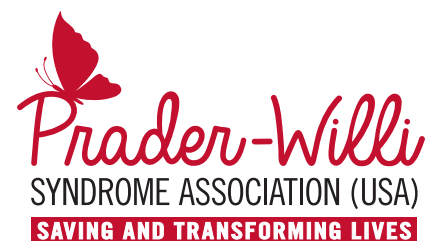


The Gathered View

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



Angel Drive

The 2018 Angel Drive campaign kicks off November 13th and we're counting on YOU to be our Partner of Hope!

By Rikka Bos, Development and Chapter Relations Specialist, PWSA (USA)

Every year over two thousand individuals and families turn to PWSA (USA) to find hope and help when they need it most. Ours is the only organization that provides the comprehensive support, tools, and resources families need to thrive in the face of a rare genetic condition.

"PWSA (USA) offered hope when the NICU doctor said that the best we could hope for was an "awful to tragic life" for our daughter with PWS. I'll never forget their kindness and understanding when we reached out to them after our daughter's diagnosis." – Monique, PWS Parent

There's No CommUNITY Without You

Because most resources are provided to individuals and families completely free of charge, the 2018 Angel Drive is crucial to ensuring PWSA (USA) can be here for the PWS

CommUNITY now and in the future. When you make a gift to this year's Angel Drive, you become a PWSA (USA) Partner of Hope and help us:

continued on page 2



Individually we are rare,
together we are strong
See Parent Mentors, page 5

Left to right: Front Row: Jessica Duis, (Vanderbilt); Steve Queior, Stacy Ward, Diane Seely, Mary Burr, PWSA (USA); Jennifer Ebrahimi **Second Row:** Tammy Penta, Breanna York, Maggie Andrews, Jordan Rhodes, Michelle Torbert, Kathryn Lucero, Kristy Pulkrabek, Susan Fries, Sara Grosso, Amber Gaulke, Noelle Scalzo **Third Row:** Valerie Selinger, Mary Howard, Winnie White, Andrea Warren, Katie Moureau, Julie Casey, Valerie Cirino, Kenna Grigorov **Back Row:** Catt Pudney, Tanya Kaminski, Rebecca VanderBroek, Sara Rau, (Parent Mentors); Nathan Bingham (Vanderbilt)

Volume 43, Number 6 ~ November-December 2018 ~ Our 43rd Year of Publication

The PATH for PWS Study Starts...

Do you want to understand serious medical events in PWS? Enrollment for the **PATH for PWS** study is now open! This study will help us better understand serious medical events in PWS over a four-year period, as well as evaluate how PWS-related behaviors change over time. The data from this study is intended to inform the development and clinical trial design of potential new treatments.

There is no therapy provided as part of this study. **Data will be collected through internet-based surveys in the Global PWS Registry and no clinic visits are required.** You are welcome to participate in other clinical trials while you are in PATH for PWS.

We are seeking at least 500 people with PWS aged five years and older to participate. You will receive a \$100 e-gift card for completing the initial surveys and \$50 for completing the follow-up surveys every 6 months over the length of the four-year study period.

Who can participate?

To be eligible for the study, an individual with a confirmed diagnosis of PWS must:

- Be a child, teenager, or adult (ages 5 and up)
- Live in the U.S., Canada or Australia
- Be currently (or willing to be) enrolled in the **Global PWS Registry**
- Have a caregiver with internet access to enter study data (every six months)

Want to help even more?

PATH participants who live in the U.S. will be asked to consider participating in an **optional** sub-study that involves providing a blood sample for analysis of D-dimer. D-dimer is a potential marker of blood clots which

may be higher in people with PWS. You will receive an **additional** \$100 e-gift card for participating in the sub-study. Those who choose not to provide a blood sample for the sub-study do remain eligible to participate in the main PATH for PWS study.

Should you have any questions about the **PATH for PWS** study details or enrollment, please visit **www.PATHforPWS.com** or contact us at **info@PATHforPWS.com**.

We ask you to please give this key study enrollment request your strongest consideration. ■

Visit the PWSA (USA) and shop online <https://www.pwsausa.org/shop/>; besides all the informational materials, you might discover the perfect year-end holiday gifts!

Angel Drive, *continued from page 1*

PWSA (USA) FIVE PILLARS OF SUPPORT



AWARENESS



FAMILY SUPPORT



RESEARCH



EDUCATION



ADVOCACY

- Raise **AWARENESS**
- Provide holistic and comprehensive **FAMILY SUPPORT** services through all stages of life
- Facilitate **RESEARCH** that saves and improves lives
- Provide **EDUCATION** to those working with the PWS community, such as medical, education, and residential care professionals

- **ADVOCATE** for the needs of both individuals and the entire PWS community
"This organization met us at an extremely difficult time. The amount of information and support they give is unparalleled. When we have needed advice about

care, they have been there. They help take the scary unknown and make it ok."
— Christa, PWS Parent

Become a Partner of Hope

Donations received during the 2018 Angel Drive help pay for the programs and services our PWS families have come to rely on.

Your donation makes a real and meaningful difference in the lives of individuals and families across the country and helps make our work through the **Five Pillars of Support** possible.

Thank you!

Watch for your 2018 Angel Drive letter in the mail, or make your year-end gift today at

<https://www.pwsausa.org/angel-drive/>. ■





All children with PWS have hypotonia at birth and for many it is an obstacle that they deal with throughout their lives. Hypotonia is characterized by a depressed ability to organize and use the motor system against the pull of gravity.

The foundation of growth, development, and learning in a child starts with sensory and motor interaction with the world. The brain is built from the bottom up and this starts with movement and sensory exploration. Sensory stimulation and feedback drive the brain, but the motor system drives sensory stimulation—you can't have one without the other. Our children are significantly delayed in both because they are not moving at birth. They have limited interactions at birth with their environment including limited suck, swallow, infant reflexes etc.

Children with depressed sensory and motor systems have issues with:

- **Sensory Processing**, in which the vestibular, proprioceptive and/or tactile (touch) systems fail to alert the brain of changes in body position.
- **Praxis or Motor Planning**, in which the body is unable to formulate the proper motor response.
- **Balance**, with the body unable to sustain co-activation of muscle groups working against gravity both statically and dynamically.
- **Coordination**, with difficulty coordinating upper and lower body movements or visual system to produce fluid and efficient movements.
- **Touch**. People with sensory processing issues can be over or under sensitive

Ask The Expert:

"I know that hypotonia, low muscle tone, affects muscular strength, muscular endurance, balance and coordination. Does hypotonia affect sensory integration?"

Answered by Janice Agarwal, PT, CNDT

to touch. Wearing certain clothing textures, clothing tags, food textures, even hugs can be challenging.

Children with sensory processing issues have trouble organizing information the brain receives from the senses. By senses we are referring to the sense of control of body (proprioception) and balance and spatial orientation (the vestibular system).

Sensory stimulation and feedback drive the brain, but the motor system drives sensory stimulation – you can't have one without the other.

What Proprioception Does

We all have receptors in our muscles that tell us where our body parts are. For example, if you raise your hand, you know that your arm is over your head. You don't have to think about it or look in a mirror. But kids with poor proprioception may think their arm is over their head when it's really straight out in front of them.

What the Vestibular Sense Does

The vestibular system includes the parts of the inner ear and brain that help control balance, eye movement and spatial orientation. It helps keep you stable and upright. Children with vestibular issues may not know where their body is in space. This can make

them feel off balance and out of control.

Trouble with Motor Skills

Children who have trouble with proprioception or the vestibular sense could struggle with motor skills in a number of ways.

They may seem awkward and clumsy. An activity like running or even going up and down stairs may be hard for children who have difficulty knowing how their body is oriented and whether it's stable. They may move slowly or avoid activities that are too challenging.

They may not know their own strength. Imagine you are holding a newborn chick. You are trying to be gentle and not drop it but want to feel how soft it is – but you squeeze it too hard and hurt it. You have used more muscles than you needed.

Sensory-related difficulties can make it tough to gauge movements for all kinds of tasks. Children with sensory processing issues may break the pencil point because they're writing too hard, rip a page when they just meant to turn it or give overenthusiastic hugs.

They may not like physical activities that other children find fun. For example, they may not feel safe on the swings because they're not getting the sensory input that tells them they're securely seated. As the swing moves, they may have difficulty understanding how to shift their weight to balance.

They may be in constant motion, bump into things or seem out of control. When kids don't get enough feedback from the sensory system, they may exaggerate their movements to get the information they need from the environment. When they walk down a

continued on page 6

Part two of a two-part series

The Over-Looked Sibling:

Increasing Awareness and Support for Siblings of Individuals with PWS

By Stefanie Varga, Ph.D., LP, Clinical Neuropsychologist

In continuing the sibling article from the September-October issue, a few recommended strategies for addressing some of the issues addressed are outlined below.

Issues:

1. A different experience of family and togetherness.
2. Trouble sharing feelings.
3. Pressure to be better, stronger, or perfect.
4. Feeling as though their problems are not important.
5. Feeling isolated.
6. Always needing to help.

Strategies:

1. Be open and honest. Parents should talk openly with children (particularly older children) and explain what is going on. If we do not discuss the situation openly with children, they may feel guilty or confused. It is critical to help siblings know that their problems and concerns are important. Parents should avoid using jargon or big terms, but rather focus on the behaviors that are concerning. Talking about strengths and weaknesses that are present in all children can be helpful. This avoids targeting or focusing only on the child with special needs. Parents should try to be as open as possible with children and include them in decision-making. Some parents may try to shield siblings from what is happening. Families should

feel like a team and make decisions together. Older siblings should not be unnecessarily forced to accept certain problematic or very stressful situations.

Siblings may have questions about their sibling with PWS. They may be provided with limited information and tend to have fewer resources available to them. During doctor visits, siblings may not be left in the waiting room or even need to sit with the child with PWS while the parents talk with the doctor. As a result, the sibling is often left feeling “in the dark” about what is going on, have many unanswered questions about their sibling regarding the extent of their disabilities, whether their issues may become worse, and what the future will look like for their brother or sister. Lacking information and confusion may lead to the sibling developing their own ideas about what is happening (which may be worse than is actually true.) Talking openly with older children (8 years and up) and adolescents is critical in supporting their emotional needs.

2. Special Treatment for Siblings.

Parents should try to set aside 1-1 time with each child in their family, especially in the family with a child with PWS. Even small amounts of 1-1 time on a regular basis can help each child feel loved and important. It may be not be equal time for each child, but it should be meaningful and consistent. For example, spending 10-20 minutes each night before bed, uninterrupted, can be special. Parents may choose to set up “dates” every week with each child, doing something they enjoy and look forward to. Parents should try to be especially sensitive to the siblings of their children with disabilities. Being mindful

of the differences in the amount of time spent with each children is important.

Parents should avoid, however, allowing their typically developing child to get away with bad behavior or get whatever they want. Parents with children with special needs often feel guilty or worry that they are not able to give their “typical” child/children a normal upbringing. Parents should try to teach all of their children to be responsible for their decisions and negative behaviors.

3. See the positives. Parents should be mindful that growing up with a special needs sibling offers opportunities and teaches valuable skills in empathy and compassion. Such children tend to be very good friends, as they tend to be more tolerant, understanding, supportive and patient. They may also develop a deep loyalty and protective attitudes towards their sibling. Their involvement with their sibling may even lead them to choose future occupations in the helping professions. If a child is struggling in being supportive to their sibling or chooses not to help, they should not be judged or punished. Talking with children regarding their attitudes and behaviors toward the sibling with PWS is helpful.

4. Be mindful and aware of possible emotional stress or adjustment difficulties. Siblings of children with disabilities in general are at a greater risk for developing emotional issues, anxiety, or stress. These issues may be invisible to the parent. Siblings may appear well-behaved to protect their already over-burdened parents. Peer problems may be more common in children with special needs siblings. Some siblings may not wish to engage in extracurricular activities or may experience academic issues as a result of limited time and money. If there are concerns, professional consultation with a psychologist or

continued on page 7

Family Support

Individually we are rare...together we are strong!

Building a Parent Mentor Program

By Winnie White, Ed.D., mother of Sandy Kay with PWS, PWSA (USA) Parent Mentor

PWSA (USA) is committed to reaching families through a well-developed mentor program. The family mentor program has been in existence for several years, but has made some major changes these past three years. They have grown from 10 mentors to 44 mentors. The recent mentor workshop at the Monroe Carrell, Jr. Children's Hospital at Vanderbilt in Nashville, TN, was the first of its kind. Diane Seely, PWSA (USA) New Parent Support Coordinator, created a workshop designed to educate our parent mentors in various topics that include current trends in dietary management, advantages and safety of various dietary supplements, the benefits of an active lifestyle, abnormalities in sleep/wake cycles, growth hormone therapy, and more.

On September 8, 2018, twenty-five parent mentors, seven different speakers, and four PWSA (USA) staff members gathered together in Nashville, TN, to learn from each other, share experiences, and grow in knowledge of the whole child.



It was a very comprehensive approach to gaining knowledge about PWS as well as how to effectively reach out to new families who need the message of hope.

The goal of the mentoring program is to utilize past experiences to help reach out and connect to new families. During this workshop, mentors not only learned about PWS and all the many facets of the spectrum, but they also were encouraged to build ongoing relationships through friendship and shared experiences (the good and the bad). *Sharing our stories and passions is vital to the healing process.* The mentors experienced that first hand as parent mentor Sara Grosso opened up her heart and shared her NICU experience. There was not a dry eye in the room. Everyone was drawn to Sara



and thankful for her transparency. They encouraged her to share that story on Facebook so that they could share with their personal families they mentor. Thankfully, Sara agreed; and her message continues to reach families through social media.

Mentors were also encouraged to give new families empathy and to share their expertise, but to stay away from the long "to-do lists" that comes so easily to us as the conquering mom. Parents need to know that they CAN and WILL survive this diagnosis, and that they have found their tribe. A parent mentor's job is to let new families know that *WE are their people.*

As the parent mentors reflected on the weekend, one statement was repeated by several mentors. Dr. Nathan Bingham, Pediatric Endocrinologist from Vanderbilt, opened with, "If you've met one child with Prader-Willi, you've met one child with Prader-Willi" (an adaptation of Dr. Stephen Shore's quote for individuals with autism). This is important to remember as mentors. We pass along information to new families to empower them to make informed decisions and get the right members on their teams. Thankfully, parent mentors get to be a part of those teams that new parents rely so heavily on for success for their children with PWS. Parent mentors do not have all the answers since every child is different, but they do have shared experiences that are valuable to newly diagnosed families. ■



Parent Mentor Workshop - A Perspective from the Director

By Jessica Duis, M.D., M.S., Medical Director, Prader-Willi Comprehensive Clinic at Vanderbilt University Medical Center

In reflection of the opportunity to work with the wonderful individuals who volunteer their time as parent mentors, I can only use one word – **humbled**. I was sitting there in the room, tears streaming down my face as I listened intently to a mother share her experience in the NICU and PICU with her son. I listened to a mother reflect on how her special needs daughter WILL be attending college. I could never forget the time leading up to the meeting in which I engaged in discussions with Diane Seely that brought new perspectives on characteristics of PWS, in addition to therapeutic discussions. I am thankful for all of these moments and more that weekend that changed me as a doctor and person.

- It was an inspiration for the parent mentors to share in their experiences, questions, discussion, and nervousness and excitement for the future.
- **Our aim in the PWS Comprehensive Clinic is to create a Center of Excellence in which we are a resource.** To make this a possibility, we envisioned a program that was for the families, in which we would be accessible and engaged in a way we felt was important for how people communicate today.
- The entire process from taking a part in planning the event to spending time getting to know these mothers, we saw their strength and determination to understand the best standards of care. This evidence showed how they could serve their mentees and children selflessly. This work helped us refine that vision to make expertise accessible to everyone no matter where they live and what their resources.



Jessica Duis with Mary Howard

- When I put together the clinic at Vanderbilt University Medical Center, it was based

on **forward-thinking, compassionate, and inquisitive providers** who would work hard to take care of families as people. The parent-mentor program at PWSA (USA), the families and individuals with PWS, are a large part of working with us to make that program a reality.

- **We want to hear unfiltered feedback** about how medical care could improve the lives of families with PWS. The parent-mentor program is a fantastic partnership so do solicit this feedback and work with families to refine our medical approach. This ensures we are providing not just the information but the support needed to improve the quality of life of individuals with PWS and their families.
- Together we CAN and we WILL move the field forward with this goal in mind!

Our team – Dr. Ashley Shoemaker (pediatric endocrinology), Dr. Nathan Bingham (pediatric endocrinology), Dr. Althea Shelton (sleep medicine), Dr. Amy Whigham (pediatric otolaryngology), Dr. Megan Johnson (pediatric orthopedics), Erika Williams (dietician), Margaret Anderson (pediatric and adult endocrinology), Carla Jackson (social work), Rebecca Hardin (clinic coordinator) and I (pediatric geneticist, clinic director) thank PWSA (USA) for having us to participate in this groundbreaking event. ■

Ask The Expert, continued from page 3

hallway, they may knock into the wall to feel more anchored. They may kick their legs under their desk for the same reason.

For treatment of sensory integration or processing problems, look for an Occupational or Physical Therapist who is certified in Sensory Integration Therapy.

Janice Agarwal is a pediatric physical therapist with over 20 years of experience treating children birth to 3 years of age. Using techniques incorporating Sensory Integration to normalize development, she now only treats children with PWS. She is the author of the book, Therapeutic Interventions for Children with Prader-Willi Syndrome published by PWSA (USA) in 2011. Janice is a former nine year member of the PWSA (USA) Board of Directors. She is the mother of two boys, one of whom has PWS. ■

-Submitted by Lisa Graziano, PWCF.org

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PWSA (USA) CFC ID # is 10088

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

Andy Maurer Awarded Self-Advocate of the Year

The South Carolina Chapter of American Association on Intellectual and Developmental Disabilities (SC-AAIDD*) met for their annual conference October 3-5 in Myrtle Beach, SC. In addition to training and learning, awards are presented. Little did one recipient know he would be receiving an honor that coincidentally was given on his birthday!

We are pleased to announce and recognize Andy Maurer for being named Self-Advocate of the Year by SC-AAIDD. Not only is he a strong self-advocate, he is a mentor for his peers to help them learn to speak for themselves and exercise their rights. The son of Bronnie and Stewart Maurer, Andy was nominated by Dr. David Kammerer, Director of Training & Special Events at Babcock Center in West Columbia. Andy has demonstrated that he is a leader and strives to be a role model to all those that he meets. Andy is active in his home, work site and community. He is always advocating for the rights of people with lifelong disabilities. He creatively gives back by educating the



Andy Maurer, proudly displaying his plaque and honorarium.

public, organizations/schools, etc. via presentations, active participation and other interactions.

Employed part-time at the Babcock Center's Batesburg Work Activity Center where he is the receptionist, Andy educates for advocacy for the rights of persons with Prader-Willi syndrome to staff, peers and families of the Babcock Center community. He was honored as employee of the month in November 2017.

Andy is experienced in advocating with elected officials and community leaders through events like the Community Engagement Day

(Disability Advocacy Day) at the South Carolina State House where he was a speaker. Nationally he also serves as co-chair of the Adults with PWS Advisory Board for PWSA (USA) and advises, serves and supports this board and chairs their annual meeting in Florida. Andy was a featured presenter at the 2017 National PWSA (USA) convention in Orlando, Florida. Internationally, Andy ranked third place in the 2003 Special Olympics World Equestrian competition.

A great leader, Andy has positively influenced other peers, staff, and the community. Andy has been an instructor for the *Voice Your Choice* rights training program. This program teaches people with lifelong disabilities about their rights and how to exercise them responsibly. Andy continues to participate in the Special Olympics.

Congratulations Andy on your recent achievement and accomplishments. We are very proud of you and your great works.

**AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.*

To learn more about Babcock Center and AAIDD, please visit their websites: <https://www.babcockcenter.org/> and <https://scaaid.org/> ■

Overlooked Sibling, *continued from page 4*

therapist is recommended. Children with siblings with special needs can benefit from supportive counseling to help mitigate chronic adjustment difficulties, share their experiences in a safe environment and learn adaptive coping skills.

5. Seek supporting counseling and therapy services. Working with a psychologist or supportive counselor or therapist can be extremely helpful

to siblings. Therapy time may be spent voicing frustrations and concerns, exploring anxiety or fears about the family or their sibling, and learning adaptive coping strategies. Talking with a therapist versus a parent may feel more safe and relieving, as siblings can worry about their parents as well. Family therapy may also be of benefit in situations where families experience very high stress, conflict or family dysfunction as a result of the PWS child's difficulties.

Dr. Stefanie Varga is a clinical neuropsychologist with expertise in working with children with comorbid medical and mental health needs and their families. Dr. Varga also has a daughter Sabina, age 10, with PWS. She has a special interest and passion in working with families of children with rare genetic disorders and mental health conditions. Dr. Varga can be found at the PWSA Convention in 2019 offering sibling workshops and mental health consultation to families. ■

Matthew Wynne: Special Olympics Assistant, The Coca-Cola Company

Submitted by Andrea Warren, mother of four including Taylor, age 14 and Lizzie, age 9, both with PWS

Matthew Wynne, 20 years old, has been a Special Olympics athlete for 10 years. He plays not one Special Olympics sport, but three, excelling in basketball, softball and soccer. And Coca-Cola, 132 years old, has been a Special Olympics founding partner for the past 50 years. To celebrate the 50th anniversary of this partnership, Coca-Cola renewed its commitment to fostering inclusion and understanding by employing individuals with intellectual disabilities... now Matthew helped Coca-Cola understand what athletes and fans wanted in preparation for the 2018 Special Olympics USA Games.

When Matthew Wynne received his first paycheck at his first job, he was ecstatic. "I never had a job before," he explains. "So getting my first paycheck really felt exciting. The best thing about working is that feeling like you're a responsible adult earning your keep in the world while contributing to society's well-being."

That his first paycheck came from The Coca-Cola Company was an even bigger thrill. "Landing my first job at Coca-Cola is really special," Wynne says. "Coca-Cola is a really well known and respected company. When I'm working, I get to add value in meetings."

He adds, "I am so proud of my company, that they were a founding sponsor of Special Olympics and that still they are 50 years later. Both Special Olympics and Coca-Cola are great organizations that give opportunities to athletes like me to feel respected and included in the Games."

Wynne worked closely with Becki Cedrone, director of Coca-Cola North America's Community Marketing, to plan Coca-Cola's presence and interactions with athletes and fans. Prior to the Games, he selected the giveaways for Coca-Cola's Special Olympics activations, budgeting and communicating those decisions to team members. During the Games, Wynne set up product distribution points, dispensed product to athletes and refilled coolers.

More than a first job, Wynne saw his work with Coca-Cola as evidence of the value individuals with intellectual disabilities bring to the work place. "I'm the voice of the athletes," he explains. "I know what they know and like. I represented the athletes' point of view."

Cedrone believes that as a subject matter expert on Special Olympics with 10 years of competition under his belt, Wynne provided essential insights that helped Coca-Cola to understand what athletes want from sponsors and partners. "Coca-Cola's shared values with Special Olympics are inclusion, optimism and moments of happiness," she adds. "I truly feel that all of these came to life by having Matthew on our team. We became a better, stronger team because of him."

To hear and see Matthew: <https://youtu.be/0oBXwZFXeZs>

~ Published by the Coca-Cola Co.: Hannah Nemer, Jun 29, 2018 *Voice of the Athletes: Meet Three Special Olympic Athletes Working with Coca-Cola to Support the 2018 USA Games*

Editor's note: Parents Noreen and Brian live in Milton, Georgia and have three children. Shannon the eldest is a Board-Certified Behavior Analyst working at the University of Georgia. Matthew graduated from High School and now attends Gwinnett Technical College and is studying to be a Veterinarian Technician. Matthew is currently the torch run representative for Georgia Special Olympics and works with the Georgia Police Department representatives year-round to help raise money for Georgia Special Olympics. Matthew has a younger sister Allison, who attends Villanova University in Pennsylvania. We also have a beloved pet dog, Tucker. ■

"The best thing about working is that feeling like you're a responsible adult earning your keep in the world while contributing to society's well-being."

~ Matthew Wynne



Matthew had the opportunity to interview golf professional Jordan Spieth, whose sister is a Special Olympics athlete.

Planning Tips for the Holiday Season

By Stacy Ward, M.S., Crisis Intervention and Family Support Counselor, PWSA (USA)

It's the most wonderful time of year! Or, is it? The holiday season can be challenging when you have a loved one with Prader-Willi syndrome. With numerous family gatherings, routines disrupted, parties at school, and food everywhere you turn, the season can be less than jolly. With mindful planning, this CAN be the most wonderful time of year, with less stress for the person with Prader-Willi syndrome.

If you will be with relatives or close friends, remind them of the importance of food security, especially at a big event. Many people do not fully understand that it isn't just about calories but it's also about decreasing anxiety and assuring your loved one's safety. They may not recognize that a slender person with Prader-Willi syndrome (PWS) might still need protection from binge eating, which is a significant danger during the holidays.

Tips for Managing Food

- Assign a specific person to be a partner to the person with PWS at all times. Dr. Linda Gourash states, "*When everyone is in charge - no one is in charge.*" This duty can rotate as long as the switch is directly made between partners.
- Knowing the menu ahead of time will help you plan food choices; ask the hostess, whether it is a teacher or a family member for details. Consider hosting yourself to reduce surprises.
- Discuss the food and timing of the meal ahead of time to avoid surprises and disappointment.
- Plan seating arrangements to help your loved one avoid sitting near food and condiments.
- When the meal is done, make sure food is put away or constantly supervised.

Celebrate the Holidays with Non-Food Related Activities

- Play board games, cards, or other mind-challenging games.
- Participate in a Turkey Trot, Jingle Jam, or other fun 5K walk, run, or other physical activity.
- Make homemade cards for friends and family which are treasured by the recipient.
- Decorate ornaments and host an ornament swap or exchange.
- Take a walk around your neighborhood to see the lights and decorations.
- Make puzzles out of old Christmas cards <https://www.wikihow.com/Make-a-Christmas-Card-Jigsaw-Puzzle>.

In Closing

Although most people will never experience a holiday emergency, being prepared for one is still necessary.

- Please remember to carry and have handy PWSA (USA)'s Medical Alerts pocket-sized booklet with you, especially if you travel, and/or download the PWSA (USA) app to your smart phone. And,
- Don't forget to take any abdominal complaints seriously during this festive season and be sure to seek urgent evaluation if you have any reason to worry. ■

*We wish you a joyous and safe
holiday season!*

Learn more about Saving
and Transforming Lives at
<http://www.pwsausa.org/>

Holiday Shopping?

See page 16 for great gift ideas!



Could you become Trevor's family?

Wide Horizons For Children (WHFC) would like to introduce Trevor. A content little guy, needing a family of his own, is ready and they are looking for a special family who is prepared for the unique needs of a child with Prader-Willi syndrome.

Now age 4, Trevor is quiet and shy and close with the nannies that care for him. Abandoned in Asia as a 9-month-old infant, Trevor was delayed in his growth and development. After extensive genetic testing it was determined that he likely has Prader-Willi syndrome or another syndrome related to the same genetic defect. Wide Horizons has requested updates and hopes to share how how this sweet little boy has grown and developed in the last two years.

Any interested families should email contact@whfc.org. WHFC is delighted to share his full file (at no cost) with a prospective family after they speak with a social worker at WHFC. This call is usually 20 minutes with the goal to share more info about Trevor, and learn a bit about the family and explain the waiting child adoption process from Asia. His information is on file with Wide Horizons For Children until Dec. 12, 2018.

- Married couples and single women up to age 53 are eligible for consideration.
- Families may qualify for a \$5,000 WHFC subsidy; additional subsidies may be available through other adoption grant organizations.

Photo shown was taken at age 18 months. **Trevor (m) DOB 11/1/2014, ASIA** ■

Adoption carries the added dimension of connection not only to your own tribe but beyond, widening the scope of what constitutes love, ties, and family. It is the larger embrace.

~ Isabella Rossellini

Every Person Matters

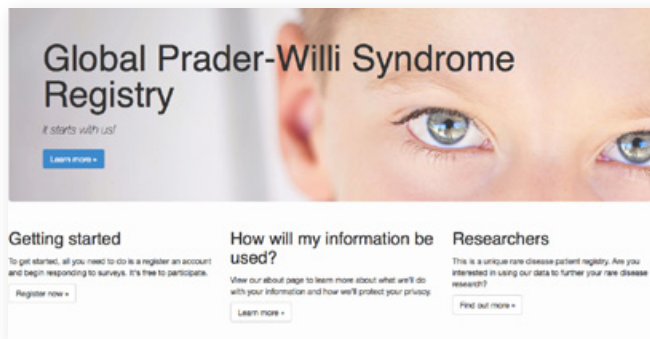
Register Now

Global Prader-Willi Syndrome Registry

Advance PWS research faster than ever by providing researchers with comprehensive, accurate, and research-ready data that is easily accessible.

Whether your loved one with PWS is 2, 15 or 52, we need your help in making sure they are ALL included to provide a complete picture of the PWS community. This is a great way people with PWS – of all ages – can help advance research, develop new treatments and improve the quality of life of the entire PWS community.

The Global PWS Registry is a secure database compliant with U.S. Health Information privacy laws and FDA regulations. To create the most robust PWS registry possible, every person with PWS should be



included in the registry. Through a series of electronic surveys, the registry collects information on a wide range of topics including developmental history, medical complications, and quality of life issues.

If you are a parent or guardian of a person with PWS, join the movement today to build the Global Prader-Willi Syndrome Registry by visiting www.pwsregistry.org. ■

We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more resources like this. Please visit our Web site, www.pwsausa.org

The Israel National Multidisciplinary Prader-Willi Syndrome Clinic

Editor's note: We were delighted to receive this wonderful article from Dr. Gentsil about the clinic and staff for PWS in Jerusalem.

We in Israel have a PWS Multidisciplinary Clinic at Shaare Zedek Hospital in Jerusalem. We've been here since 1996 and see almost every person with PWS in the country (160 out of 170 so far). Below is a brief description of our work. All of us in the clinic have direct connections to working with people with the syndrome. The physicians all specialize in PWS. I am a psychologist and run a large group home for people with PWS and am also a member of the PPCB of IPWSO. The dietitian is also the dietitian of my group home already for eight years.

We all are very dedicated to treating people with PWS, in order to improve their lives and also to add years to their expected life spans.
~ Larry Genstil

In order to encourage physicians and caregivers to work together and to establish multidisciplinary clinics for the benefit of PWS patients, we would like to describe our holistic approach to treating our PWS individuals during the last two decades.

Since 1996, the Israel national multidisciplinary Prader-Willi syndrome clinic at the Shaare Zedek Medical Center in Jerusalem has provided comprehensive care for more than 160 PWS individuals ranging in age from newborn infants to adults in their 40s. With the increased awareness of signs and symptoms of PWS in newborns, nearly all of our newly diagnosed patients are young infants. These young patients are seen and examined at three to four month intervals by Dr. Harry Hirsch, pediatric endocrinologist and Prof. Varda Gross-Tsur, pediatric neurologist for management of cryptorchidism, treatment with growth hormone and guidance regarding developmental issues, educational placement, etc. Older children, adolescents and adults with PWS are followed with routine visits once or twice yearly to our multidisciplinary clinic for "round-table" sessions led by the clinic director, Prof. Varda Gross-Tsur, with active participation by Dr. Fortu Benarroch, pediatric and adolescent psychiatrist, Dr. Harry Hirsch, Dr. Larry Genstil, psychologist and director of a residential PWS group home, and Dorit Forer, registered dietitian. Patients are accompanied by their parents and/or caregivers and have an opportunity to provide information regarding their progress and problems, and discuss various medical, psychiatric, psychological, educational, social, employment and housing issues. The opportunity to interact with professionals from a variety of disciplines, all of whom

have accrued experience in caring for PWS individuals, offers a holistic approach for coping and managing the difficult developmental, medical, and behavioral issues at each stage of the life-cycle in this population. After each clinic visit, a summary letter with specific recommendations is sent to parents and caregivers in the community.

Other specialists, including an orthopedic surgeon (Dr. Harel Arzi), a geneticist (Dr. Reeval Segal) and a gynecologist (Dr. Naama Srebnick) are available on PWS clinic days for "real-time" consultations in areas of their respective expertise. Gynecological ultrasounds, imaging and bone density testing may be performed on-site as needed. Our clinic administrator, Nava Badichi, maintains the appointment schedules, keeps track of test results, and arranges for transportation to our facility when needed for families living outside of the Jerusalem area.

Because our clinic cares for nearly the entire PWS population of Israel, we have had the opportunity to observe the full clinical spectrum of this condition across all age groups throughout our country.

Research activities on topics including pubertal and hormonal development, prenatal diagnosis, behavioral and psychiatric manifestations, and metabolic effects of exercise have led to numerous publications in international medical journals, as well as presentations at medical and PWS conferences in the USA, Canada, Europe, and Asia.

We hope to continue to build on our experience to further expand the services we provide in order to improve the health, well-being and quality of life for our PWS individuals and their families. ■

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Georgia Chapter Annual Family Gathering

By Debbie Lange, Executive Director, Prader-Willi Syndrome Association of Georgia

Another annual meeting is in the books. The September 22, 2018 family retreat was held at at Stone Mountain Inn, inside Stone Mountain Park, Stone Mountain, Georgia. This was our biggest retreat ever, with more than 36 families and a total of 130+ people in attendance. The Retreat included overnight lodging, three meals, and all activities at NO cost to our families. The only requirement to attend is residence in the state and registered membership in the chapter. This is a well-loved event and everyone looks forward to it each year.

We were incredibly fortunate to have a team of interns from the Terry College of Business at the University of Georgia, to manage our “kids activity program” at the retreat. During this program, participants enjoyed arts and crafts, **Bingo!**, music and games. A special meal was provided with PWS in mind for the evening meal. These allowed parents to enjoy a non-PWS meal knowing the “kids” were well cared for. Parents/families have the option of registering their “kids” and their siblings for this



Interns from the Terry College of Business made the day fun!

program. This year we had a team of nine interns who served 42 individuals for over six hours. We were fortunate to have the PWSA (USA) CEO Steve Queior join us. So grateful and truly appreciate the effort Steve made to be with us.

We hold several other annual activities throughout the year including an educational event, a family picnic, plus six support groups and six presentation/exhibits throughout our state.

The Georgia chapter is very fortunate to have a “fee for service” contract with our state to cover the costs of our retreats and all planned events. This

annual event provides our families an opportunity to enjoy a beautiful environment, enjoy fellowship with other families and a chance to relax for the “retreat.” This year was a little different in that we are actively working to build our board. In previous years, this “gathering” has been truly a “retreat” with no business discussed. But this year we needed our families’ input regarding future retreats; both positive and helpful comments were offered.

They shared what they liked about the retreat as well as what changes they might like to see considered. We also solicited active participation in the governance of the chapter.

The organization depends on its members and other volunteers to ensure these events can continue. Your time and support are critical to being able to offer these great PWSA-GA events. Please contact the chapter to offer your gratitude, comments and commitment for our “kids.” pwsaga@earthlink.net, 505 Lakeland Plaza, Ste 327, Cumming, GA 30040. 770-886-2334 ■



Bill, Karen, and JoAnna Ripley



*Left: Ann Margaret Bagley
Right: Lizzie Warren*



*Left: Zachary Mattingly
Center: Evan Matesevac
Right: Lucian Nixon*

Caregiver Burnout -

Whether you are a parent, family member, or paid provider, being the caregiver of a person with PWS can be incredibly rewarding – and it can be equally as stressful. Mental exhaustion, loss of hope for the future, fatigue, and irritability are all signs that you are starting to experience caregiver burnout. Here are some ways to get reenergized and reinvested in making and reaching goals for your child or person in your care:

- Don't focus on what you can't control. Find something, anything, that you can control and write it down.
- Keep a running list of every achievement. Even tiny steps lead somewhere and being able to go back and see progress will help energize you to keep going.
- Find a support group. If you feel isolated, reach out to online support groups if you are not physically near people who you can connect with. Social media is full of groups that can offer you support, an ear, or a sanity check any hour of the day.

Most importantly, if you feel like you are experiencing burnout, be sure to let yourself have those feelings. Loneliness, confusion, and resentment are powerful emotions that deserve to be acknowledged. Reach out to this PWS community. We are here for you. You are not alone. ■

~ Submitted by *Patrice Carroll, Director of PWS Services at Latham Centers*

Chapter Events and Happenings

PENNSYLVANIA – 2018 Pennsylvania PWS Conference
November 9-11, 2018

Registration, Nov. 9th from 7 – 9 P.M.
Conference begins at 7:30 A.M. on Nov. 10th
Doubletree by Hilton Hotel, Mars, PA
Contact: Deb debpwsapa@yahoo.com
Bonnie bonniepwsapa@yahoo.com

OREGON/WASHINGTON – Annual PWS Christmas
Party and Mini Conference
December 8, 2018, 1 – 5 P.M.
Pleasant View Church of Nazarene, Ridgefield, WA
Contact: Vonnie Sheadel 360-887-3304

WISCONSIN – Seventh Annual Snowflake Ball
Saturday, January 27, 2018 at 4 – 7:30 P.M.
Watertown Country Club, Watertown, WI
Hosted by PWSA of WI, Inc.

Chapters: Send your info on upcoming events, news and announcements; *The Gathered View* can help you announce your news. Next deadline: December 1 for the January/February 2019 issue. Email: editor@pwsausa.org

Carry PWSA (USA) Wherever You Go!



Are you carrying PWSA (USA) in your phone or tablet? If not, why not? Thanks to the Settles family, you can download the **FREE** PWSA (USA) app for mobile devices via iTunes or Google Play. With this app, you will have immediate access to all the important information you need on the PWSA (USA) website with a touch of your phone screen. Forget a handout you wanted to share with a teacher or doctor? No problem. It's all on your phone! Through this app you can:

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

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

Link: <http://bit.ly/2CsJHsnPWSAmobileapp>



Unmask the Possibilities
PWSA (USA) NATIONAL CONVENTION 2019
AWARENESS FAMILY SUPPORT RESEARCH EDUCATION ADVOCACY

October 23-26
Caribe Royale, Orlando, Florida

Events

Medical & Scientific Conference
October 23rd & 24th

Professional Providers Conference - October 24th

General Conference - October 25th & 26th

Youth & Infant Program
Youth & Adult Program
Sibling Program

Questions? Contact Jackie Mallow at jmallow@pwsausa.org or 941-487-6726

Medical & Scientific Conference – During this two-day event, scientists, researchers, and medical professionals from different disciplines share ideas and report on progress, helping to meet the ever-present goal to support research that will identify effective treatment, and improve the quality of life for individuals diagnosed with PWS.

Professional Providers Conference – Educational, social services, and residential professional providers come together to discuss identified and supported best practice and standard of care approaches, as well as to provide a critical in-person, solution-orientated exchange of ideas for specific concerns that can be addressed by experts in the field.

General Conference – This two-day event attracts parents, grandparents, caregivers, and professionals. The attendees are skillfully guided through a choice of multiple learning tracks covering an array of topics that can be tailored to their individual preferences. It is a time to build relationships with other families, attend counseling sessions and support groups, meet with top specialists and authorities on PWS, and just have fun. Experts in the field provide attendees with up-to-date information and resources for addressing the very complex needs of supporting and caring for an individual diagnosed with PWS.

Additional Meetings/Programs

Welcome Reception – October 24th (6 – 9 P.M.)

Chapter Leaders Meeting – This is a special two-day event for the leadership of the organization's network of chapters.

New Parent Mentor Meeting –

Where our mentors collaborate on information and support systems available for the families and individuals. ■



Interested in becoming a Convention Sponsor or Exhibitor? Details at link:
<http://bit.ly/2yuflAQpwsaUSAsponsor>



PWSA (USA) board member, Marguerite Rupnow, presents check to PWSA (USA) board chair Jim Kane.

PWSA (USA) welcomed its first official Corporate Partner; Prader-Willi Homes of Oconomowoc, at the PWSA (USA) Board of Directors meeting on September 14th. A premier residential facility located in Wisconsin, Prader-Willi Homes of Oconomowoc has been supporting individuals with PWS and their families for over 35 years.

PWSA (USA) works with Corporate Partners to coordinate the efforts of PWSA (USA) and corporate leaders, in a collaborative environment, to advance the field of Prader-Willi syndrome research, patient care, and family support. Positive recognition and other benefits are provided at three different levels of partnership. Both PWSA (USA) and Corporate Partners benefit from the relationship, as each assists the other in achieving its mission.

To learn more about becoming a Corporate Partner, contact Steve Queior at 941-487-6730 or squeior@pwsausa.org. ■

Staff and Key Contacts

Steve Queior, Chief Executive Officer
Debi Applebee, Business Manager
Kate Beaver, M.S.W., C.S.W., Alterman Crisis Intervention
and Family Support Counselor
Rikka Bos, Development and Chapter Relations Specialist
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The Members Only section requires a password:
member20

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

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

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<https://www.pwsausa.org/shop/>

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