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

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

Our Gift to you

The Prader-Willi Syndrome Association (USA) asked member and mom Lisa Peters if her holiday story could be shared with our readers. She was honored and pleased her family's story was selected.

Season's Greetings from Lisa and the Association-

On A Life Less Perfect

Our family life managing Prader-Willi syndrome, Asperger's/Autism and ADHD.

This blog chronicles our life raising two children, Nicholas 12, diagnosed with Prader-Willi syndrome and Weston 15, diagnosed with Autism/Asperger's/ADHD. It's the ups, the downs, the joys, the sorrows and most importantly, the beauty of living...a life less perfect, a life more meaningful.

Dec. 30

Trucks, Kitty Crates and the Overwhelming Favorite...Fake Farts

Christmas arrived with Nicholas feeling relieved of his strep throat, thanks to our Christmas Eve trek to the pediatrician for some good old antibiotics.

He awoke at 5:30 a.m. eager to venture into the living room to see if Santa had validated his good behavior by rewarding him with lots of presents. I think he was more interested, however, in learning the fate of his older brother since there was some serious concern that Weston's morning rambunctiousness would result in a noticeable decline in presents or at least a lump of coal in his stocking.

He was relieved to discover that Santa Claus was very forgiving this year of his persistently pestering older brother, who somehow managed to dodge an almost certain placement on the Naughty List.

This year for Nicholas it was all about the trucks.

His best buddy at school is Alex. Alex is a high-energy boy with a fascination for big rigs. He is a miniature version of Weston and I am not surprised that Nicholas is attracted to his energy. Together they obsess about Coke trucks and tractor-trailers with two smoke stacks. You may recall our many rides to school searching for these monstrous vehicles.

Jolly Old Saint Nicholas did not disappoint the budding young truck enthusiast.

Now in high school, Weston's Christmas list consisted mostly of video games and gadgetry. Noticeably absent from his list this year were these multi-wheeled beauties. He was relieved, however, that Nick's Dora obsession has been temporarily replaced, thanks to Alex, by a lust for heavy machinery. He unapologetically asked his younger brother if he could take a few laps around the living room with the big rigs.

Of course Nicholas was not entirely ready to abandon his dear friend Dora just yet. He asked for only one Dora-themed present this year. The non-judgmental, ever tolerant Santa did not disappoint him.

Flash, the cat, enjoyed the festivities until the noise level and wrapping paper began to rise to an intolerable level. He sought refuge in a quiet place and found the big rig garage Santa had so kindly provided.

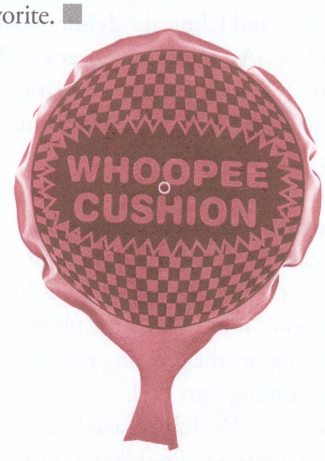
Nicholas thought it was hysterical and named the garage..."the kitty crate".

Muffy spent the entire morning frantically searching for a place to bury her new bone. She could not understand why the carpet would not create an open hole when she scratched it. She finally gave up and hid the bone in her crate.

The boys were happy and well entertained.

Of course, I didn't forget the prerequisite for any proper "boy Christmas".

Once again, the 99-cent fake flatulence maker was the overwhelming favorite. ■

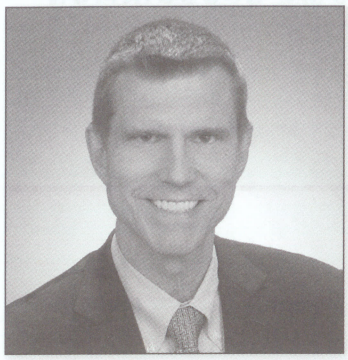


Volume 39, Number 6 ~ November-December 2014 ~ Our 39th Year of Publication

A Tale of Two CMOs

Aka Chief Medical Officers

By Lota Mitchell



Dr. John Cassidy



Dr. Matthew Masiello

The Prader-Willi syndrome community is fortunate to have not one, but two, facilities that provide intense, expert inpatient care for the obesity and/or behavior problems of children and adults with PWS, plus support for their families. One is at HealthBridge Children's Hospital in Houston, Texas; the other is at The Children's Institute (TCI) in Pittsburgh, Pennsylvania.

In July 2014, Dr. Matthew Masiello, MD, MPH, FAAP, became Chief Medical Officer, Medical Director, Coordinated Care, at TCI. Since 1981 TCI has had a special unit for PWS. Today's unit can accommodate up to 16 patients, both children and adults, who come from all over the country and some even out of the country, and whose stays at TCI can range up to several months.

Dr. Masiello has oversight of the several doctors tending to the medical needs of TCI's patients in various areas, including the PWS program. (Dr. Greg Cherpes, who serves on both the Governance and Clinical Advisory boards of PWSA (USA), specifically oversees the PWS unit.) To gain greater familiarity, Dr. Masiello will be working in the unit over the next several months.

His career, he says, has been "one third pediatrician, one third public health scientist, and one third lots of administrative experience." He sees his key role now "is to expand the physician cadre to support the growing number of children coming into TCI."

In contrast, Dr. John Cassidy is founder, Chairman, President, CEO, and Chief Medical Officer of Nexus Health Systems, which he created in 1992. HealthBridge Children's Hospital, one of its several specialized facilities, was established in 1999. With the help of Ken Smith, who is still an active consultant, the PWS component opened 3 ½ years ago, also drawing patients from everywhere. It serves patients up to the age of 22, with a maximum of 10-12. Very hands-on, he doesn't want it to get too large, and he wants "time to get to know the kids."

A neurologist and psychiatrist, Dr. Cassidy is consulting physician with almost all the patients with PWS and has direct contact with their families, who receive training that they can handle for when their child goes home. He first encountered PWS during his internship at Harvard Medical School Teaching Hospitals in Boston. Interestingly, Dr. Masiello also did training at the Children's Hospital, Harvard Medical School, in Boston.

There were kids there with PWS who were often avoided by other medical people. Dr. Cassidy observed that obesity and behavior problems are frequently difficult to handle. He loves doing medical care, and he developed a real passion for patients whose needs are underserved. This led to him establishing the Nexus Health Systems of specialized healthcare facilities where he felt he had the ability and knowledge to help that population.

Dr. Masiello became familiar with PWS when he was briefly Director, Pediatric Critical Care Services at Allegheny General Hospital in Pittsburgh and referred patients with PWS to TCI. His career has taken many roads in addition to pediatrics, including teaching, public health where he was active in bullying prevention efforts among other areas, and involvement with the World Health Organization.

Obtaining insurance coverage for patients and working with insurers from all over the country are struggles facing both organizations. Dr. Masiello, who has a special needs daughter, feels the challenge for parents and professionals is to be able to provide topnotch research into the outcomes of these children. TCI has a research component.

He took on the CMO position as a commitment to excellence for these children, the PWS unit being a center of excellence for clinical and psycho-social management. His hope is that a research foundation could develop from that, able to provide top level scientific demonstration of the importance of managing these problems to managed care organizations, a resource for people across the world.

Dr. Cassidy emphasizes the importance of advocacy, not just by medical people, but also by families. He reports that over 95% of their patients with PWS return home with good outcomes and the parents are happy with their treatment. A 25% weight loss is the goal, and there is a clinic to see families. His wish list for the future would be to evolve small group homes, three to a house, to facilitate their return into the community.

He has spent 32 years working with people falling through the cracks, patients that no one else wanted. He says it has been a rewarding mission. Now an enthusiastic member of the PWS community, he was introduced to the PWSA (USA) Clinical Board at their meeting. ■

A Primer on Scoliosis Surgery for Prader-Willi Syndrome

Harold J. P. van Bosse, M.D.
Shriners Hospital for Children® - Philadelphia; PWSA (USA) Clinical Advisory Board member

- Individuals with PWS often have decreased bone density. With growth hormone, the bone strength is usually satisfactory. Occasionally, the surgeon may need to add fixation points. This also presents a risk for Posterior Junctional Kyphosis (PJK) and Distal Junctional Kyphosis (DJK).
- Individuals with PWS have a different center of balance. They often have increased cervical-thoracic kyphosis, and walk with their head jutted forward. Avoid the temptation to improve their kyphosis. Most of the revision cases referred to me have failed due to overcorrection of the kyphosis, leading to a compensatory kyphosis above the construct, leading to PJK, and screw pull-out. I try to make my highest instrumented vertebrae T3 or lower, so that they have plenty of room to adjust kyphosis. In cases of spinal fusion for kyphosis, my goal is often to only correct the kyphosis to about 60°.
- Patients should have a sleep study, to rule out central or obstructive sleep apnea, and a pulmonary consult. They may need CPAP or BiPAP post-operatively.
- Patients with PWS can have both central and obstructive apnea and typically have an altered response to anesthesia. This can cause problems with extubation immediately post operatively. Frequently they may need to remain intubated in the ICU while they recover from anesthesia, anywhere from a few hours to overnight. Planning for that can help expedite transfer out of the operating room.
- Skin picking is a huge problem. Patients will tend to pick their incisions leading to infection. Placement of an incisional VAC (Vacuum Assisted Closure) will help with any seepage, but more importantly can act as an early alarm system, should they try to scratch their incisions in early post-op. I will usually outfit them with a light brace to protect the incision for about 2-3 months.
- Patients with PWS can frequently have gastrointestinal problems:

  a. They are always very, very constipated. You may want to do a 1-2 week slow bowel clean up pre-op, so that there's less in place to cause post-op constipation. Start constipation medications early post-operatively.

  b. They will be hungry immediately after surgery, but their actual ileus (obstruction of the intestine {caused by inactivity of the bowel}) usually lasts longer than usual. These patients are susceptible to gastroparesis (paralysis of stomach motility), causing them to have severe distension, to the point they can even have gastric perforation. Advance diet really, really slowly, relative to bowel sounds. Limited water is OK for first few days. Once solids started, get an abdominal x-ray to make sure there is no huge gas distension. Erythromycin can act as a gastric motility aid (better than Reglan for kids with PWS).

  c. Have your dietician talk to family before admission to find out what the current diet plan is (usually 800 – 1000 calories per day).

  d. Make sure nursing unit knows that there's a food seeking issue, and do not underestimate the craftiness of these children in finding food. This latter point is especially important if others are bringing food into the room, or the patient has a roommate.
- Patients with PWS frequently have impulse control or emotional/temper issues. It helps to have someone from psych or social work talk to family and school, and have a plan way ahead of time. The children respond well to well displayed schedules, so that they know what to expect, especially in relationship to meals. Plan ahead to have a family member with the patient essentially 24 hours per day. Soft restraints are often needed, to prevent pulling of intravenous lines and drains, as well as skin picking of the operative site. ■

Pilot Study Examining Swallowing Function in Persons with Prader-Willi Syndrome

Roxann Diez Gross, Ph.D.,CCC/SLP and Greg Cherpes, M.D. -- The Children's Institute, Pittsburgh, PA

(More details on the results of this important grant sponsored by PWSA (USA) cannot be published until after it is presented at a major conference in March which will follow up with a formal publication, but we have permission to share the following with our members.)

Conclusions: Persons with PWS are highly likely to have an undetected swallowing problem that places them at risk for asphyxiation of a food bolus (choking), and they require a specific type of swallowing evaluation. A clinical or bedside evaluation is not sufficient to detect dysphagia in this population. Videofluoroscopic assessment of swallowing function that includes the esophagus is necessary. Although it is important to rule out any disease process or anatomic problem that may exist, a traditional barium esophagram alone will not suffice because the procedure does not use solid food or natural eating positioning, etc. The traditional videofluoroscopic swallowing study

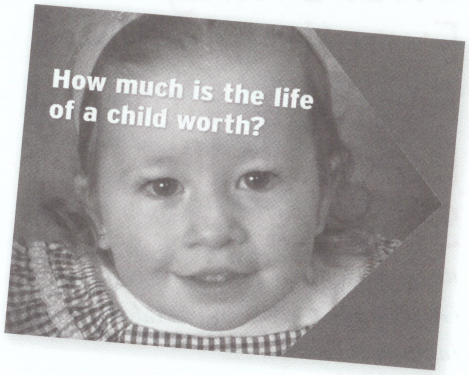
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Executive Director View

By Ken Smith, Executive Director

We at PWSA (USA) really delight in being able to help our families and provide services like crisis assistance, information, and support to parents of the newly diagnosed. What we don't delight in is having to raise money to provide those services. Yet it is necessity and fact—no funds, no services, or even maintaining the ones we have, let alone the plans, ideas, dreams of what else we would like to be able to do.

It's that time of year again when you will receive your Angel Fund card, our one annual fundraising campaign.



Please consider thoughtfully as you make your donation. Every dollar raised, large or small, goes to fulfill our mission of caring for those with PWS and their families.

In addition to the Angel Fund, we have taken another step to increase our revenue, and that is hiring a new Development Director, Jack Hannings, officially on board as of October 27.

Jack offers years of leadership and results in building nonprofit organizations stronger. This includes event fundraising and working with volunteer committees, with great success for organizations including the American Heart Association.

We hope indeed that Jack will be able to put his skills to work to strengthen the financial base of PWSA (USA). Welcome aboard Jack!

In the meantime, don't forget that EVERY DONATION, NO MATTER HOW LARGE, NO MATTER HOW SMALL, IS IMPORTANT! ■





Nancy Behringer (Proud mom of an awesome boy who has PWS) with Peter (8) the day of the garage sale. He was quite the salesman that day talking to all the customers.
Nancy Behringer with sister, Molly Nocerito (left), and dear friend, Chris Kroeber (middle). "They both donated tons of items to sell and helped organize and work the sale. It was a great success and we would like to do it again in the spring."

Pilot Study, *continued from page 3*

(VFSS) which is also known as the modified barium swallow (MBS) or "cookie swallow" will not suffice because it does not always include the esophagus. Therefore, whoever conducts the study must also examine for esophageal clearance using food items. The other instrumental method that is commonly used to evaluate swallowing function is called FEES for fiberoptic endoscopic evaluation of swallowing. This type of exam cannot examine esophageal clearance and, therefore, will be inadequate for persons with PWS.

The recommendation for PWS-specific videofluoroscopic exams may not be widely accepted without offering compensatory strategies that have been shown to be effective. Clinicians may alter diets and eliminate solid food unnecessarily when significant amounts of residue are observed. Most speech pathologists and radiologists may not know how to compensate for esophageal dysphagia and may make reflux-related and unnecessary recommendations such as 6 small meals per day.

Current recommendations: Drinking SIPS of liquids during a meal or snack (i.e. liquid washes) MIGHT clear the mouth and throat of any remaining, undetected residue. Taking additional saliva swallows may also be beneficial in clearing food residue. Any person with PWS who complains of food sticking in their throat or chest, is diagnosed with rumination, reports ongoing episodes of regurgitation, has a choking history, needed the Heimlich maneuver, or shows other signs of dysphagia should give the above information to their physician or speech pathologist. Doctors and therapists can also contact Roxann Diez Gross, PhD, CCC/SLP for management recommendations. She will work with physicians and speech pathologists to ensure that proper evaluation and management occurs. ■

Introducing Bonnie Shelley, Ph.D. to our PWSA (USA) team

Dear PWSA (USA) members,

I want to notify you that as of December 1st, my position at PWSA (USA) will be changing and I will no longer be covering direct medical crises and questions. I will still cover research (which is taking more of my time due to collaborating with the pharmaceutical companies and the FDA regarding clinical trials), and international support, but will be reducing my hours. This is strictly my choice. I will be turning 70 in January, and after being on call throughout my professional career with child abuse, pediatric oncology, hospice, and PWS, it is time for me to have more freedom to do some of the things that "almost retired" people do. I love working with Prader-Willi syndrome and with all of you, but it is past time to give my family some priority over the thousands of people I have worked with in crises.

The good news is we have hired a wonderful person to cover the medical issues for PWSA (USA) – Bonnie Shelley, Ph.D. She will have a learning curve regarding the medical issues of PWS, but due to the uniqueness of the syndrome, anyone would have a lot to learn coming into this role.

The following is Bonnie's clinical experiences:

- Twenty-nine years as a licensed clinical psychologist
- Provided mental health services in diverse settings, including rural and urban mental health centers, hospital inpatient adult psychiatric unit, state psychiatric hospital, hospital emergency rooms, and private practice
- Community-based crisis intervention directed at suicide prevention
- Reviewed psychiatric medical records for representation of Medicaid in administrative hearings for managed care corporation
- Many years of practical experience, exposure, and interfacing with various levels of medical personnel, including physicians, pharmacists, nurses, ward clerks, clerical/secretarial
- Provided informed consent regarding medical/treatment issues, especially pharmaceutical interventions, in the provision of limited guardianship services to patients in state psychiatric hospitals



What Bonnie brings to her position, besides her professional degree and clinical background, cannot be taught. I think this is best described from the following quotes from reference letters:

"Through her personal attributes of warmth and compassion, along with her extensive knowledge base and outstanding verbal and written communication, she was able to translate criteria created by our clients for various levels of care, into sound and meaningful human terms. … I came to greatly appreciate Dr. Shelley's gentle spirit, dedication and enthusiasm."

"She is the most skilled supervisor I've known. Undoubtedly, much of this skill is the result of her clinical education and training; however, she is intuitive and as kind and gentle in confrontation as she is effective….I know Bonnie to be a gentle, compassionate soul and an advocate for those who cannot speak for themselves."

When families first contact us with medical issues, they need more than strictly medical advice – they need a tender, understanding heart. I trust implicitly that Bonnie will give them what they need.

We can only do what we do if we have your financial support. We have thousands of PWS families with needs and very limited funding. I hope…PWSA (USA) will be able to meet the needs of the many families to come.

Bonnie will be working 20 hours a week with Evan and Ken as backups, and I will continue to be a consultant for her. She will also have our wonderful clinical and scientific advisory board members to turn to for advice. If our funding improves, we should be able to increase her hours and/or bring on extra support.

We are fortunate to have such a wonderful family support team of Evan and Kate doing the challenging behavioral, school, placement issues, etc., Nina Roberto working with the Spanish-speaking families, and to have Cindy working with the New Parent program, and Ken with so many years of experience working at The Children's Institute with the worst of the weight and behavior problems. Getting to know other rare disease organizations, I have come to appreciate how unique our services are regarding the kind of individualized support we do provide for families and professionals.

We can only do what we do if we have your financial support. We have thousands of PWS families with needs and very limited funding. I hope someday (not yet) to fully retire and know that PWSA (USA) will be able to meet the needs of the many families to come.

My warmest regards,
Janalee Heinemann

PWSA (USA) October 2014 Board Meeting

Two productive days of meetings were held in Orlando, Florida, at the Buena Vista Palace Hotel – the site of the 2013 and upcoming 2015 conference. Following the board meeting, Chapter Leaders met for a day and a half. Some of the chapter leaders that arrived early were able to join the board for their meeting as well.

National Office: Ken Smith, Executive Director, reported that the new website is up and running, though still a work in progress. Please email the office if you notice any broken links or missing pages. He also introduced our new Director of Fund Development, Jack Hannings, who will begin work at the end of October. Jack was able to join the board and the chapter leader meetings. Ken also noted that crisis and family support involve approximately 60% of our staff's time. In a given year, roughly 20% of our population contacts the National Office for assistance. The staff and volunteers at the National Office really are touching the lives of everyone in our PWS community.

Finance: While our revenues are slightly behind our expenses, we expect a change in that situation with the hiring of the Director of Fund Development, a position which has been unfilled for the past year. A successful Angel Fund Campaign is also anticipated.

Research: Janalee Heinemann reported the Obesity Week Conference will take place November 2-7, 2014, in Boston. This conference reaches beyond our PWS community of researchers and has been instrumental in the current Phase 3 clinical trial currently being conducted by Zafgen. Several other drug studies are underway or in the planning stages with other pharmaceutical companies. This is the first time in Janalee's long history with the Association that there has been so much interest by the drug companies to find the elusive, but desperately needed, obesity drug or shot. Of course, this benefits our children because of the interest in doing their clinical trials with PWS through the Orphan Drug Act. A five-hour listening group meeting was held with the FDA where for an hour five key FDA personnel asked questions of eight of our parents. The progress we have made with the FDA has been a 10-year work in progress – thanks to the dedication and efforts of Janalee Heinemann, Rob Lutz, Jim Kane, and Theresa Strong (FPWR). The 2014 research grant cycle is underway, with submissions due on October 7th. Three to four grants will be funded by the end of the year.

Various committee meetings were held, with each committee providing a report to the Board. The Board endorsed the Strategic Plan for 2015-19, the draft Business Plan for 2015, and the Budget for 2015.

Conference: Conference 2015 planning is well underway so SAVE THE DATE: November 4-7, 2015 in Orlando, Florida.

Finally, Michelle Torbert was elected for another one-year term as Board Chairperson, and Jim Koerber was elected for a one-year term as Board Vice Chairperson.

Julie Doherty, Secretary, PWSA (USA) Board of Directors ■



At the Orlando meetings, a true sense of community is shared during a meal filled with smiles, conversation and nourishment.

Creating A Chronicle

By Andrea Glass

My son with PWS is now 19. Imagine that. We've been through so many different stages of raising a child with PWS and surviving more or less. I feel like an expert. Each time we transition into a new phase of development it is always an adventure. Now is one of those transition times: planning for the future. Frankly, I'm not sure yet what his future looks like, but there are a few things I do know. My young man does not want to live with his parents forever. He is an only child so there are no siblings to come to the rescue when we're gone. This means, as his primary caregivers, we have to establish a future life for him outside our home, at some point.

Toward this goal, we have been enlisting the help of State agencies that can assist now and in the future. Every state has these agencies. In Massachusetts you apply for programs that are run by the Department of Developmental Disabilities, Mass Health, and the ARC. One such State agency asked us to fill out a form that would help them assist with our son should he require an emergency alternate caregiver. The form included his doctors and the name of our designated people that could step in if something happened to us. This form struck me as so incomplete, and although our affairs are in order legally, it made me think how much different his life would be without us. To this end, I want a future caregiver to know EVERYTHING about him. How he got to this place in his life; thin, manageable, eccentric and happy. How easy it would be to undo all this hard work by both him and us. I felt I must ensure that anyone that may be involved in his future in our absence has our hard earned knowledge by writing everything down in DETAIL.

I started to think about the lecture I give at an IEP meeting when he has switched schools. I thought this was a good place to start. I have a two page written sheet that tells every person who comes in contact with our son the basics about PWS and how that relates specifically to him. How he communicates, what makes him escalate, how to bring him down, how food affects his moods and ability to focus.

On the subject of food, what and when he is allowed to eat, and how important this is to us. If you have ever travelled and left your child with PWS with a caregiver, then you have made these lists. I have them to the very detail of which stores carry his brands (we shop in 5 stores), how much food to give him for meals and snacks and what time he eats. What the combination is to the locks on the refrigerator and pantry. It is certainly in our son's best interest that an alternate caregiver understands this most important aspect of his care. Food security is probably #1.

Next I bring my attention to what an average day looks like. What time he wakes up is very important to his overall mood. We discuss constantly with him the need to stay in bed and rest. Sometimes this works. If not monitored, he will not sleep very well. It is very easy for him to surrender to the sleep disregulation of PWS. It is important to get him in bed early when he is looking exhausted. I don't think this would occur to someone unfamiliar with him.

I will list all my son's grooming habits and requirements. He is not entirely self-sufficient. He can't manipulate a razor at 19, clip his own finger nails or wash his own laundry. He needs to be told to pick up his room and needs assistance doing it. He doesn't know what clothes to wear for a given temperature since he can't seem to feel when it's hot or cold. He can't manipulate zippers and I deplore sweatpants in public. We buy all his pants at Sears with elastic waistbands. I'm certain an alternate caregiver would not know where to buy them.

I will make an exhaustive list of all the difficult behaviors he has and how we break the cycles. What works best to stop skin picking, obsessive/compulsive behaviors, and outbursts (both public and private). Specifically, how to distract him when he is upset or hungry. I really can't imagine someone taking over for us that has no clue how to handle these somewhat bizarre behaviors. I really want them to know everything I know.

It is important that he have scheduled physical activity. We have a membership at our local Y, and have a couple of young women that we pay to work out with him a couple of days a week. This helps motivate him to work out on the days they are not with him. I will definitely include the contact information for these girls. Additionally, his day program is required to make sure he works out each day for 30 to 45 minutes. It is not in his basic nature to exercise due to the difficulties of having low muscle tone. Therefore, it is important to register him in the local Challenger sports programs. This facilitates exercise and provides a social outlet. I will definitely include the coordinator of this program in my list. Also, I will include his desired weight, so that an alternate caregiver will know when to cut back his calories, as he gains weight so easily.

I will never forget how hard I have fought to receive all the services he receives at school. Every IEP has important information that shows the evolution of these services. Many people have used advocates and friends to help with IEPs. This would be important information to record.

I am going to make a list of all our son's friends and acquaintances. All the people that make his world a better place, including, all our friends that have children with PWS. These people are very important to our well being

continued on page 8

Special Olympics Turns a Negative into a Positive

This past summer Erika Breneisen, 39, demonstrated once again the value—and the heart—of Special Olympics.

Erika, who lives in a group home with three others with PWS in Pennsylvania, has participated in Special Olympics for the past 17 years in swimming, bowling, roller skating and, most recently, gymnastics. She was thrilled to be chosen this year to represent Pennsylvania in gymnastics at the National Games 2014 in Princeton, New Jersey, in June. She trained for over a year to compete on the balance beam, uneven bars, and in the floor exercise. But a month before the competition, she broke her ankle, was operated on and confined to a wheelchair with a bright red leg cast.

Her mother, Isa Breneisen, said, "We knew she couldn't compete, so we called to ask if she could come as a guest, and they were just so incredibly wonderful."

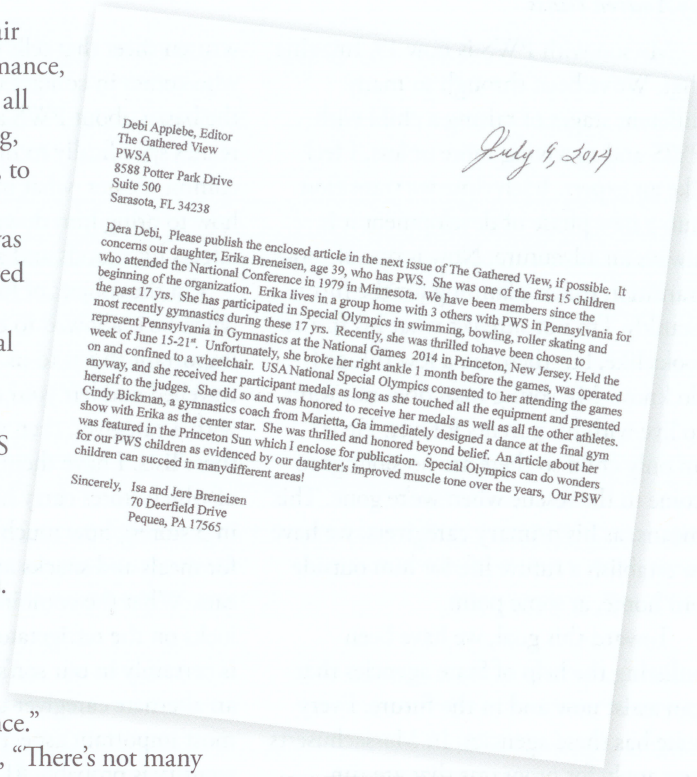
Not only did they consent to her attending, but she received her participant medals as an official competitor by touching all the equipment and presenting herself to the judges.

But that wasn't all. Cindy Bickman, a gymnastics coach from Marietta, Georgia, immediately went to work designing a dance at the final gym show with Erika as the center star. Thirty two Special Olympians took time out from competing to learn a routine using white scarves to a ballad from Disney's "Tangled." A new friend, Emily Belk, pushed Erika's chair during the performance, which ended with all the women turning, arms outstretched, to face Erika and her wheelchair. She was thrilled and honored beyond belief.

Isa says, "Special Olympics can do wonders for our children with PWS as evidenced by our daughter's improved muscle tone over the years. It has been an absolute godsend to increase her strength and balance."

Bickman noted, "There's not many people like me that are working in Special Olympics, so we've been doing a big push to educate coaches. Just because they're Special Olympians doesn't mean they're second class. They should walk on the floor with the sparkles on their leotards, the hair put up, everything just like in the regular Olympics."

Erika was one of the first 15 children who attended the national Prader-Willi conference in 1979 in Minnesota, and her parents, Isa and Jerry Breneisen, have been members since the beginning of PWSA (USA). ■



Debi Applebe, Editor
The Gathered View
PWSA
8588 Potter Park Drive
Suite 500
Sarasota, FL 34238

July 9, 2014

Dera Debi, Please publish the enclosed article in the next issue of The Gathered View, if possible. It concerns our daughter, Erika Breneisen, age 39, who has PWS. She was one of the first 15 children who attended the Nartional Conference in 1979 in Minnesota. We have been members since the beginning of the organization. Erika lives in a group home with 3 others with PWS in Pennsylvania for the past 17 yrs. She has participated in Special Olympics in swimming, bowling, roller skating and most recently gymnastics during these 17 yrs. Recently, she was thrilled tohave been chosen to represent Pennsylvania in Gymnastics at the National Games 2014 in Princeton, New Jersey. Held the week of June 15-21st. Unfortunately, she broke her right ankle 1 month before the games, was operated on and confined to a wheelchair. USA National Special Olympics consented to her attending the games anyway, and she received her participant medals as long as she touched all the equipment and presented herself to the judges. She did so and was honored to receive her medals as well as all the other athletes. Cindy Bickman, a gymnastics coach from Marietta, Ga immediately designed a dance at the final gym show with Erika as the center star. She was thrilled and honored beyond belief. An article about her was featured in the Princeton Sun which I enclose for publication. Special Olympics can do wonders for our PWS children as evidenced by our daughter's improved muscle tone over the years, Our PSW children can succeed in manydifferent areas!

Sincerely, Isa and Jere Breneisen
70 Deerfield Drive
Pequea, PA 17565

Today, remember that it is not enough to be grateful for the people and things of your life. For your gratitude to impact others you must also express it.

Win Your Day!

Steve Gilbert

Contributed by Clint Hurdle

Chronicle, *continued from page 7*

and our ability to care for our son. An alternate caregiver would benefit from these connections. Also on my list will be the PWS associations that we belong to. They will need this information, for sure.

Of course, I will list his doctors and medications. Who prescribes which medication and all the medications we have tried that did not work for him. All the battles we have fought with the insurance companies and won or lost. I wouldn't want my son or his caregiver to have to go through that again! I will record each doctor that he sees and for which aspect of his health care. We have not always stayed with the same doctor. There have been some we didn't like or agree with. I think I will record this as well.

Then again, knowledge is power; I will make sure I pass it on.

Please feel free to contact me for an outline and ideas on creating your own chronicle at andreaglass33@gmail.com. ■



Cindy Beles, right, receives recognition from Janalee.

Celebrating Ten Years with PWSA (USA)

■ Congrats to Cindy Beles on her 10 years with PWSA (USA)!

Debi

■ **You are such an asset to our organization and all of our families-**

Julie

■ *Cindy – You have blessed so many lives over the last ten years. Thank you for all you do and for always giving so much of yourself. With appreciation and love,*

Jackie

■ We are truly blessed to have you and I personally am glad that the first contact our new parents have is with such a loving and understanding person. Thanks for all you do for our families!

Michelle

■ **What a tribute to you and your patience. Many thanks for all you have done for us over the years!**

Jim

■ *You and I BOTH have a decade with PWSA (USA). Unlike me, there has never been a day when I called and there was not a smile on your face and a good word for everyone.*
I am not smart or articulate enough to express how much you mean to our Association and our families.
Your dedication - especially given the turmoil we put you through - is appreciated by me and our entire community.
Here's to another decade.
THANKS!!

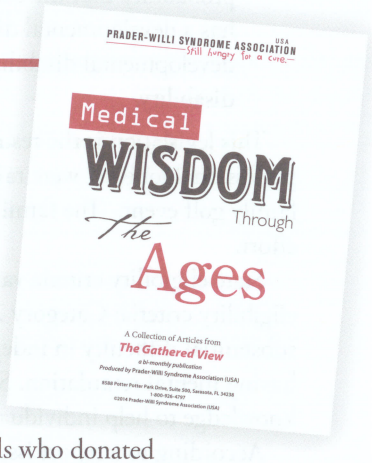
Stephen

Medical Wisdom Through the Ages

There has been a wealth of medical information on PWS published throughout the years and we want to share it with our current generation of parents and professionals. This newly published booklet is a collection of articles and information about the syndrome and the unique challenges it presents in the health and medical area.

If you wish to place an order for this booklet, please contact the national office. The cost for this nearly 200-page informational booklet including tables, research data, etc. is $25 and members get a 20% discount.

A debt of gratitude is owed to all of our dedicated medical professionals on our Clinical and Scientific Advisory Boards for their many dedicated hours of volunteer work for PWSA (USA) through the years, and for their donation of articles to our newsletter, *The Gathered View*. And thank you also to the other medical professionals who donated articles on needed topics at our request. ■



The Suncoast Saltwater Shootout

A benefit for the Prader-Willi Syndrome Association (USA) united great fishing with a great cause September 19-20 in Sarasota, Florida. This fishing fundraiser in Sarasota brought greater awareness of PWS to the community through the meetings, events and media coverage leading up to tournament day.

A big thank you from PWSA (USA) goes out to Maduro Cigar for hosting the Suncoast Saltwater Shootout Captain's meeting that matched anglers with Captains a week prior to the tournament.

Friday night, PWS board members, the Suncoast Saltwater Shootout executive team, guest families, sponsors and supporters came to share stories as well as information about Prader-Willi syndrome at The Ritz-Carlton, Sarasota. Andy Eggbrecht, President of Andros Boatworks presented Miss Keaton Hunt with a fishing pole in honor of her late father and



fisherman with much emotion. Saturday, the Shootout began! The crowds gathered for the big weigh-ins.

Thank you to all who contributed to and shared in the Suncoast Saltwater Shootout. All your efforts and participation made this a great event and helped to gain greater awareness of Prader-Willi syndrome! See you on the docks next year! ■

Massachusetts Disability Bill Passed

By Andrea Glass

The Prader-Willi Syndrome Association of New England (PWSANE) is pleased to announce a successful legislative effort. Massachusetts House Bill 4047 was signed into law by Governor Patrick on August 5, 2014. The new disability law includes those with PWS as being eligible for disability services and removes any relationship to IQ measurements. Below is the text:

> Person with a developmental disability, (1) an individual 5 years of age or older with a severe, chronic disability that: (i) is attributable to a mental or physical impairment resulting from intellectual disability, autism, smith-magenis syndrome or Prader-Willi syndrome; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (1) self-care; (2) receptive and expressive language; (3) learning; (4) mobility; (5) self-direction; (6) capacity for independent living; and (7) economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, supports or other assistance that is of a lifelong or extended duration and is individually planned and coordinated; or (2) an individual under the age of 5 who has a substantial developmental delay or specific congenital or acquired condition with a high probability that the condition will result in a developmental disability if services are not provided. A person who has a developmental disability may be considered to be mentally ill; provided, however, that no person with a developmental disability shall be considered to be mentally ill solely by reason of the persons developmental disability.

This legislation is the result of a large state lobbying effort in which PWSANE was an active participant. Funds for a professional lobbyist were raised through an annual walkathon sponsored by Jared and Cindy Wells and PWSANE and the Lens family golf event. The families affected by PWS are grateful to certain legislators and PWSANE members that assisted in this effort.

State eligibility criteria vary by state and fits into one of three categories. Category 1 would be those states that list PWS as an eligibility criteria; Category 2 are those states that have a broader definition of intellectual disability or a definition that includes substantial difficulty in independent living. Category 3 would be those states that strictly limit eligibility criteria to individuals having mental retardation. State PWS Chapters can have a pivotal role in not only changing legislation, but sharing strategies and knowledge to help individuals obtain services in the Category 2 and 3 states.

According to a report issued in 2008 by the NASDDDS.org, states that specifically include those with PWS as an eligibility criteria are: AK, CT, DE, DC, FL, GA, MS, MO and now MA. There are many states in Category 2 as they include individuals with substantial limitations in 2 or 3 of the 7 functional living skills regardless of IQ number. This definition typically includes a person with PWS, although it is not an absolute. These states are: AR, CO, HI, ID, LA, MI, NE, NV, NH, NJ, NM, NY, NC, ND, OH, OR, WV, WY. The remaining states list an IQ criterion at 70 or below. Those States are: ME, CA, IL, IN, IO, KS, KY, MN, MT, OK, PA, SD, TN, TX, UT, VT, VA. It is more difficult to qualify for disability services in these Category 3 states particularly if the individual with PWS has an IQ over the threshold.

Each state determines how they interpret the Federal guidelines for defining developmental disability. In Massachusetts, the state government was challenged by the disability community a couple of years ago as not meeting Federal guidelines. At that time, the state eligibility criterion was changed through legislation to a Category 2. Now MA has joined 8 other states in recognizing the special challenges of caring for a PWS individual. ■

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

CHUCKLE CORNER

Our daughter Anna Kathryn is now 13 but when she was about 8 - we were getting ready for church one morning - while we were also listening to a church program on TV. I was brushing Anna's sister's hair - and Anna was coloring at her little table when all of a sudden she said, "That is so silly."

I asked her, "Anna, what is silly?"

Anna said, "That man on TV, he said that some people think God is a girl!"

I asked her, "Anna you don't think God can be a girl?"

Anna said, "NO Mommy he isn't; I know he isn't."

I asked her again, "how do you know that Anna?"

Anna answers very matter of factly, "Mommm, all the songs we sing in Church, they're called HIMS (Hymms)".

~ Lori Guthrie, Powhatan, VA

Our Little Pioneer Tianni

By Janalee Heinemann, M.S.W.
Director of Research & Medical Affairs, PWSA (USA)

The newest treatment being offered for young children with scoliosis curves too large for bracing is the MAGEC (MAGnetic Expansion Control) Spinal Bracing and Distraction System. Children worldwide are affected by scoliosis, or a curvature of the spine, and Shriners Hospitals for Children® — Philadelphia has an extensive scoliosis program that is designed to treat all forms of the condition, using every tool available.

In the past, these large and potentially life-threatening curves were treated with traditional growing rods, which require a moderate surgical procedure for implantation, then a smaller procedure every six months to lengthen the spine. Although the lengthening procedures are relatively minor, they still involve general anesthesia, anxiety and discomfort. The MAGEC rods are an alternative to the emotionally and physically painful treatment regimen of the traditional growing rods. With MAGEC rods, there is still a moderate procedure for implantation, but the non-invasive lengthening procedure eliminates the need for repeated lengthening surgeries. This results in significant safety, health, mental and physical benefits for the child and their family. Patients will also be able to get back to their activities of daily living sooner with this surgical option.

After the initial MAGEC surgery, this specially designed rod can be gradually lengthened from outside of the skin, and in the exam room, avoiding the need for general anesthesia and an incision, with the External Remote Control (ERC). Magnets outside the body contained in the ERC device communicate with the magnets of the implanted rods. The ERC is a portable, hand-held unit that uses permanent magnets to automatically modify the length of the growing rod through the touch of a button. The ERC will be used a few times a year as the child continues to grow.

"The MAGEC system is a game-changer in early onset scoliosis care. We expect that it will decrease the number of surgeries these young patients have to undergo. The decrease in surgeries will translate into decreased complication rates," said Philadelphia Shriners Hospital orthopedic surgeons, Patrick J. Cahill, M.D., and Harold J.P. van Bosse M.D., regarding this historic case.

The first patient to benefit from this procedure is Tianni Swint, a four year old with infantile scoliosis and Prader-Willi syndrome, from Brooklyn, N. Y. Her parents, James Swint and Shakema George, did a lot of research to seek out the best option for Tianni. They welcomed this new innovative option to aid in their daughter's treatment for scoliosis. Tianna's father, James, is excited about Tianni already being a pioneer at such a young age, they have been on "The Doctors Show", http://www.thedoctorstv.com/articles/2741-breakthrough-procedure-for-scoliosis, and are pleased that PWSA (USA) wants to shout this out, loud and clear! Thank you, little precious Tianni, from all the parents who have and will have little ones with Prader-Willi syndrome.

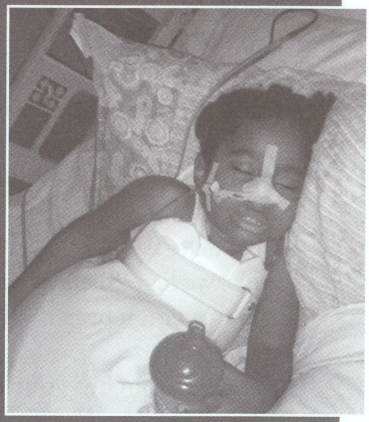
PWSA (USA) sends our sincerest gratitude to Harold J.P. van Bosse, M.D., Pediatric Orthopedic Surgeon and PWSA (USA) Clinical Advisory Board Member, for truly caring for children with Prader-Willi syndrome. ■



Exciting things are happening at the Shriners Hospitals for Children in Philadelphia. Orthopedic surgeons, Harold J.P. van Bosse and his colleagues, part of the spine team members at the Philadelphia Shriners, are performing the newest treatment for young children with scoliosis curves that are too large for bracing. The first patient to benefit from this procedure was Tianni Swint, a four year old with infantile scoliosis and Prader-Willi syndrome. According to Dr. van Bosse, "we were the first hospital in the US to use the MAGEC rods after the FDA approval...We put MAGECs now in four PWS patients, with a number more on the horizon." The FDA approved this new procedure in February 2014.



Five days after surgery



Three days after surgery

The Role of IPWSO at ESPE in Ireland 2014

By Janalee Heinemann ~ IPWSO Vice-President

Although the European Society for Pediatric Endocrinology (ESPE) is three days of long hours and a lot of work preparing before the conference, it always revitalizes our spirit and enthusiasm. Giorgio Fornasier and I distributed memory sticks with extensive information on Prader-Willi syndrome, including the Medical Alert booklet in 16 languages, to 330 endocrinologists from around the world. They all were absolutely delighted to get so much information in such a small package. We had all of the articles displayed so they could see what information they were getting, and also gave some of the endocrinologists a hard copy of the Medical Alert booklet in their own language. There were eight posters presented on PWS at the conference. **We want to give a special thanks to Global Pfizer for their donation of an unrestricted educational grant that makes our involvement in these conferences possible.**

Besides general education for physicians working with the syndrome, the ESPE meeting gives us an opportunity to learn a lot about what is going on in each country, and how to enhance our connections with that country. ***The following are some examples of touching stories that show the impact IPWSO has had on the world***:

- **China is a good example** – A country where there had been no diagnosis or education on the syndrome – to the first ESPE where we acquired a professional delegate -- followed up by free diagnosis -- to helping put together the first PWS conference in China in 2005 -- to now less than 10 years later where they are creating guidelines on the syndrome and we had 14 endocrinologists from China come to our booth for more information all stating they now have patients with the syndrome. Several asked if they could take a memory stick back to their colleague who could not attend.
- **Iran is another good example** – Just a very few years ago, for the first time, we met a wonderful endocrinologists from Iran who attend ESPE and stopped by our booth to get information – she agreed to be our professional delegate -- followed up by free diagnosis – at this ESPE, we had 20 endocrinologists stop by our booth for information because they are treating patients with PWS.
- **Honduras touches your heart** – At ESPE we met the endocrinologist who became the professional delegate for Honduras – followed up by free diagnosis – then two years ago Giorgio and Dr. Moris Angulo went to Honduras to meet with medical professionals and families (our professional delegate said they knew of 12 families dealing with PWS, but they never succeeded in getting them together) – when Giorgio and Moris came to speak, 10 of the families attended – at this ESPE our professional delegate said they are starting an Association and will have a PWS clinic at their new hospital. Thanks to Giorgio, the Vatican radio keeps promoting awareness on the syndrome in this country.



Physician from Saudi Arabia with Janalee



Giorgio with doctors from China

- **Bulgaria also stopped to give praise** – through the same type of evolution – a professional delegate through ESPE – free diagnosis – Giorgio and Pam Eisen (now deceased) going to Bulgaria to meet the professionals and families – to the professional delegate at this ESPE thanking Giorgio and saying now they have an Association. He said they have officially made Giorgio half Bulgarian!
- **United Arab Emirates endocrinologists said we as parents are an inspiration** – two female endocrinologists told of a few very tragic situations in their country, including one mother who cried every time she came to see them because her 15-year-old child with PWS was so obese he had to be in a wheelchair and mom did not know how to handle him. They said they wished she could meet parents like us and know there was hope.
- **Then there are the countries in the early evolution** – an endocrinologist from **Uganda** was very eager to get the information and get more connected, a wonderful physician from **Saudi Arabia** showed great interest in PWS and getting more connected; we met our first

continued on page 13



Physicians from United Arab Emirates with Janalee



Dr. Yang from China with Janalee

We Remember

At this time, we remember Brandon Mosley, with Prader-Willi syndrome, who passed away at the young age of 39. According to his family, Brandon loved family gatherings and made it a point to hug everyone as soon as he walked through the door. He loved God and going to church. "When the pastor would tell the congregation to shake a few hands and greet the newcomers, Brandon made it a point to never miss anyone in the congregation," said his mother, Daphne Mosley. Brandon looked forward to going to a camp for individuals with PWS, called Camp Horizon in Guthrie, Oklahoma. His favorite activities at the camp were fishing, swimming, playing basketball and singing in the talent show.

> *You will show me the path of life; In your presence is fullness of joy; At your right hand are pleasures forevermore.*
>
> *Psalm 16:11*

"Brandon and his good friend Hunter Rozell, would dress up like Hula Girls and sing, "Girls Just Wanna Have Fun!" All of our campers looked forward to this every year," said Mosley.



Brandon on left

"Our hearts are broken and we will miss him terribly; but, he will remain in our hearts forever. We are comforted to know that he has been made perfect in Heaven and no longer struggles with the challenges of Prader-Willi syndrome."

He leaves behind his parents, Russell and Daphne Mosley (Daphne is the President of the Oklahoma PWS chapter), his sister Tiffanie Mosley, two nieces Madison and Lauren, and one nephew, Hunter.

"Before he took his last breath, he squinted his eyes and a big smile came on his face. It was then we knew he had seen the bright lights of Heaven and most likely Jesus was standing there welcoming him with a big plate of donuts - his favorite." ■

ATTENTION Federal Employees!

If you work for the Federal government, 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**

For more information about the CFC program and how it works, go to their Web site at http://www.opm.gov/cfc/index.asp, or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee. ■

ESPE *continued from page 12*

contact for **Azerbaijan**... and the list goes on.

When you think about the fact that besides a wonderful board of PWS parents and professionals, and only two part-time parent employees who get very minimal salaries, it is amazing to realize that with very limited funding, how much IPWSO does and how many lives are saved around the world! ■

¡HOLA!

By Nina Roberto, E.D. of the New York Association and on the State Chapter Leaders Team as representative to Spanish-speaking families with PWS.

¡Hola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi. Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que nececitan informacion y ayuda. Les quiero directar a www.pwsausa.org donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, ninaroberto@verizon.net. ¡Hablamos pronto! ■

Contributions

Thank you for contributions in August-September, 2014. We try to be accurate in recognizing contributions above $25, and apologize for any errors or omissions. If you notice an error, please tell us.

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We Want to See Your Smiling Faces!

PWSA (USA) is accepting pictures of your child/adult with PWS for use in our publications, on our website, and in various other formats. We need photos of individuals of all ages, both genders, and all ethnic backgrounds. The picture must be a MINIMUM of 1200 pixels high OR wide, in a JPG format. The 1200 pixel requirement is only for height or width; it is not necessary to be that size in both directions.

Please complete a Permission Form: http://www.pwsausa.org/photo%20release%20fieldform%20PWSA2010-08.pdf , and email the completed form and photo to news@pwsausa.org.

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Deadlines to submit items to *The Gathered View*: Dec. 1; Feb. 1; Apr. 1; June 1; Aug. 1; Oct. 1

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

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The Members Only section requires a password. Please enter PWS for the code.

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

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Mary K. Ziccardi, REM Ohio, Inc., Valley View, OH

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Conor Heybach, Illinois
Kate Kane, Maryland
Lauren Lange, Georgia
Andy Maurer, South Carolina
Abbott Philson, Maine



See page 9 for a followup on the Saltwater Shootout tournament.



With warmest wishes
to you and yours
for a joyous and peaceful
Holiday season

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