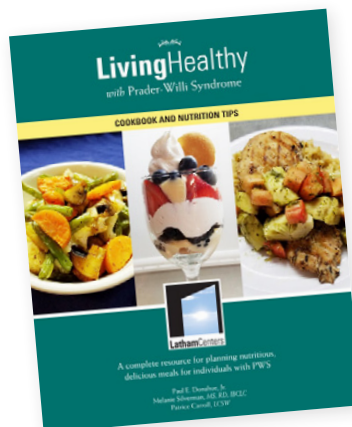
Chapters: Send your info on upcoming events and announcements; *The Gathered View* can help you announce your news. Next deadline: August 1.



Federal Employees! 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.”

PWSA (USA) CFC ID # is 10088

Click or visit <http://www.opm.gov/cfc/index.asp> to learn more



Living Healthy with Prader-Willi Syndrome Cookbook and Nutrition Tips

By Paul E. Donahue, Jr., Melanie Silverman, M.S., R.D., IBCLC®, Patrice Carroll, L.C.S.W.

This beautifully-illustrated cookbook contains menu items in an easy-to-follow format, as well as a seven-day meal plan (breakfast, lunch, dinner and snacks) based on calorie count. The menu is a **Mediterranean-based diet** low in carbs and dairy and high in Omega 3s. **This spiral-bound book also includes** articles on physical fitness,

nutrition, and holiday meal preparation tips. The residents at Latham Centers have seen dramatic results since the implementation of this menu. (2018) 78 pages, \$32.50 Visit: <http://bit.ly/2l6B3E8CookbookPWS> for purchase. ■

Meet Kate Beaver

You may have spoken with Kate on the phone; you may have received an email or met her at a meeting, seminar or convention. Do you know Kate? The Association would like to share with you a bit about Kate Beaver, one of our Crisis Intervention and Family Support Counselors, and how our counselors work with you to help your child/relative with PWS when times become difficult.



Kate with Hana

By trade, Kate is armed with a master's in social work (M.S.W.). Personally, she has a family: husband Dan, two sons, and their adopted daughter named Hana, with PWS.

In 2006, Kate had been working in substance abuse; a friend (with a child with PWS) approached who mentioned she had heard that PWSA (USA) was looking for a social worker to work as a crisis counselor with families. At that time, David Wyatt was the only crisis counselor on staff. Subsequently, Kate was hired, and the rest is a glimpse into how Kate balances this workload.

Priority for daily managing includes taking emergency crisis calls from not just families, but also professional

providers, school staff, medical professionals, grandparents, and others who are seeking help and guidance in a stressful time.

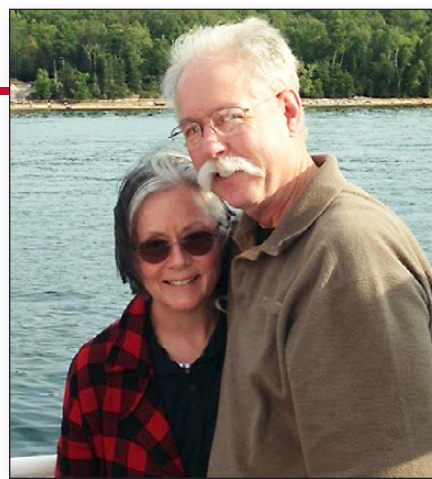
Equally important is maneuvering and responding to support requests on a wide range of topics that include:

- Calls from hospitals and doctors' offices
- Denials from SSI
- Manageable weight and/or behavior issues
- Schools and parents and the IEP process
- Residential issues
- Guardianship questions and processes
- Transitioning resources for an adult with PWS

The goal is to work
TOGETHER and
maintain the focus
on the person with PWS
that needs the help.

In speaking with Kate, I asked how can callers and writers achieve good outcomes to the multiple crises she/the association encounter every workday?

Yes, it is a challenge, but what is important is that all are clear of the roles of the parent and the crisis counselor. The goal is to work **TOGETHER** and maintain the focus on the person with PWS that needs the help. Good outcomes can occur when changes/tweaks are made. It's important to approach the crisis/dilemma at hand as a "team."



Dan and Kate Beaver

The staff that works with you will encourage and inspire you, and help you assess what is the best response and follow-up for the situation being addressed. Locking arms with your team, recognizing the environment, and determining what each call/email is requesting is important, to calmly assess and direct each request towards a successful outcome.

There are multiple resources available including various handouts by topic (i.e., medical alerts booklet, menus, transitioning, therapeutic interventions) and by groups (i.e., teachers, law enforcement, residential, grandparents).

In closing, Kate reminded me there are many factors that can make the experience easier. The basics include:

Consistency- with schedules, diet, care. Maintaining a normal routine can help greatly for the person and their caregiver.

Stay Connected- Please know you are not alone. Even though PWS is a rare syndrome, the network of support is out there.

Life Happens- Quality of life is important to everyone in the situation. Sometimes a day may be one of frustration, tears, etc. Yes; take a breath and know there is a network out there of others just like you. A tweak of your solutions, good management can benefit so both you and the person with PWS do better.

Remember, we are a commUNITY. ■

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>

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Steve Queior, Chief Executive Officer
Debi Applebee, Business Manager
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research, and more.

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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Sara Dwyer, Editor
Lota Mitchell, Andrea Glass, Denise Servais, Kathryn Lucero

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The information provided in *The Gathered View* is intended for your general knowledge only and is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this publication.

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Be The One

Thanks to your support, **over \$100,000** was raised during the May 2018 Giving Challenge for PWSA (USA)!

464 members of the PWS Community came together and made a difference!

Donations received during the Giving Challenge were matched by the Patterson Foundation and private donors and will be used to fund services for family support, crisis intervention, new diagnosis, research, and advocacy and education for individuals with PWS and their families.

Again we **THANK YOU** for your support, hardwork, dedication to this successful campaign and to the PWS community!

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NEW ... a complete menu/cookbook resource
for Prader-Willi syndrome "Living Healthy" See page 13