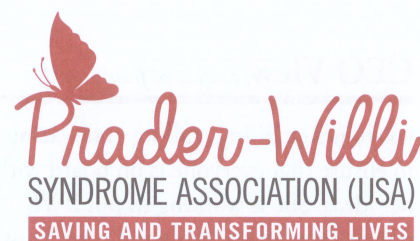


The Gathered View

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

Our mission: To enhance the quality of life and empower those affected by Prader-Willi syndrome.



Parent Mentors Support Families



Above: 2019 Youth Infant Program (YIP) families pause for a photo during the General Conference.

With the goal of serving families, thirty-six parent mentors from across the country gathered for 1.5 days during the PWSA (USA) national convention. On the first day we joined the Chapter Leaders meeting where PWSA (USA) staff provided an overview of national's recent activities and discussed the various ways in which the association supports

both families and state chapters. That first afternoon focused on the "Five Pillars of Support" (Awareness, Family Support, Research, Education, Advocacy) and how they work together to support our PWS community. Understanding the resources offered is key to a mentor's ability to guide families to appropriate information and assistance.

The parent mentor group met the second day focusing on the specific

supports of the Parent Mentor program. We discussed the role of the mentor and how important it is for newly diagnosed families to have someone they can reach out to who has walked in their shoes. Our SWOT (Strengths, Weaknesses, Opportunities, Threats) brainstorming session was a good discussion including program aspects that are working and areas that can be improved. Two topics were also presented: behavioral strategies from Elizabeth Roof, MA (Research Associate at Vanderbilt University) and information about the Partners in Policymaking Program from fellow parent mentor Jenny Gibbons.

Additionally, our parent mentors took shifts in the Millendo Therapeutics-sponsored Zen Lounge during the two-day General Conference. The Zen Lounge was the safe place where parents could take a break/relax, and wait if

continued on page 3

CEO View

At our heart and soul, PWSA (USA) is an organization of *people* who are dedicated to the business of helping *people*.

There's the group of people who work hard, frequently quietly and behind the scenes, *donating* their time, energy and talents for the sole purpose of helping families.

These are our Volunteers.

Volunteer Coordinator Lisa Graziano said "while PWSA (USA) has *always* benefited from and appreciated the work of some truly extraordinary volunteers over our decades of existence, this year we thought it was time to *publicly* recognize and celebrate them". The following "Fab Five" exceptionally generous and talented

Celebrating our Volunteers of the Year



Left to right: Tammie Penta, Lisa Mateševac, Paige Rivard, Lisa Thornton, Lisa Graziano.

people were presented with Prader-Willi Syndrome Association's First *Outstanding Volunteer Awards* at our recent 2019 national convention.

Lisa Mateševac

Lisa Mateševac, vice president of the Georgia Chapter, works full-time in a PWS-related field, and is the mother of three, including her son, Evan, who has

PWS. Lisa joined Georgia's board last year, and has really taken the ball and run with it.

She took our Spring meeting and turned it into a full-sized educational seminar which was nothing short of exceptional, and she planned Georgia's Fall Family Retreat. Lisa spends count-

continued on page 2

Volume 45, Number 1 ~ December 2019-January-February 2020 - Our 44th Year of Publication

less hours emailing, calling and texting to ensure that everyone is on board with her ideas. She is working to put PWS publications in hospitals and physicians' offices so we reach families earlier, and she's been wonderful at getting families the information they need while raising money for our cause.

Lisa Matesevac was awarded the Outstanding Volunteer Award for Education.

Tammie Penta

The nomination of Tammie Penta reads: For many years, Tammie has served on Arizona State Chapter's Board of Directors, PWSA (USA)'s Board, and chaired the Family and Medical Support Committee. Tammie's commitment to supporting, guiding and helping families affected by Prader-Willi syndrome and raising awareness of PWS in the community are unparalleled.

Tammie's previous experience in law enforcement is invaluable not only to the Family and Medical Support Program, but to *all* of our families. She has spent countless hours speaking with and educating parents whose child has been involved in sometimes terrifying legal situations, speaking with arresting officers, and writing letters to attorneys and the Courts. Tammie has created law enforcement statements that are now regularly used as templates to help other families in need.

It was our honor to present Tammie with this year's Outstanding Volunteer Award for Awareness.

Paige Rivard

Paige Rivard is spearheading a major Telehealth project that will allow hundreds of individuals with PWS, who otherwise would not, have access to endocrine medicine and endocrine system monitoring, including growth hormone.

Paige, a Parent Mentor and Vice Chair on PWSA (USA)'s Board of Directors, is starting a PWS chapter in Nebraska, and regularly fundraises for the PWS CommUNITY.

She is passionate about ensuring that educational communication flows freely to the PWS community and that it provides hope in a realistic, honest manner. Paige routinely visits hospitals and clinics to share information and educational materials about Prader-Willi syndrome, neonatal care and general best practices. She has gone to hospitals to sit with and comfort families whose baby has just been diagnosed.

Paige rarely shares how much she does behind the scenes to educate families, physicians, nurses and support staff.

This made it an honor to recognize her with this year's Outstanding Volunteer Award for Advocacy.

Lisa Thornton

In 1991, there was a limited PWS chapter and *no* direct supports for people with PWS. All that changed with the driving force of Lisa Thornton. She is the President of the Utah Association and under her leadership the chapter has flourished.

She spearheads the Utah chapter's:

- Annual swim party and annual park event featuring games, a silent auction, and fund-raising
- She works with a local camp to accommodate the special needs of our kids
- She coordinates scholarships so families can attend PWSA (USA)'s national convention

Lisa is an attorney by profession and provides FREE seminars on legal issues and support, and Lisa worked with the University of Utah medical system to develop a PWS Clinic.

Every year Lisa coordinates efforts to lobby the Utah Legislature to provide *more* funding to enable persons with PWS to enter the group home system.

For these reasons and more, Lisa Thornton is well-deserving of this year's Outstanding Volunteer Award for Family Support.

Julie Doherty

There are many people who do kind things for others, who donate their money to good causes, and maybe even give some of their time too.

And then there are those special people who give *so* much, who *truly* make a difference in the lives of others, who share their time and talents *so* generously and passionately that they actually *change* the people around them, and actually inspire you to be a better person.

This is Julie Doherty, our Outstanding Volunteer of the Year.

Julie is one of those individuals who, after the birth of her beautiful niece, stepped up to support her family in any way she could. She got involved to help not only her niece and family, but also to help *other* families as well.

Julie looks for no recognition. She seems to find joy in giving, whether it's her time or talents. Julie has worked on PWSA (USA)'s Board as secretary for over two decades, done thousands of edits of professional articles, ensured others were recognized for their achievements, organized volunteers for *many* PWSA's Conventions, and supports the mission and vision of PWSA (USA) through countless tasks and projects behind the scenes.

The people who are PWSA (USA) thank these five honorees, and ALL those who volunteer, for their years of dedication. Your hard work and everything you do makes us better and stronger. ■

Steve Queior, CEO, PWSA (USA)

We hope you find this publication and our materials helpful; consider a donation to PWSA (USA) to assist in developing more resources like this.

Please visit our website,
<https://www.pwsausa.org/>

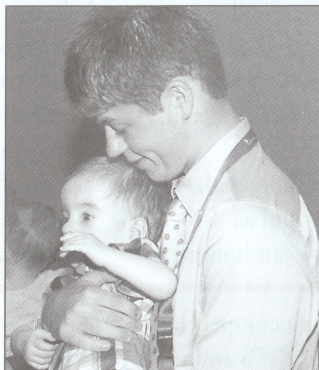


#GrowingUpRare PWSA (USA) Kicks Off Its 2019 Angel Drive Campaign

PWSA (USA) is thrilled to announce the launch of its 2019 Angel Drive Campaign, *Growing Up Rare*. This year's campaign presents exciting opportunities to build on the significant progress our community has already made, and to help raise awareness and spread hope like never before.

"This year's campaign will feature stories of what it's like to grow up with, or raise a child with, a rare genetic condition...We'll hear from parents, siblings, grandparents, and most importantly, from children, teens, and adults who have PWS. We're giving the microphone to those whose voices matter most," says PWSA (USA) staff member, Rikka Bos. "Of all the things you can do to raise awareness, few are more valuable and beneficial than telling your story. We want to share your stories, from your perspective, about the challenges and opportunities you have faced, with a variety of voices representing the full spectrum of individuals with PWS."

Beyond raising awareness outside the PWS community, the Growing Up Rare initiative will help bring hope to families who are learning to thrive with the rare genetic condition. A family shared: *When Hunter was diagnosed with PWS, my husband and I resolved to treat him like any other kid but doubted whether this was possible. Hearing Griffin [a teen who has PWS] share his story filled me with hope and reaffirmed*



we're doing the right thing. If Griffin can overcome these obstacles, perhaps Hunter can as well. We never want to put any limitations on what he can accomplish; Griffin reminded us that a bright future for Hunter isn't something we hope for, it's something we can also claim as our own.

Your year-end donation to the 2019 Angel Drive will help lift voices, facilitate life-changing research, and provide life-saving information, resources, and support so individuals with PWS can live healthier, more joy-filled lives...YOU are making a difference!

Watch for your 2019 Angel Drive letter in the mail, or make your year-end gift today at: www.pwsausa.org/angel-drive. Thank you! ■

Parent Mentor, continued from page 1

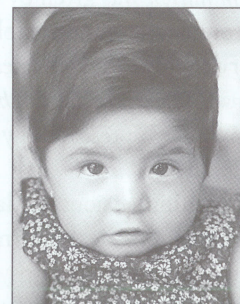
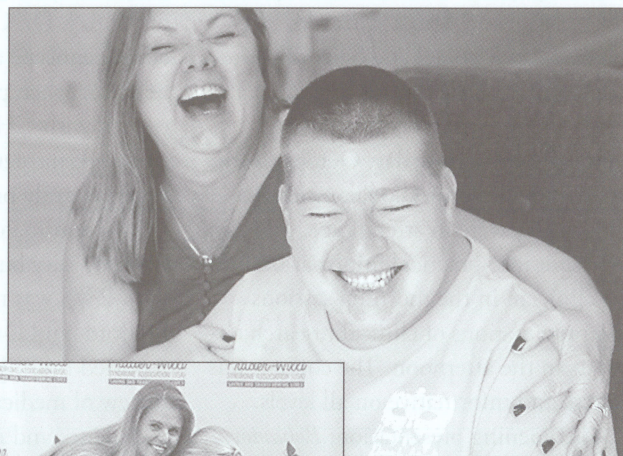
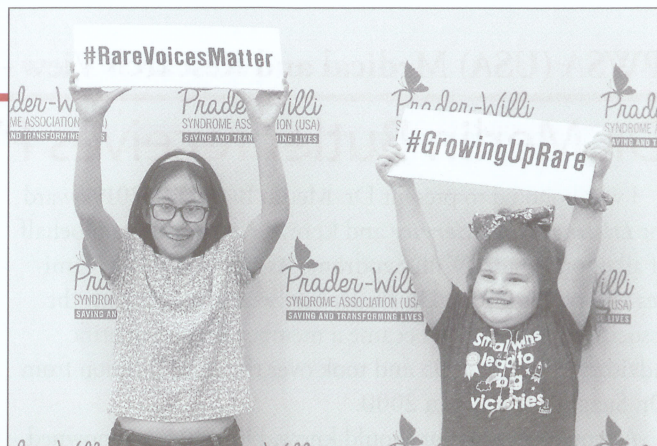
needed for their Global Assessment. Mentors were present to provide support and guidance; this general sense of family support is the mission of the parent mentor program.

It's hard to summarize the amazing energy of meeting at the convention.

1. Families meet face-to-face with mentors who have supported them from across the miles. New connections with other families and first-time attendees grow!
2. Mentors likewise meet each other in person after virtually communicating. Reunions of returning mentors allow our PWS family bonds to deepen and grow.

3. Most mentors attend the general conference where PWS experts in a variety of fields fill our heads with invaluable information. The support and community of PWSA (USA) fills us with hope and energy.

It is an honor and privilege to be a part of this program. PWSA (USA) parent mentors feel a great responsibility and commitment to the families we work with to assure them they are not alone – our CommUNITY is indeed strong and here to help. ■
By Julie Casey, Mom to Ryan, 15 years, with PWS, PWSA (USA) parent mentor



Dr. Merlin Butler receives PWSA (USA) Award

I was honored to present Dr. Merlin Butler the 2019 award for *Distinguished Service* and know I am speaking on behalf of all of our Prader-Willi Syndrome Association (USA) families and professionals. Dr. Butler has been involved with the association since 1985, became a member of the Scientific Advisory Board in 1995 and took over the chair position from Dr. Suzanne Cassidy in 2000.

As you all know – or should know, Dr. Butler is renowned worldwide for his research and writing on Prader-Willi syndrome. He did some of the key pioneer research on the syndrome and *has written more on PWS than anyone else in the world*. I would describe his achievements more in detail, but his curriculum vitae is 70 pages long!

Most importantly though, I worked almost daily with Merlin for over 19 years, as Executive Director and as Coordinator of Research & Medical Affairs, so can honestly

attest that beyond being brilliant, Merlin is a kind, ethical and humble professional who was always available. He has donated *thousands* of hours to PWSA (USA) to help our families, plus supported and educated nationwide and worldwide medical teams. We can never repay Merlin for all he has done, but want him to know he will go down in history as one of the greatest contributors of all time for Prader-Willi syndrome. ■

Submitted by Janalee Heinemann



Merlin Butler and Janalee Heinemann

2019 Medical and Scientific Conference Recap

By Mary S. Burr, DNP, CPNP, Medical and Research Coordinator, PWSA (USA)

Led by Conference Co-Chairs James Loker, MD, and Ann Manzardo, PhD, the two-day Medical and Scientific Conference was held prior to our national convention on Wednesday, October 23rd - Thursday, October 24th. Many provider professionals, scientists and parents were in attendance. The days were split into practical information for the clinician in the morning sessions and presentations of clinical research abstracts in the afternoon. The content was diverse and informative on all levels.

The opening presentation; *Behavior Formulation* was given by keynote speaker Tony Holland, PhD, followed by an overview of the newly released: *IPWSO Consensus Guidelines for the Evaluation of Care in PWS* presented by Dan Driscoll, MD, PhD.

Morning sessions on day one were filled with practical information such as an overview of psychotropic medications by Dr. Jan Forster, as well

as a compelling presentation on aging in PWS and transitioning care by Dr. June-Ann Gold. We concluded with Dr. Moris Angulo presenting on the use of Growth Hormone (GH) in PWS across the spectrum.

The afternoon abstract presentations included the results of some of the current research being done in our community. In her second presentation of the day, Dr. Gold presented on the effect genotype and phenotype have on behavior when persons with PWS are treated with GH. The PATH survey study recruitment results and a summary of study progress was presented by study coordinator Lisa Mateševac AuD. Comorbidity burden among persons with PWS was reviewed by Dr. Diane Stafford, and Dr. Shawn McCandless reported findings from his retrospective review of medical claims reflecting the prevalence and mortality of PWS in the United States.

Multiple industry-based research abstracts were presented on the development and safety of Levoletide by Dr. Andrew Spencer representing Millendo Therapeutics, as well as the results of the GLWL-01 phase 2 trial in the treatment of PWS presented by Caroline Fortier. Dr. Althea Robinson-Shelton's keynote address on day two of the conference de-

scribed the effects of increased sleepiness and Obstructive Sleep Apnea (OSA) on the cardiovascular system and cognition in persons with PWS. A description of the model being used in the provision of multidisciplinary specialty healthcare in PWS was provided by Dr. Jessica Duis from Monroe Carell Jr. Children's Hospital at Vanderbilt.

Dr. Jennifer Miller spoke on endocrine issues in PWS, and Dr. Harold van Bosse presented the current treatment options for scoliosis in PWS. Dr. Ann Manzardo gave an extensive and informative overview of the ABC's of CBD.

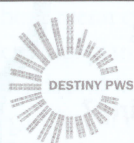
Scientific abstracts were again presented in the afternoon sessions of the day and included Dr. Jan Forster's work on the variability of the food drive in PWS and a session on the psychosocial adjustment of siblings of persons with PWS. Industry abstracts were also presented and discussed.

Multidisciplinary Clinic guidelines were presented by Emma Thornton, a member of the team from University of Utah; the day concluded with Dr. Amy McTighe presenting her very impressive data on the Care Coordination Program at the Children's Institute in Pittsburgh, PA. ■

Millendo Therapeutics Completes Patient Recruitment for Pivotal Study of Livoletide in Prader-Willi Syndrome

On November 13, 2019 *Business Wire* news outlet reported the completion of recruitment for the Phase 2b portion of the ZEPHYR trial of Livoletide for ages 8-65 years. The study is one of the largest PWS trials ever to be done; 150 subjects were recruited across 38 sites worldwide. The primary aim of the study was to evaluate the effect of Livoletide on hyperphagia (the constant feeling of being hungry), which is one of the major symptoms of the disorder. The study was initiated in March 2019 and is a two-part, randomized, double-blind, placebo-controlled trial. The second part of ZEPHYR is a Phase 3 study

that will recruit additional patients at the same clinical sites and consists of a six-month double-blind, placebo-controlled core period in which patients will receive Livoletide or placebo followed by a six-month extension period in which all patients receive Livoletide. The primary endpoint for both the Phase 2b and Phase 3 portions of ZEPHYR is the change in food-related behaviors using the validated Hyperphagia Questionnaire for Clinical Trials (HQ-CT). Topline results are expected in the first half of 2020 and may support a New Drug Application (NDA) filing for Livoletide. ■



DESTINY PWS – Phase III Clinical Study

Soleno Therapeutics is currently conducting/recruiting in the U.S. and the U.K. for phase III DESTINY PWS

What is being studied?

This study is evaluating Diazoxide Choline Controlled-Release (DCCR), a once-daily oral tablet, to see if DCCR can reduce hyperphagia. The study also evaluates the effects of DCCR on overall body composition. The safety of DCCR in patients with PWS as well as the effect of DCCR on BMI, waist circumference, lipid parameters, patient's health-related quality of life, caregiver burden and various PWS behaviors are also assessed.

Why we believe DCCR may work

In a previous study with DCCR in overweight or obese patients with PWS ages 10-22, there were improvements in hyperphagia, lean muscle mass, decrease in body fat mass, and reductions in waist circumference and aggressive behaviors.

KEY eligibility criteria

Eligible participants must be four years old or older, have genetically confirmed Prader-Willi syndrome, be hyperphagic, and have a caregiver with the participant

at least 4 hours a day from 6 months prior to the first study visit and throughout the length of the study. Participants must be on a stable regimen of medications for at least three months prior to Visit 1.

What does this study involve?

This 15-week study has seven clinic visits. Participants are monitored at every visit for safety using physical exams, blood work and questionnaires. Participants need to fast at least 8 hours prior to every visit for fasting blood tests. Questionnaires for the parent/caregiver are required, an ECG, DXA scans, urine tests as well as a diet, physical activity and sleep assessment. The double-blind, placebo-controlled study has 33% of patients receiving placebo (a tablet with no active drug in it); there is no guarantee participants will receive the study drug during this study. At the end of the trial, each participant who successfully completes this study has the option to enroll into a safety extension study where everyone will receive DCCR.

– Study Locations –

More information and sites currently recruiting participants is available at:

<http://bit.ly/2X4VQwj-PWS-DCCR>.

For any questions, please contact: <https://soleno.life/dccr/> or info@soleno.life

*Best wishes to
all the members of
the Prader-Willi
syndrome family,
near and far,
for a safe holiday
filled with
the joy of
family and
friends*

Federal Employees! PWSA (USA) CFC ID # is 10088 To learn more click or visit <http://bit.ly/2UHGXJv-CFC-PWSAUSA>

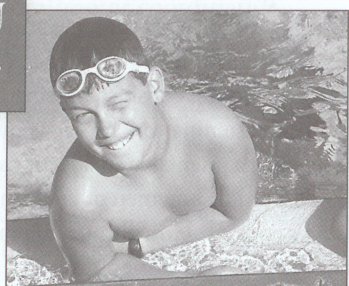
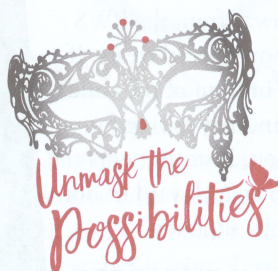


The Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide

“all federal employees the opportunity to improve the quality of life for all.”

#GrowingUpRare – CommUNITY is Celebrated

SAVE THE DATE! 36th National Convention – June



Coloring Tiles for Research



Our corporate sponsor, Millendo Therapeutics celebrated the diversity of the PWS community by raising awareness and support for PWSA (USA) and FPWR in a very fun and colorful way.

At our national conference, families, children and caregivers participated in expressing their inner artistic talents and loved knowing their creativity would result in helping research. What a great way to break up time and focus on something different for a few brief minutes.

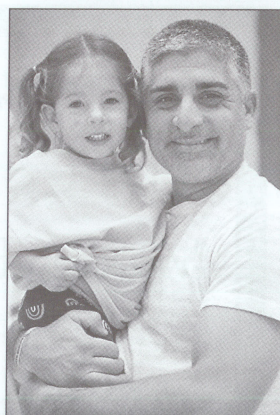
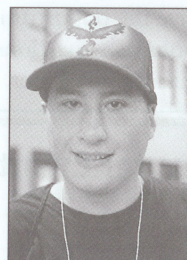
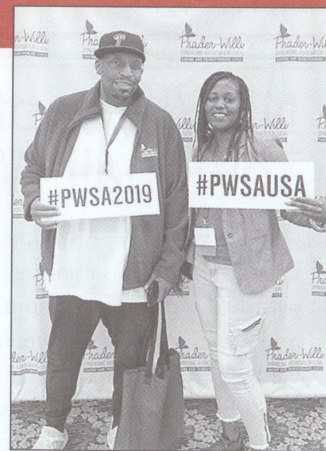


Each tile colored = a \$10 donation towards research. At last count there were 216 tiles from our conference!

"We also found when people were coloring tiles, they ended up meeting new people they may not have otherwise; lots of great conversations sparked," shared Alisha Sternberger, of Millendo Therapeutics, Inc.

Together, these creations expressed wonderful images of our diversity and CommUNITY. ■

12-26, 2021 – Hilton Orlando Buena Vista Palace



Join Our Family!

Our deep gratitude to the photographers for their gracious contributions of our convention family pictures for this issue of *The Gathered View*.

NEW! Chapter Leaders Townhall Webinar Series

Take your PWSA Chapter to the next level with this exciting, new townhall series focused on personal and professional development. The Chapter Townhall Webinar Series, like a traditional townhall event, will be conducted as a live public meeting with open dialogue between PWSA (USA) chapter leaders, experts, presenters, guest speakers, and facilitated by PWSA (USA) staff. Webinars will be held on Monday mornings; a recording of the webinar and materials will be available for those unable to attend live.

As a chapter leader, you will enjoy the format, which is designed with three key components to allow you the opportunity to network, get informed, and ask questions.

1. **Network:** attendees will be invited to casually get to know other chapter leaders during an informal "coffee chat" 30 minutes prior to the start of the webinar.
2. **Get Informed:** each webinar is designed to accelerate chapter growth by enabling PWSA (USA) Chapter leaders to build their leadership toolbox, with three focused 45-minute webinars each quarter. Each webinar is exclusively tailored to meet the needs of Chapter leaders around the world.
3. **Q&A:** during the last 15 minutes of the townhall, attendees will have the opportunity to find out more, ask questions, and engage with the presenter. ■



Mom: *Addy, I'll show you how to use the washing machine.*

Addy: *I already know how and know where the washing syrup goes.*

Mom: *Washing syrup?*

Addy: *Yeah, some people call it that.*

~ Submitted by: Bobbi Pogradt
De Pere, WI, Mom to Addy, age 13, with PWS



Save the Date for Upcoming Chapter Events:

Wisconsin Snowflake Ball

Saturday, February 1, 2020, 4 PM - 7:30 PM

Red Circle Inn & Bistro, N44 W33013 Watertown Plank Road, Nashotah, WI Visit: <http://pwsaofwi.org/>

Phone: 920-733-3077 Email: ProgDir@pwsaofwi.org <https://pwsaofwi.regfox.com/pwsa-of-wi-9th-annual-snowflake-ball>

Oregon/Washington Conference

Saturday, March 21, 2020 at 8 AM - 5 PM PDT

Seattle Children's Hospital, 6901 Sand Point Way NE, Seattle, WA

We are in the planning stages for a one-day conference for Prader-Willi syndrome families and providers. Please contact us at <https://www.pwsausa.org/oregon-and-washington-chapter/> Feel free to volunteer to help or recommend a speaker, topic, or sponsor. We will be planning a social event over the weekend as well. Watch for updates!

SUPPORTING FAMILIES



Best Wishes From...
The Cohen Family
Mitch, Fran, Aaron
and Ali

Global Assessment

The PWSA (USA) 2019 Convention was a huge success with informative sessions and incredible presentations. As part of the experience, PWSA (USA) offered young families the opportunity to meet with PWS experts in a group setting. These professionals have dedicated their lives to help change the outcomes for those with PWS.

Ashley Jones attended the Global Assessment with her daughter Sophie Jane. Ashley shares: *This conference was indispensable to not only our daughter but the entire family. Those who led the workshops conveyed groundbreaking research with clarity and presented innovative standards of care, as well as guidance and support for families. The team of doctors and specialists who met with our daughter during the Global Assessment truly safeguarded her future by equipping us with knowledge, resources, and tools that we could not have received elsewhere.*

The atmosphere created opportunities to connect with other families and the feeling of community was palpable. We left the conference feeling confident, understood, supported, and hopeful about the future. I cannot express the gratitude we have for the Prader-Willi Syndrome Association (USA), those fighting to find a cure, the medical team, the families who have gone before us, and the new friends we have made.

PWSA (USA) extends a huge and very grateful Thank You to those who met with over 50 families in two very long, yet fulfilling days.

■ Michael Tan, Nutritionist, RD
■ Jennifer Miller, Endocrinologist, MD
■ Kasey Bedard, ABA Specialist, BCBA
■ Janice Agarwal, Physical Therapist, PT, cNDT
■ Stacy Hiller, Speech Therapist, SLP
and a very special shout out to Harold J.P. van Bosse, MD, and Professor Dan Driscoll, MD, PhD, for their participation as well. ■

Submitted by Diane Seely, Parent Support Coordinator, PWSA (USA)



Our deepest appreciation to the PWS experts who worked tirelessly in assessing over 50 families during the two-day Global Assessment program.



Inflating the Balloon

By Kathryn Lucero, mom to Ronan, age 5 with PWS, Parent Mentor Ambassador

During the 2019 PWSA (USA) National Convention we definitely “unmasked the possibilities” of our community and our kids. I hope that just like myself, parents felt empowered and realized that our kids ARE incredible and are destined to do wonderful things.

At Convention I had the honor to present with two fellow PWS moms who have helped me during my journey and happen to be friends of mine. Kristi Rickenbach, Michelle Torbert and I spoke during our session “Creating a Positive Message” about allowing our children to reach their fullest potential.

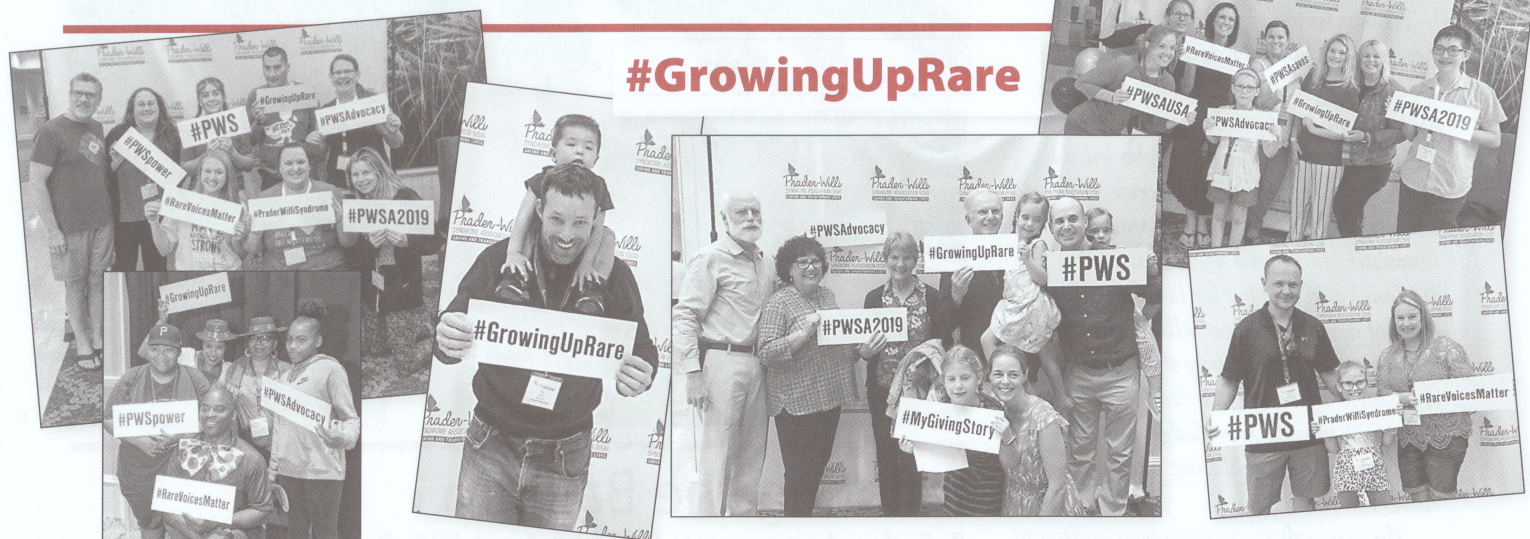
In this discussion we wanted our audience and fellow PWS parents to reach outside of the box and look at all the Positive things our children do on a daily basis, instead of what they have been told they can't. During this discussion we had each parent shout out five positive things about their children which ranged from climbing stairs to not being afraid of horses and playing with friends. We had an overwhelming response of positive things shouted out, but when we asked for one negative thing, interestingly enough, not very many hands went up. As each positive message was shouted out, the parents could blow up their balloon, and with the negative message they could deflate a little bit. By the end of our talk everyone's balloon was inflated! We wanted to show that with every negative message or response we receive from our kids (or their providers), we as parents know there are more positive responses in their lives; we just have to look beyond the negativity.

The next time you feel like you want to pull out your hair because of the constant questions your children ask or the frustration with doctors, grab a balloon; each funny thought or positive thing your child has done can fill it up. Remember: even though you may feel that your balloon is completely deflated, there will be at least five positive things your child has done that made you feel proud or smile. ■

Sibling Support Group on Facebook



PWSA (USA) has started a Facebook support group for siblings! Siblings are often the lifelong support system for people with PWS. They deserve close attention and support from PWSA (USA) and here is the first step in providing that. The support group is a safe place for siblings of all ages to share, vent and support each other. The group is moderated by Rockie Penta and Kady Sweeney who each have a sibling with PWS, and PWSA (USA) staff Stacy Ward and Kim Tula. ■ <https://www.facebook.com/groups/471674476890783/>



CARbetocin Efficacy and Safety Study in PWS

Research is uncovering new approaches to treating the hallmark symptoms of Prader-Willi syndrome. Levo Therapeutics is currently enrolling patients with PWS in our Phase 3 clinical trial investigating intranasal carbetocin (LV-101) in children ages 7-18 as a treatment for hyperphagia and behavior associated with PWS.

levō

www.levotx.com/care-pws



CAREPWS

<https://www.carepwsstudy.com/>

www.clinicaltrials.gov
NCT03649477



Our Story

This review is of a recent national convention panel discussion featuring Olivia Luening, a teenager from Grafton, Wisconsin who loves volunteering at a special summer recreation program that she used to attend; Kian Tan, a teenager from Oak Park, Illinois who enjoys spending his free time training his Samoyed to be a therapy dog; Abbott Philson, co-chair of the Adults with PWS Advisory Board, lives in Bedford, Maine, loves selling his artwork and the advocacy groups he is a part of; and Kate Kane, co-chair of the Adults with PWS Advisory Board from Baltimore, Maryland, who just happens to be the best aunt in the world to her nephew Kane. The panel was moderated by Stacy Ward, Director

of Family/Medical Support & Special Projects, PWSA (USA).

The presentation was designed to give the panelists an opportunity to share a first-hand glimpse into living with Prader-Willi syndrome. Each panel member shared their story, captivating the audience, prior to answering questions from the audience such as:

- What are some of the accomplishments you are most proud of?
- What do you wish your parents knew when you were younger?
- How do you cope with the tough days?

If the panelists could leave all the readers with one thought, it would be this. "We are people first. We have PWS but PWS is NOT who we are. Each one of us is unique and have different strengths and challenges. Please talk to us, not just about us. Include us in the discussion about our

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Please talk to us,
not just about us.
Include us in the discussion
about our lives.
Let us take risks so we grow.
We are all more
than our diagnosis,
we are all awesome.*

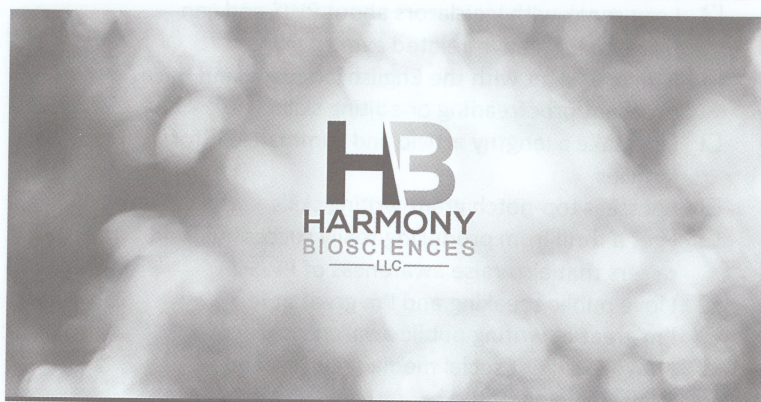
lives. Let us take risks so we grow. We are all more than our diagnosis, we are all awesome." ■

Living Healthy Podcasts

Latham Centers announces the launch of its podcast series entitled LivingHealthy! Led by Patrice Carroll, Director of Prader-Will Syndrome Services, and Katrina Fryklund, Director of National Outreach, the team will explore the changing landscape of the special needs field. Topics will range from: the challenges of a Prader-Willi syndrome diagnosis and paths; happy, healthy lives of those with PWS (PWS University series); overarching considerations in the special needs field-transitional and vocational programming (LivingHealthy series)

Professionals, including international specialists, Latham colleagues well-versed in PWS programming, clinical services, and nutrition, review strategies for success in special needs supports and services. Interviews with Latham students are also featured. This information is designed to be helpful to all parents of children with special needs. Patrice shares: "the purpose of the podcast and what we want everyone to take from this is that people living with PWS can live full, quality lives. Much information seen online is either outdated, misinformed, or generally negative, and that is absolutely NOT the reality of life with PWS in the majority of cases."

Podcasts may be heard online or downloaded from <https://pwsuniversity.podbean.com/> To learn more about Latham Centers visit lathamcenters.org or contact the Admissions and Outreach Team at 508-896-5776 ext. 237. ■



WHO WE ARE

Harmony Biosciences is an innovative pharmaceutical company dedicated to developing and providing new medications to help people living with rare diseases. With a focus on central nervous system disorders, we put breakthrough science within reach to improve the lives of those whose medical conditions could benefit from the potential of first-in-class, mechanism-based treatment approaches.



PATIENTS ARE AT THE HEART OF ALL WE DO.

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Call for Volunteers with Talent and Heart!



Do YOU have what it takes to contribute to PWS progress?

Got SKILLS and TALENTS or know someone who does? Tell us what you do well and we'll tell you how you can help! PWSA (USA)'s Committees that need your skills: Advocacy, Convention, Chapter Relations, Family & Medical Support, Finance & Endowment, Fund Development, Publications, Research, and Strategic Planning. If you have a project you'd like to lead, let us know! **Return this form to Lisa Graziano at LisaG@pwcf.org.**

- | | |
|--|---|
| <input type="checkbox"/> I understand how Federal and State governments work and how bills are passed | <input type="checkbox"/> I'm a big picture thinker and am great at strategic planning |
| <input type="checkbox"/> I can review legislative bills and summarize them so they can be easily understood by legislators | <input type="checkbox"/> I'm familiar with the research process from a clinical or industry perspective and can speak the language of statistics |
| <input type="checkbox"/> I can speak with legislators about PWS and can travel to legislative-related events | <input type="checkbox"/> I'm interested in the area of telehealth and continuum of care issues for the PWS population |
| <input type="checkbox"/> I am proficient with the English language and have excellent proofreading or editing skills | <input type="checkbox"/> I'd love to reach out to minority populations to encourage their involvement and ensure their interests are represented by PWSA (USA) |
| <input type="checkbox"/> I can take a lengthy article and summarize it for families | <input type="checkbox"/> I parent someone with PWS and would love to mentor a family with someone in the same age range |
| <input type="checkbox"/> I possess top-notch grant writing skills | <input type="checkbox"/> I'm a young adult and would like to help moderate or develop a program for siblings |
| <input type="checkbox"/> I get a thrill from producing really successful fund raisers that also raise awareness of PWS | <input type="checkbox"/> I'd love to identify local professionals and clinics in my State who work with the PWS population and provide them with PWSA (USA) materials |
| <input type="checkbox"/> I love public speaking and I'm great at it | <input type="checkbox"/> I have computer skills and am willing to help my State's families of an adult complete the PWS Global Registry |
| <input type="checkbox"/> I'm great at writing public awareness pieces | <input type="checkbox"/> I have experience with my State Chapter and can make phone calls to help other Chapters reach their next level of growth |
| <input type="checkbox"/> I have excellent social media skills (Facebook, Twitter, Instagram) | |
| <input type="checkbox"/> I'm excellent with WordPress | |
| <input type="checkbox"/> I can get information about PWS on the radio | |
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volunteer
do good, feel good

YES! I Have What it Takes and I Want to Learn More or Help Now!

First and Last Name	Email	Phone
I'm great at the skill(s) checked above or written below and would love to help!		

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I wish I could go back to the day my mom and dad were given my PWS diagnosis and tell them I am going to be ok. I am going to be happy. I am going to do everything I want to do. I will have an endless amount of joy and love to share. Thanks to the people of PWSA (USA), this diagnosis is just part of my journey, but it does not define me.

— Justice, Age 16

You
 are Making a Difference.