


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.


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

CEO View

Let's Pass Some Positive Legislation... Make your voice heard through advocacy!

Effective advocacy is essential to ensuring health, safety, and enhanced quality of life for those affected by Prader-Willi syndrome. As such, the PWSA (USA) Family & Medical Support team has provided hundreds of families with individual-focused advocacy. Now, our association is expanding its advocacy efforts by providing training and assistance to parents and caregivers that empower them to advocate for their child or loved one with PWS.

Our new coordinator for Membership & Engagement, Andrea Lucy, wrote the following update:

"Recently, PWSA (USA) staff and volunteers have committed to informing the broader community of critical public policy issues and leveraging the power of grassroots supporters to enact change on vital issues – from laws and regulations on access to prescriptions and medical treatments, to government funding of residential placement and new drug research. The Advocacy Committee has developed an Advocacy Toolkit to cover topics related to public policy. The toolkit offers engaging techniques for effective advocacy, including:


- A beginner's guide to U.S. government and legislative process
- PWSA (USA)'s current advocacy priorities and why

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Unmask The Possibilities – 35th PWSA (USA) National Convention

Justice Faith, age 15




Unmask the Possibilities

The stage is nearly set for this year's 35th National Convention, but as many of you know, the true excitement is in the exceptional learning and networking opportunities that come from being with hundreds of Scientific, Medical and Professional Providers and other families throughout this amazing five-day event. Knowledge is shared, compassion is given and support for all who attend is key to the future growth of our kiddos, young and old. The possibilities are endless. We could not be where we are today if not for all those individuals who walked before us, stumbled at times and got up again. To those PWS champions, we are beyond grateful. The torch is once again lifted to bring together the world's experts, friends and families to open our hearts and our community to those who may be attending for the first time or are reunited once again.

Facts about Convention:

- Professionals & families travel from all around the world to attend
- The Largest PWS Convention with over 800 in attendance in 2017
- Three Separate Conferences – Medical & Scientific, Professional Providers & General Conference
- Three Separately Staffed Programs – Infant/Youth, Siblings and Adults structured activity programs supporting over 200 individuals and staffed by trained professionals
- Seven separate meetings – Scientific Advisory Board, Clinical Advisory Board, Professional Providers Board, Chapter Leaders, Parent Mentor, Rare

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Volume 44, Number 5 ~ September-November 2019 ~ Our 44th Year of Publication

they are important

- Tips for Chapters to effectively advocate as a group
- Letter templates, call guides, and meeting request forms so you can reach out to your elected officials
- A place to take notes during your interactions with lawmakers
- Assistance with putting your advocacy strategies in action

This toolkit has been designed as a “living document”, which will evolve as we incorporate best practices learned from the shared success of our advocacy efforts. It is our hope that the PWSA (USA) Advocacy Toolkit will provide you with a set of practical tools to implement and sustain our collective advocacy efforts.”

Newborn Screening Saves Lives – Add Your Voice to the Cause

This month, the Newborn Screening Saves Lives Reauthorization Act of 2019 passed in the House and is on its way to the Senate for consideration.

The Senate Bill, S.2158, will continue critical federal programs that provide assistance to states to improve and expand their newborn screening programs, support parent and provider education, and ensure laboratory quality and surveillance for newborn screening.

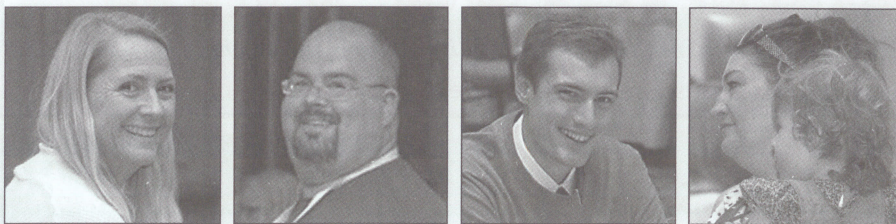
While introduction in the Senate is a crucial milestone, it's not a victory yet. We need you to raise your voice and encourage your Senators to support Senate Bill 2158.

Taking action is as easy as visiting the PWSA (USA) Public Policy Action Center at <https://p2a.co/KglyyNs> to add your voice to the list. With your support, we can educate lawmakers about the importance of S.2158 in the rare disease community. If you have questions, please contact PWSA (USA) team members Stacy Ward at sward@pwsausa.org or Andrea Lucy at alucy@pwsausa.org or 941-487-6738.

Thank you for advocating on behalf of the PWS community. Together, we can make a difference. ■

Best regards,
Steve Queior

PWSA (USA) Outstanding Volunteers



Introducing the PWSA (USA) Outstanding Volunteer Program!

Volunteers are the lifeblood of PWSA (USA) and are instrumental in delivering services, advancing legislation, raising awareness, and providing support and resources the PWS community has come to rely on. We couldn't do what we do without them, and that's why PWSA (USA) is so excited to announce its all-new Outstanding Volunteer Awards! Winners will be selected from across several volunteer categories and will be recognized at the Gala Dinner at the 2019 PWSA (USA) National Convention in October. Award categories are based on PWSA (USA)'s Five Pillars of Support and include: Advocacy, Family Support, Research, Education, and Awareness.

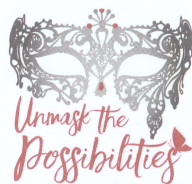
For more information about the Outstanding Volunteer Awards, please contact Julie Doherty at jdoherty88@yahoo.com.

AWARD CATEGORIES

- **AWARENESS** This award reflects work that has increased the public's awareness of PWS from distributing PWS brochures at a garage sale, to having PWS displayed on a sports arena Jumbotron, to writing articles that are published or widely distributed, etc.
- **FAMILY SUPPORT** This award reflects work that has provided some type of support to one family or a hundred families.
- **RESEARCH** This award reflects work that has in some way progressed research efforts.
- **EDUCATION** This award reflects work that has in some way educated families, professionals, or persons with PWS.
- **ADVOCACY** This award reflects advocacy work such as in the school or residential or work setting, to passing legislation.
- **FUNDRAISING**
 - A. **INDIVIDUAL** This award reflects work that has raised funds for PWSA (USA).
 - B. **CHAPTER** This award reflects work that a PWSA (USA) Chapter or Affiliate has done to raise funds for PWSA (USA).
- **OUTSTANDING CHAPTER** This award reflects work that a PWSA (USA) Chapter or Affiliate has done that is worthy of special recognition.

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/>

Convention, continued from page 1



2019 Convention News

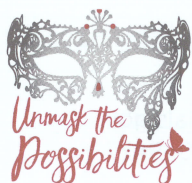
Disease Consortium, Friends of IPWSO, and the Multi-Disciplinary Clinic

- Global Assessment Team – Offers families of infants an opportunity to meet with a specialized team of experts and have their child assessed onsite
- Onsite Nursing
- Entertainment & Networking Opportunities
- Each family's registration fee is less than ½ the actual cost for the conference

We all know that over the years, many have challenged what could and couldn't be. We as a PWS community have stood arm in arm to open many closed doors, offer new opportunities and dream of future possibilities that no one would have thought possible for those affected by Prader-Willi syndrome. This is the reason we gather, the reason we are stronger, the reason we can do more and be more, and the reason we desire to share all we know with one another. Too many times in our day-to-day struggles we run into roadblocks, but as a community we can and will **"Unmask the Possibilities"** through awareness, family support, research, education and advocacy.

Safe travels and hope to see you all in Orlando, October 23rd-26th, 2019.

By Jackie Mallow, Convention Coordinator, PWSA (USA) ■



**Spot a
Mask and
read other
Convention
moments.**

Research Committee Aims to Facilitate Medical Breakthroughs for the PWS Community

The PWSA (USA) Research Committee is chaired by Rob Lutz and is comprised of seven dedicated and diverse professional volunteers. The Committee is supported by PWSA (USA) staff members Steve Queior (CEO) and Mary Burr (Medical and Research Coordinator). The Committee meets monthly with a focus on previously identified research priorities for the PWS community.

This summer, an in-depth discussion ensued on how PWSA (USA) should vet survey study requests that we receive. From this meeting, a policy for processing these requests was developed and approved. Additionally, Corporate Partnerships were discussed and updates on their trials were communicated to the Committee. There was considerable discussion on proposed projects that would benefit the PWS community, especially the adult population, which will be supported by PWSA (USA).

At the most recent meeting, the committee was given an overview of the status of current projects, as well as completed and upcoming research. Adult Growth Hormone treatment continues to be a priority and the committee discussed ways we should move to support the adult population with PWS. Issues being investigated by the Committee also include a study on gut microbes, stress experienced by fathers, and a GI/constipation survey to seek best practices.

Through these efforts, the PWSA (USA) Research Committee has focused on facilitating research that can more immediately enhance quality of life of individuals affected by PWS. The desire to find more and better treatment options to manage and diminish challenges inherent to PWS will continue to guide the Research Committee. ■

Gut Bacteria Study of Children with and without PWS

The human gut contains bacteria that play an important role in food digestion. When the stomach and small intestine are unable to digest certain foods, gut microbes ensure nutrients are digested. Changes in gut microbes may lead to obesity, but the specific role of gut microbes in weight control in Prader-Willi syndrome (PWS) and childhood obesity is not yet fully understood. Dr. Andrea Haqq, MD, Associate Professor at the University of Alberta, and her research team investigated the gut bacteria of children with and without PWS. The study was conducted from April 2017 to July 2018, in which a total of fifty children from 3 to 17 years old participated. The research team found that children with PWS had greater bacterial richness than the rest of the children who participated in the study. The researchers think that this unique bacterial profile might be linked to the particular appetite behaviors and weight gain characteristic of PWS. These findings suggest that a more personalized intervention for children with PWS is needed. For this reason, Dr. Haqq and her research team have now designed a follow-up study (currently recruiting participants) in which children with PWS are asked to consume a high fiber diet for three weeks. Dr. Haqq believes that a high fiber diet will change the gut bacteria and therefore better control weight and appetite behaviors, which will ultimately provide an effective way of improving the overall health and quality of life of children with PWS. ■

Research funding provided by the Prader-Willi Syndrome Association (USA).

Venous Thromboembolism in Prader-Willi Syndrome: A Questionnaire Survey

By Ann M. Manzardo¹, Janalee Heinemann², Barbara McManus², Carolyn Loker², James Loker³ and Merlin G. Butler^{1*}

¹Departments of Psychiatry & Behavioral Sciences and Pediatrics, University of Kansas Medical Center, Kansas City, KS 66160, USA ²Prader-Willi Syndrome Association (USA), Sarasota, FL 34238, USA ³Department of Pediatrics, Bronson Hospital, Western Michigan University, Kalamazoo, MI 49008, USA *Author to whom correspondence should be addressed. Genes 2019, 10(7), 550; <https://www.mdpi.com/2073-4425/10/7/550>

Prader-Willi Syndrome Association (USA) monitors the ongoing health and welfare of individuals with Prader-Willi syndrome (PWS) through active communication with members by membership surveys and data registries. Through the information gathered from the surveys and registry data, it appeared that persons with PWS may be more at risk for thromboembolism and blood clots than the general population. A panel of PWS medical and scientific experts developed a 66-item questionnaire with input from Prader-Willi Syndrome Association (USA) leadership, to probe the membership on the frequency, risk, and protective factors for venous thromboembolism, pulmonary embolism, and related findings. The characteristics of those with and without a reported history of blood clots and related health factors were tabulated and analyzed.

There were 1067 individuals with PWS that responded to the survey, 554 females and 513 males. Of those that responded, 38 had a history of blood clots. The individuals with clots were fairly well distributed female to male but were significantly older 32.8 ± 15 years vs. 20.4 ± 13 years, and were more likely to have a reported history of obesity (76%), edema (59%), hypertension (24%), vasculitis (33%), and family history of blood clots (33%) than those without clots. Growth hormone treatment was more common in individuals without clots, possibly because of the decreased incidence of obesity in the GH treated population. The risk factors for thromboembolism in PWS overlap those commonly observed for the general population that are obese and have the related risk factors.

Published: 19 July 2019

View full text here: <https://www.mdpi.com/2073-4425/10/7/550/htm> ■

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



For Chapter Leaders!

You are invited to attend the Chapter Leader's Meeting at the 2019 PWSA (USA) National Convention!

Don't miss joining your fellow chapter leaders from across the country for two days of learning, networking, brainstorming, and more! Gain valuable insight from peers, discover helpful resources available through PWSA (USA), and learn how to increase your chapter's impact in the areas of advocacy, fundraising, chapter engagement, and awareness-building. Attendees will also walk through exciting changes to National-Chapter administrative processes designed to make chapter membership more rewarding than ever before. The cost of the meeting for chapter leaders is included in their General Conference registration. Additional attendees are welcome to join for \$125. Register today at <https://pwsausa.regfox.com/chapter-leaders-meeting>. We look forward to seeing you there!

Questions before the event? Email Crystal Boser at crystal.boser@aol.com ■

School is starting. The holidays are coming.

What are you going to do about the food?

By *Melanie R. Silverman, M.S., R.D., I.B.C.L.C.*

When you have a child with Prader-Willi syndrome, food is always a concern. The mere thought of your child going to school and/or holiday parties can incite panic. Please...try not to panic. The first step is to look at how food is handled in your home. Once you understand your home plan, it can help support your efforts to create school and holiday food plans. Here is a list to the right to help you get started.

HOME

- Offer a balance of nutrient-dense foods that contain carbohydrates, protein and fat
- Cook meals and prepare snacks with as many fresh foods as possible
- Purchase fruits and vegetables at farmer's markets
- Shop the perimeter of the grocery store for the freshest ingredients
- Read food labels closely – less ingredients are best
- Limit sugar intake **and** artificial sweeteners – use fresh fruits/vegetables to flavor water
- Don't offer juice or soda
- Structure meals and snack times as much as possible
- Eat together at a table without television or other distracting technology
- Lock cabinets and refrigerators to keep children and adults safe

Before or when school starts, communicate with administrators and teachers about your child. Everyone should be aware of the diagnosis to keep your child safe. Below are suggestions for a smooth transition.

SCHOOL

- Create an 8 1/2 X 11 laminated sheet with your child's picture and what he/she can and cannot have

in terms of food. Distribute to all teachers and administrators who come in contact with your child. (Laminating seems to help elevate its importance.)

- If your child is going to participate in school lunch, ask to review menus in advance. If they are not going to work, send lunch from home.
- If your school has the dreaded "every week birthday cupcake celebration", request the teacher or administration to institute a new policy. Provide a list of non-caloric birthday treats that parents can bring to share (e.g. pencils, erasers, stickers, books) instead of sweets.

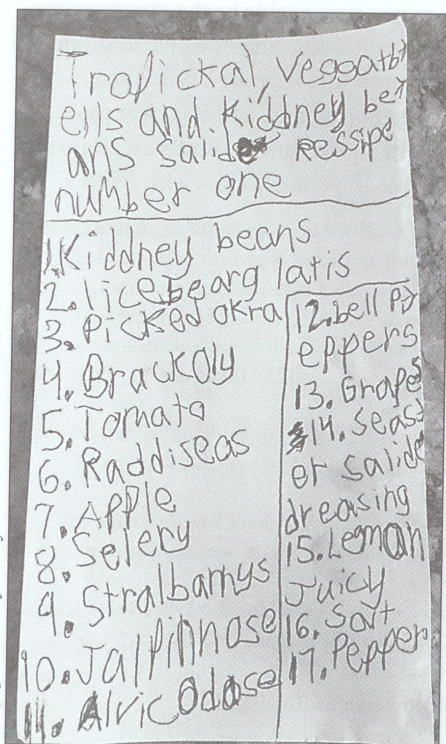
The holiday season is a special time of year. And the food is delicious! Each family handles holidays differently. If you decide to allow your child to have foods you don't always offer, set limits ahead of time and return to good eating and exercise habits immediately after the celebration.

HOLIDAYS

- **HALLOWEEN:** Do what's best for your family. Some families allow for trick or treating and then trade-in candy for a special toy. Other families may allow children to pick a couple pieces of

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Image provided by Cindy Peek-Windham Brooks



Food, continued from page 5

candy once for a few days after the holiday and donate the rest. And some families allow no trick or treating. You have choices based on your comfort level.

• **FAMILY/RELIGIOUS HOLIDAYS:** Chances are you will be invited to (or host) celebrations throughout the holiday season. Pay closer attention to food and exercise a few days before and afterwards so there is room for special treats. ALERT: Keep a close eye on buffets and the easy access to food.

This time of year can be stressful as it relates to food but the suggestions presented here can make it more manageable.

Please enjoy the start of school and the upcoming holiday season!

If you have questions about this information, please contact me at: melanie@melaniesilverman.com

Safety and Efficacy of Growth Hormone (GH) Treatment in Infants with PWS: Findings from Current Research

Submitted by Mary S. Burr, D.N.P., C.P.N.P., Medical Coordinator PWSA (USA), edited by Rikka Bos, Development & Chapter Relations, PWSA (USA)

There is very little scientific evidence regarding the effects of early treatment with Growth Hormone (GH) in infants with PWS. Most of the information we have is anecdotal or reported case by case. The aim of this article is to review the evidence available regarding the effectiveness and safety of GH therapy in infants less than two years of age.

The most current evidence we have is a study titled, “Safety and Effectiveness of Growth Hormone Therapy in Infants with Prader-Willi syndrome Younger than two years: A Prospective Study”. In this study, 14 infants with PWS under the age of 24 months were started on GH treatment and monitored over a two-year period. There were nine infants with deletion type and five infants with the maternal uniparental disomy (UPD) type. The average age of starting GH was 9.6 months.

The results were a significant decrease in skin fold thickness, a decrease in BMI, and an upward trend in height in all subjects. Additionally, if the infant was started on GH before 15 months, they started walking earlier (average 18 months) than infants that started after 15 months (average 36.6 months). There were no serious adverse events reported during the study (such as hypothyroidism, hypercholesterolemia or diabetes). None of the subjects had scoliosis at enrollment nor did any of them develop scoliosis during GH treatment. (Scoliosis is a

major concern for patients with PWS and its frequency rises with age. However, scoliosis is no longer considered a contraindication for GH treatment in children with PWS. Studies have shown that GH therapy does not increase curve progression or the probability to develop scoliosis.)

Regarding cognitive development, the median age the study subjects started walking was 19.5 months, and the median age they started talking was 16.9 months. In the literature, it has been reported that untreated children with PWS start talking between 21 and 23 months, but some as late as 5 or 6 years. Walking in untreated children began between 24 and 30 months. It seems that treatment with GH helps to reach major milestones earlier. Additionally they found that infants who began treatment with GH before 15 months of age started walking at a significantly earlier age than those who initiated GH treatment after 15 months of age.

The researchers conclude that the use of GH in infants under two years of age was safe and effective in improving body composition. Early treatment of GH might also play a role in the age an infant with PWS will start walking.

These findings are consistent with data reported by other studies. For example in 2004, one study found that patients who receive GH treatment before 18 months of age showed an improvement in mobility significantly greater than matched controls, whereas patients who were older than 18 months of age when they started GH treatment did not show any effect on mobility. Another randomized controlled study concluded that motor development significantly improved during the first year of the study in the GH group versus the control group, particularly in children with initially earlier developmental age.

Based on the limited evidence available in the literature, it appears the early GH treatment is safe and effective in supporting growth and development in infants with PWS. There were limitations to the evidence reported here and it is clear more research will need to be done in the future to fully ascertain the safety and efficacy of GH use in young infants with PWS.

Corripio R¹, Tubau C¹, Calvo L¹, Brun C², Capdevila N³, Larramona H⁴, Gabau E³. 2019, Safety and effectiveness of growth hormone therapy in infants with Prader-Willi syndrome younger than 2 years: a prospective study. *J Pediatr Endocrinol Metab*, July 4. doi: 10.1515/jpem-2018-05

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⁴ Service of Pediatric Pneumology, Parc Taulí Hospital Universitari, Institut d'Investigació i Innovació Parc Taulí I3PT, Universitat Autònoma de Barcelona, Sabadell, Barcelona, Spain.

<https://www.ncbi.nlm.nih.gov/pubmed/31271556>



Dental Problems in Children and Adults with Prader-Willi Syndrome

Compiled and Reviewed by B. Dorn, R.N., Dr. T. Hughes, D.D.S., and Dr. K. Wachter, D.D.S.

Persons with Prader-Willi syndrome (PWS) of all ages face lifelong challenges in dental health. A few of the more common dental problems include enamel erosion, tooth sensitivity and severe tooth wear. The following information provides information on causes, signs, prevention and treatment options that may be helpful.

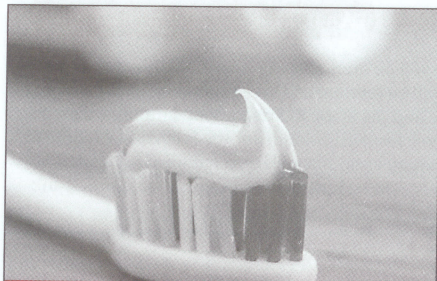
Enamel Erosion and Tooth Sensitivity

What is it?

Enamel erosion is the wearing down of the protective coating (enamel) of the teeth. When enamel wears down, microscopic channels in the tooth open up and become exposed. Most people with this problem complain of discomfort and pain. However, since persons with PWS have an altered pain response, they may or may not experience and report this sensation.

Common Causes:

- Abnormal salivation (low production of saliva)
- Grinding of the surfaces of teeth
- Health conditions including gastric reflux



October is National Dental Hygiene Month.
Fresh breath, strong teeth and healthy gums are all part of good oral health. Remember to brush every day, and get regular checkups and cleanings!

- Medications (aspirin, antihistamines and some vitamins)
- Diet high in sugars and acid

Examples of foods and beverages with high acidity:

- Soft drinks, sport drinks, fruit juices, lemonade, coffee, tomatoes, strawberries. (Citric acid, phosphoric acid, and ascorbic acid are a few ingredients to watch for in foods.)

Signs of this Problem:

- Translucency of the enamel (you can almost see through the tooth)
- Darkening or discoloration of the teeth
- Pain or cold sensitivity (may not always be reported in persons with PWS)

Preventing this Problem:

- Drink water. Limit soft drinks, sport drinks, juices and coffee in moderation. Dilute juices with water.
- Swish mouth out with water or brush teeth after drinking or eating items high in acid.
- Don't sip on beverages for extended periods of time.
- Do not drink or eat high acid beverages/food in the evening after supper.
- Use a straw to keep acids away from teeth.
- Brush with fluoride toothpaste. Minimize swallowing. (This condition can occur in children and causes defects in the enamel of the teeth. Ingesting large amounts of fluoride can cause nausea, stomach pain and/or vomiting. It may not be quickly detected in persons with PWS.)
- Get regular dental checkups and cleanings every 6 months.
- Talk to a dentist about daily non-alcohol fluoride mouthwash. (Use as a rinse; do not swallow.) If needed, apply with Q-tip.
- Consult dentist on use of sealants in preventing enamel erosion and tooth decay – even in adults.
- Use toothpaste that helps tooth sensitivity and protects enamel.

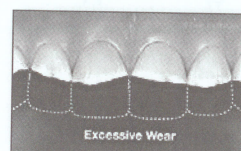
Treatment:

- Once lost, enamel cannot be replaced.
- If a person with PWS is found to have sudden loss of tooth enamel, testing should be done

to determine if a medical condition is present. Treatment should focus on identifying and correcting underlying problem. (May require special diet and medications.)

- A soft diet and avoidance of very hot and/or very cold foods often helps with tooth sensitivity.

Severe Tooth Wear / Grinding / Bruxism



What is it?

Teeth grinding or recurrent rubbing of the surfaces

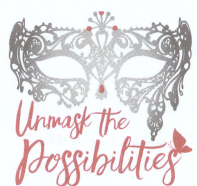
of teeth can cause damage to the teeth and result in severe wear and other oral complications. This is often seen in both children and adults with PWS. It occurs most commonly at night or while sleeping.

Causes:

- Exact cause is unknown
- Bite abnormalities
- Anxiety and/or stress

Treatment:

- Mouth bite guard – best if individually fitted by a dentist. Used while the person sleeps. May require incentive program for compliance.
- If bite abnormality is identified, referral to an orthodontist is strongly recommended.
- Avoid or cut back on foods and drinks that contain caffeine, such as colas, chocolate, and coffee.
- Discourage chewing on pencils or pens or anything that is not food. Minimize chewing gum. It allows jaw muscles to get used to clenching and makes it more likely to grind teeth.
- Work with person with PWS to learn not to clench or grind his/her teeth. Have him/her practice relaxing jaw muscles. (Try holding a warm washcloth against cheek in front of earlobe.)
- Include plenty of water; dehydration has been linked to teeth grinding. ■



I am co-chair of the Medical/Scientific conference. My wife and I have been coming to National conference for over 23 years and have always found it beneficial. We have the best scientists and clinicians in the country at the conference and all of them have a special heart for our children and will share their expertise with you. The networking with them, PWSA staff and other parents is invaluable. Being in Orlando also makes it a great vacation for the family. I honestly feel it's the best way to catch up on what is happening in Prader-Willi syndrome.

James Loker, M.D.



Adults with PWS Advisory Board Seeking Applications

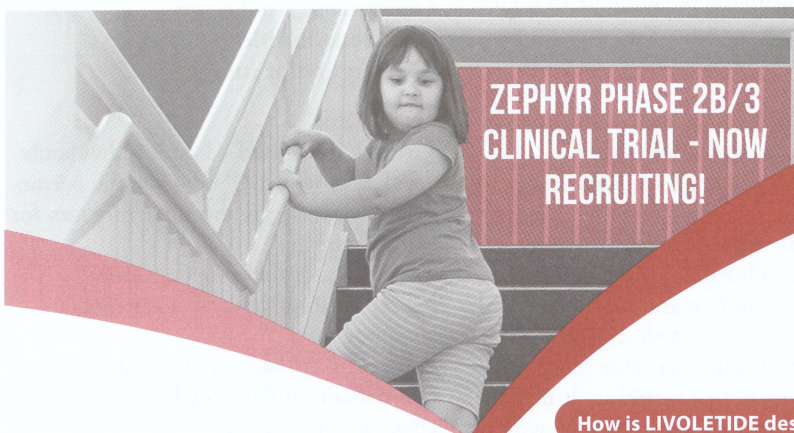
Founded in 2003, members of the PWSA (USA) Adults with PWS Advisory Board actively support the association by creating resources for its Family and Medical Support Program. This includes speaking at state and national events, serving as role models in personal relationships and group settings, and providing input, feedback and recommendations to our Board of Directors on behalf of people living with PWS. After serving many years, several members will be transitioning off the board at the end of 2019.

This will open the opportunity for filling up to five positions that may begin in the 2020-2021 term.

If you are interested in learning more about the duties and commitments of becoming a member of this PWS Adult Advisory Board and open to completing an application, please email pwaab@pwsausa.org. We look forward to hearing from you! ■

"I've seen and met angels wearing the disguise of ordinary people living ordinary lives."

~ Tracy Chapman



**ZEPHYR PHASE 2B/3
CLINICAL TRIAL - NOW
RECRUITING!**



What is the ZEPHYR clinical trial?

There will be more than 35 sites in the US and Europe. Patients will be randomized into 3 groups (high dose, low dose and placebo) and treated for 3 months, then all patients will receive livoletide for the following 9 months. The primary endpoint will be a change in hyperphagia. To be included in the study, the participant:

How is LIVOLETIDE designed to work?

Based on prior research in laboratory and animal experiments, livoletide may improve hyperphagia by counteracting a hormone in the body called acylated ghrelin, which stimulates appetite and is associated with other metabolic effects.

Has LIVOLETIDE been tested in PWS?

Yes. In a 47 person randomized double-blinded placebo-controlled Phase 2 study, livoletide showed some reduction in hyperphagia, especially in participants living at home. There were no serious adverse events (AE) or discontinuations because of AE. The most common AE were injection site reactions, but these were seen more in the placebo group.



What is LIVOLETIDE?

Livoletide is an investigational drug being studied by Millendo Therapeutics for the treatment of hyperphagia in people with Prader-Willi syndrome (PWS). Livoletide has not yet been approved for use by a regulatory authority.

- ✓ Must have PWS & hyperphagia
- ✓ Must be age 8 to 65
- ✓ Must have a primary caregiver throughout the study
- ✓ Must have a body mass index of $\leq 65 \text{ kg/m}^2$
- ✓ May have type 2 diabetes, but HbA1C must be $< 10\%$
- ✓ May be on growth hormone or insulin, but dose must be stable

For the latest information about ZEPHYR, please visit www.Millendo.com or go to www.clinicaltrials.gov for Clinical Trial NCT03790865



Friends of IPWSO (USA) is a non-profit organization established in 2017 whose goal is improving the lives of the international PWS community by funding the efforts

of the International Prader-Willi Syndrome Organisation (IPWSO). IPWSO is an organization of 103 PWS associations around the world providing family support and educational and scientific networking activities.

In 2019, Friends of IPWSO made the following grants for IPWSO projects:

Colombia Conference: A grant to help support a PWS educational and medical conference held in March 2019 for families and professionals in Colombia and surrounding countries.

The 2019 European Congress of

Endocrinologists: Funding was supplied for a PWS and IPWSO Awareness Booth at this conference of adult and pediatric endocrinologists held in France in May 2019.

The 2019 International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)

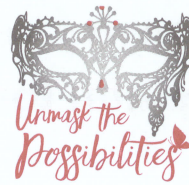
Conference: Funding was provided to support a PWS Awareness Booth at this conference to be held in August in Scotland.

Conference in Vietnam: Funding is committed to help support the first PWS educational conference in Vietnam, to take place in Fall 2019.

10th IPWSO International Conference: For this conference, held in Havana, Cuba November 13-17, 2019, we granted funds for (1) translations of educational and conference information. (2) 11 IPWSO Travel Fellowships for parents and critical professionals.

Regional and National Conferences: A \$15,000 commitment for each of three years was granted to facilitate IPWSO's ability to make timely commitments.

Friends of IPWSO invites The Gathered View readers to attend the IPWSO International Conference in Cuba in November. For details on the programme or tickets, please visit: www.ipwsoconference.org



I have been working at "the convention" for the past eight years, primarily running the Youth and Adult Program (YAP). I love being a part of the PWSA (USA) Convention by supporting the individuals that attend YAP while their parents, guardians, or staff attend the convention. I love seeing all the YAP participant faces light up as they interact with 100+ other individuals with PWS, make new friends, and enjoy two fun-packed days of activities. I also love seeing the families being able to connect with others that can truly understand the journey they are on because of the diagnosis of PWS. Being a part of the PWSA (USA) convention is a heartwarming experience as hundreds of people come together to learn from each other and to support each other.

*Kim Tula, PWSA (USA),
Alterman Crisis Counselor*

Be a part of the world's largest PWS advocacy community.



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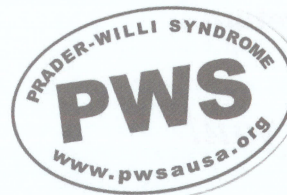
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Deals on apparel and accessories



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Make Your Gift to the 2019 Family & Medical Support Campaign Today!



FAMILY SUPPORT

Support for the 2019 Family & Medical Support campaign has been incredible! We've already made great progress towards our goal but there is still more we can do! Your gift to the campaign ensures PWSA (USA) can continue serving the PWS community by providing resources and support that truly Save and Transform Lives!

PWSA (USA)...Where Hope Meets Help

When a child is newly diagnosed, Prader-Willi Syndrome Association (USA) is there for families with information, resources, and support bringing hope at a time they need it most. As time goes on, PWSA (USA) continues to provide guidance to families as they transition through each stage of their child's life. Whether it's reassurance during a medical emergency, advocacy during the school years, or help securing safe and supportive residential care for an adult child, the PWS community turns to PWSA (USA) in their times of greatest need.

PWSA (USA)'s Family & Medical Support program is the only one of its kind. No other program is as comprehensive or life-changing, and without it many families would have nowhere to turn. What's more, PWSA (USA) does not charge for its services, nor do we receive any government funding. We rely completely on the generosity of donors like you to make our work possible.

Everyday Miracles Made Possible with You

PWSA (USA) is an organization of families, professionals, and committed individuals like you working together to provide a continuum of support and care not found anywhere else in the Prader-Willi syndrome community.

Your gift to the Family & Medical Support Program ensures families have the information, resources, and support they need to make everyday miracles happen.

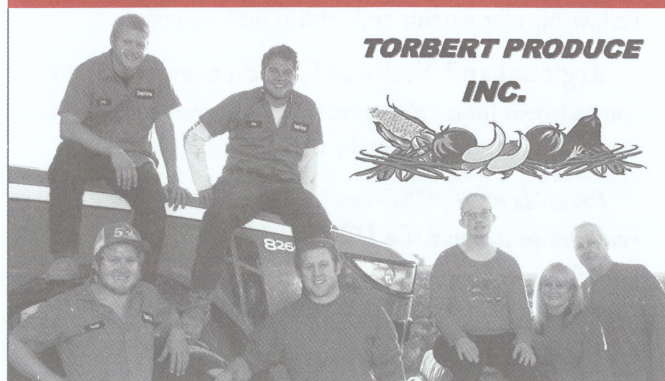
Still Time to Donate

If you haven't yet made a donation to the Family Support campaign but would like to, please visit <http://www.pwsausa.org/family-support-campaign/>. ■

**Your gift to PWSA (USA)
is an investment with
a priceless return...**

Thank you!

SUPPORTING FAMILIES



Living 69 Years Strong with Prader-Willi Syndrome

By Kim Tula, M.S., C.S.W., Alterman Family Support Counselor, PWSA (USA)

Prader-Willi syndrome was first diagnosed in 1956, only 63 years ago. With supportive living and specialized care, we now see individuals with PWS living longer and healthier lives. Susan Booth (Boothie) is one.

Born March 18, 1950, Susan was 13 when diagnosed with Prader-Willi syndrome (PWS) in 1963. Susan recalls being told she had Prader-Willi syndrome and that she would “have to live with this for the rest of your life;” and that she has. On September 2, 1963 Susan moved to Riverbrook Residence in Massachusetts. Today, Susan is 69 years old and continues to live a happy and healthy life at Riverbrook.

When asked what has been the

hardest part of having PWS, Susan stated, “not having a lot of food in front of me,” Susan admits it has been a struggle staying away from food, staying out of the kitchens and learning what foods are best for her. She shares the most helpful thing for her has been having a supportive environment with the refrigerator and cabinets locked, thus removing the temptation for food.

As we are seeing more individuals aging with PWS, many families, parents, and guardians are facing the thought of placing their loved one in a group home or supportive settings. For Susan, living in a structured group home setting improved her quality of life by always providing her 24/7 support. The community Susan has grown up in has afforded her opportunities to live her life and not having to worry about access to food.

To keep herself healthy, Susan’s exercise is a part of her daily routine. She walks on her treadmill every day, walks dogs, and enjoys practicing Tai Chi at the local Senior Center. She knows keeping herself busy throughout the day has helped



her stay strong and healthy. Susan is a very active woman who enjoys keeping her hands busy by working on word puzzles, hook rugs, and knitting; she states she even taught Elizabeth Roof (M.A., Senior Research Specialist, Vanderbilt University) to knit. She also keeps busy by working at Riverbrook on Main and is also active in her community church where she is a reader. Staying active and being involved in her community is very important to Susan and has helped her in living 69 years with PWS.

Susan offers advice to others *with* PWS, “always keep busy with your hands, go for a walk, go to different places like parks and museums; stay active! Her advice to those that *don’t have* PWS is to help them out by keeping them busy and take them to different places.

When asked how she felt about being one of the oldest people with PWS, Susan replied “I LOVE IT! I am proud.”

What would you like others to know about you? Susan replied: “I would love to have a PWS pen pal.” ■



“Providing Homes with a Heart”

Prader-Willi Homes of Oconomowoc specializes in providing residential services and support to people with PWS. For more than 30 years, PWHO has been recognized nationally and internationally by the PWS community for excellence in the therapeutic treatment and care for individuals diagnosed with PWS.

Contact us
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www.pwho.com



<https://www.pwsausa.org/family-support/>

The fourth featured icon from our Five Pillars of Support is **Family Support**. This program *provides services to families supporting a relative with PWS from birth through adulthood*. Visit and browse our website, use the search tool and see stories, resources and information. Learn more about the variety of services and education we offer. Contact us at 1-800-926-4797 and ask to speak to a Family Support Counselor (available 10AM-5PM EST) or you can e-mail us at support@pwsausa.org. We want to hear what you learned reading this issue and visiting our website. ■



The kids had fun taking turns playing "puppies" in the dog kennels today. It was Kimber's turn to be the puppy when I heard her ask "Master Brady your puppy is very hungry. Can you go ask your mom to make your puppy a sandwich?" I looked at the clock and it was indeed about snack time so I made her a sandwich, handed it to Brady and said "Ok you can go feed this to your puppy and then tell her she's all done eating until dinner time."

Brady took the sandwich, marched right past Kimber (who was literally locked in the kennel) and threw the sandwich out the back door to the REAL puppies. There was a moment of silence and I heard Kimber mutter "Huh, well that didn't work..." #PWSlife

~ Submitted by Alyssa Nielsen, mom to Kimber, age 5, with PWS
Cove, Utah

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

To learn more click or visit
<http://bit.ly/2UHGXJv-CFC-PWSAusa>



Upcoming Chapter Events:

Wisconsin-

September 29th, 2019 19th Annual Charity Golf Benefit

The Oaks Golf Course, Cottage Grove, WI

<http://bit.ly/31QbprwGOLFpwsWI> for details/register

October 12th, 2019 Fifth Annual Strike Out PWS

California-

October 12th, 2019 2019 Aquarium of the Pacific 5K Run/Walk

October 13th, 2019 JetBlue Long Beach Marathon & Half Marathon

November 2nd, 2019 2019 Annual State Conference

Delaware-

November 17th, 2019 Inaugural 5K Walk/Run

Milton, DE <http://bit.ly/2N21mfwDEPWS5kPWS-DE>

Michigan-

October 5th, 2019 On The Move walk

Millennial Park, Grand Rapids, MI

Texas-

October 18-20th, 2019 People With Smiles Camp

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



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 –

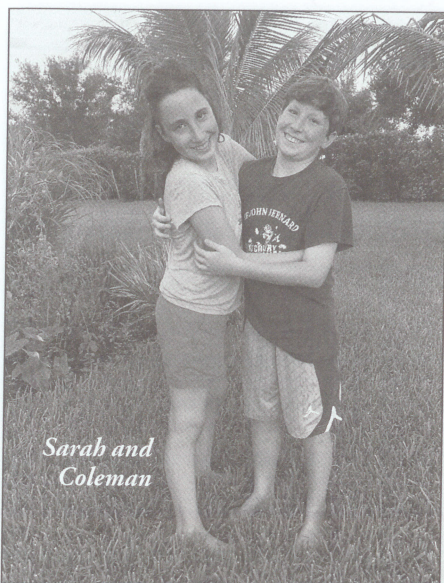
More information and sites currently recruiting participants is available at:

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

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

Created For This Moment

From the blog of Therese Maire Cheatham, edited by Denise Servais



Sarah and Coleman

The doctors told her that her newborn son needed a feeding tube, so she spooned breast milk into his mouth for hours on end every single day until he was strong enough to nurse. They told her that her

son would never walk, so she scheduled physical therapy multiple times a week so that he could defy the odds. They then told her that he would never be able to run, but now he runs so fast that she can barely catch him.

This woman is my mother, and the boy is my brother. This is the life with a child who has special needs. This is strength. This is pain. This is courage.

Coleman blessed our lives in January of 2005. He is the sixth of 11 children, and is a light to all of us. But from the beginning we knew that Coleman was different. He barely ever opened his eyes and couldn't nurse. He was so limp, so helpless, and so weak.

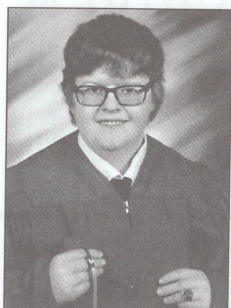
A couple months after his birth, sweet Coleman was diagnosed with PWS. And we were blessed with not only Coleman, but also Sarah. Sarah joined our family through adoption in 2009, when she was three and a half years old. What a sheer gift her life has been to us. Sarah is sassy, hilarious, and so full of joy.

I can't say that life with Coleman and Sarah is always easy. Coleman is in a phase right now where he has huge

meltdowns and runs away, and Sarah is extremely slow and belligerent. We (my siblings and I) have had to sacrifice a lot for them. The fridge and cupboards in my parents' home have to be locked up all the time. We have had to learn to live and abide by all their restrictions in the home. They also require more attention everywhere we go. This can be hard on us kids who also want our parents' attention.

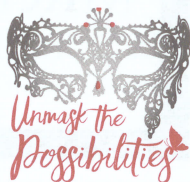
Our family has no doubt suffered due to my siblings' syndrome. But we have found beauty in it. Coleman's diagnosis was a blow to our family, especially my parents. But without his diagnosis, we never would have found our sweet Sarah. God gives us people, circumstances, and events to show us the beauty in the struggle. Your greatest struggle might just be your greatest blessing.

Therese Maire Cheatham from Houston, is a sibling to Sarah and Coleman, both of whom have Prader-Willi syndrome. She writes a blog called "Therese Maire" where the full article (Created For This Moment) can be viewed. ■



On May 15, 2019, Michael Baron Howie White graduated from Hahnville High School in Boutte, Louisiana. Diagnosed with Prader-Willi

syndrome at just a year old, Michael started school at age three in a self-contained class for students with mild to moderate disabilities. It wasn't long, though, before a self-contained class could no longer contain Michael and he soon branched out into general education classes. Michael had supports and accommodations from many devoted individuals throughout his school career; and, after 18 years of hard work, he completed his goal of graduating with a High School Diploma. Many, many congrats to Michael! ■



I attended my first conference in 1999 just a month after we received Kyle's diagnosis of PWS, a diagnosis that took 4 years and numerous tests to receive. I was a 21-year-old single mother who was extremely overwhelmed by the diagnosis and felt very alone. The only other person I knew who had a child with PWS lived over 3 hours away and coordinating schedules to chat was difficult. When I walked into the conference I didn't know what to expect, but I remember leaving with a newfound purpose and what I viewed as a new "family". Since that first conference, I have attended numerous conferences as a parent, Chapter Leader, Parent Mentor and member of the Youth and Adult Program (YAP). In addition, my PWS family has grown significantly with dear "family members" located in many of the states spanning the US. Thanks to that very first conference I went from being a lonely, overwhelmed single mom to feeling like I had an entire army standing with me. Not only does conference give attendees the opportunity to learn from the experts, but it also gives people the opportunity to meet other parents and grandparents who "get it" and are on a similar journey. Conference connects people from all over and is a place where lifelong friendships begin!

~Crystal Boser



Introducing Andrea Lucy, Membership & Engagement Coordinator, PWSA (USA)

Andrea Lucy became the new membership & engagement coordinator on our association's professional staff on July 8, 2019. Working within PWSA (USA)'s development team, Andrea is excited to join the organization to work in the areas of membership, Chapter relations, communications, advocacy, and fund/volunteer development.

Andrea is a U.S. Air Force veteran from both active duty and reserves. She graduated with her BAS in Technology Project Management in 2014. As the previous membership relations manager at the Association for Women in Science, she comes to PWSA (USA) with work experience building and directing new initiatives in areas of advocacy & public policy, membership, marketing, and Chapter relations.

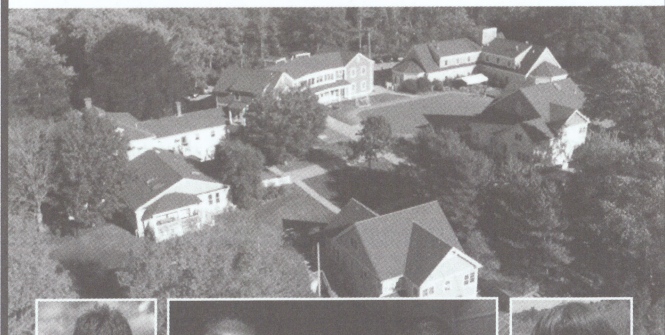
In her free time, Andrea leads a Girl Scout troop, volunteers with homeless outreach in Sarasota, and loves to crochet, read and hike in nature. Andrea is excited to learn more about and build collaborative relationships with the PWS community.

PWSA (USA) CEO Steve Queior said "Andrea fits perfectly into our staff team and expanding efforts to enhance our communications with members and to increase our engagement with the PWS CommUNITY."

Please welcome Andrea to our PWS family. ■

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Best Wishes From...

The Cohen Family
Mitch, Fran, Aaron
and Ali



<https://www.pwsausa.org/family-support/>

The fourth featured icon from our Five Pillars of Support is **Family Support**. This program *provides services to families supporting a relative with PWS from birth through adulthood.*

Visit and browse our website, use the search tool and see stories, resources and information. Learn more about the variety of services and education we offer. Contact us at 1-800-926-4797 and ask to speak to a Family Support Counselor (available 10AM-5PM EST) or you can e-mail us at support@pwsausa.org. We want to hear what you learned reading this issue and visiting our website. ■

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E-mail Support Groups: We sponsor nine groups to share
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Andrea Glass, Denise Servais
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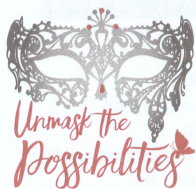
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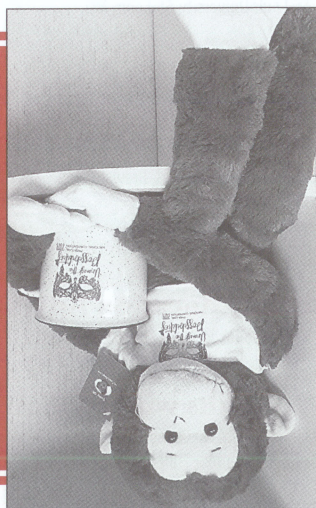
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Come visit us at the Store.

- Books
 - Clothing
 - Mementos and lots more
- See what is new
and waiting
for you at the
Convention Store!



My first conference was when
Justice was 15 months old and I
finally felt no longer alone. It was
so nice to be with other parents
who "got it". No explanations were
needed. We got to share ideas and support each other.
Now convention allows our daughter to likewise feel "no
longer alone" as she helps and connects with children like
her, who "get it" as they grow and learn from each other.
That's the best.
~Kristi Rickenbach, mom to Justice Faith with PWS



Don't be terrified (like we were).
As a new parent when we attended
our first conference in Texas, so
much was new for us. But we were
amazed by the whole experience!
We were so reassured by the staff and professionals who
became a part of our family; they made us and "our"
children feel safe and secure.
~Diane Seely, parent of a teenage son with PWS

