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

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

Dr. Andrea Prader with Andy on the left, and other children with PWS, at a June 1984 conference.

40 Year Flashback

Memories from PWSA (USA) Pioneers

By Bronnie Maurer

We became members of the PWSA in 1975 - one of the very early members. Some of the following timeline information was taken from the banquet program of 2000 - the 25th anniversary celebration of the association held in Pittsburgh.

In 1975 Gene and Fausta Deterling, together with a few other parents and professionals, started a group called "Prader-Willi Syndrome Parents and Friends". It was later renamed the Prader-Willi Syndrome Association. We attended the first California regional meeting in 1975 in Sacramento where we met Dr. Sam Beltran who would become an integral part of the association. Between 1976-1977, while living in Phoenix, Arizona, we traveled to several meetings of a support group organized by Dr. George Bray at Harbor General Hospital in Torrance, California. Together with the Forthmans, we organized AP WS chapter in Indianapolis, Indiana in 1979. While living in Atlanta, Georgia, we, along with Paul and Pam Alterman, organized the Georgia chapter of PWSA in the early 1980s.

The first conference (which we were very fortunate to have attended) was held in Minneapolis, Minnesota in June 1979. The conference meant so much to us (especially being able to meet other parents) that we attended each annual conference around the country without interruption. It was at that first conference that we met DJ and Bobby Miller and became lifelong friends. The following year at the conference on Cape Cod, we met Lota Mitchell and another lifelong friendship was born. Interaction between parents was vital to us. We were starving for information. We shared any and all ways we had found in dealing with PWS – it was the only information

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A Reflection:

My First Prader-Willi Syndrome National Conference

By Andy Maurer, member of Adults with PWS Advisory Board

Andy's speech represented the past at the 25th anniversary celebration of the association.

Thirty-five years ago in 1979, Mom, Dad and I drove to Minneapolis, Minnesota to attend the very first Prader-Willi syndrome national conference. I was excited and anxious to meet other people with my syndrome. If I remember correctly, there were not too many people with the syndrome at the first conference. I enjoyed meeting and talking to a boy whose name I can't remember from Corpus Christi, Texas, and a family from Hawaii. It was good to know there were other families facing the problems that we had.

Some of our activities while we were there included trips to the planetarium, the museum and the zoo – the kind of programs we have today – there just weren't as many of us. I was 19 years old at the time and tried to help some of the volunteers who had not had experience with PWS. It was a great adventure and at the end of the conference we left for home, feeling like we had found a new family. We couldn't wait for the following year. At the next few conferences, I met many people who would be my friends for always including

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Volume 40, Number 3 ~ May-June 2015 ~ Our 40th Year of Publication

A Message from Carolyn Loker

PWSA (USA) Medical Liaison and Coordinator of the Study of Death and Bereavement Programs

In the past few weeks, our community has lost three beautiful individuals with Prader-Willi syndrome. It's heartbreaking. It's so very, very sad. Our hearts, love and prayers go out to the families of these precious sons and daughters. These deaths have rocked our PWS community. I sense the many tears that have been shed and emotions that are so hard to put into words. I am on FaceBook… A LOT. We build friendships, oh do we build friendships! We are there to support each other, but there is one thing that stands out among anything else and it is the LOVE that we all have for each other's children. When one is sick, we are there to help and support the family; when one dies, a part of us dies, too.

Because of these deaths, I have also sensed that there is a lot of concern, anxiety and wondering what happened. Then the anxiety surfaces because they don't know and wonder if this could happen to their child. I cannot share the details of these precious souls passing, out of respect for the families or unless they give permission. We are taking this information and developing medical alerts, articles, warnings, notifying our Scientific and Clinical advisory boards, etc. We have included important new GI medical material PWSA (USA) has developed in this issue. You will receive this information if you are on PWSA (USA)'s contact list. It's important! This information can save your child's life. www.pwsausa.org

PWSA (USA) is here from the day your child is born with PWS until the day they pass away. We will support your child and your family every step of the way, including newborn issues, education issues, transitioning to adulthood, crisis, medical, plus lots and lots of publications and medical alerts. We have top professional counselors and doctors who are working with us to help your child be the best they can be and survive. An example is the MEDICAL ALERT BOOKLET. Many parents report that it saved their child's life! Another aspect of PWSA (USA) is Research. We approve research grants that will help your child right now, not just the next generation, but now!

Then, in the end, we have the Study of Death and Bereavement programs. Why are these programs so important? We want the child's legacy to live on, that their lives meant something or helped others with PWS. Many families choose to have an autopsy and donate tissue to the Brain and Tissue Bank so PWSA (USA) can have an understanding of the cause of death. At least, the parent can feel that their child can leave a legacy, give us answers, even in the end. That is where it comes full circle, supporting each other in the beginning until the end and after. ■

MEDICAL ALERT

Constipation in Individuals with Prader-Willi Syndrome

James Loker, M.D., Pediatric Cardiologist

Ann Scheimann, M.D., M.B.A., Gastroenterologist

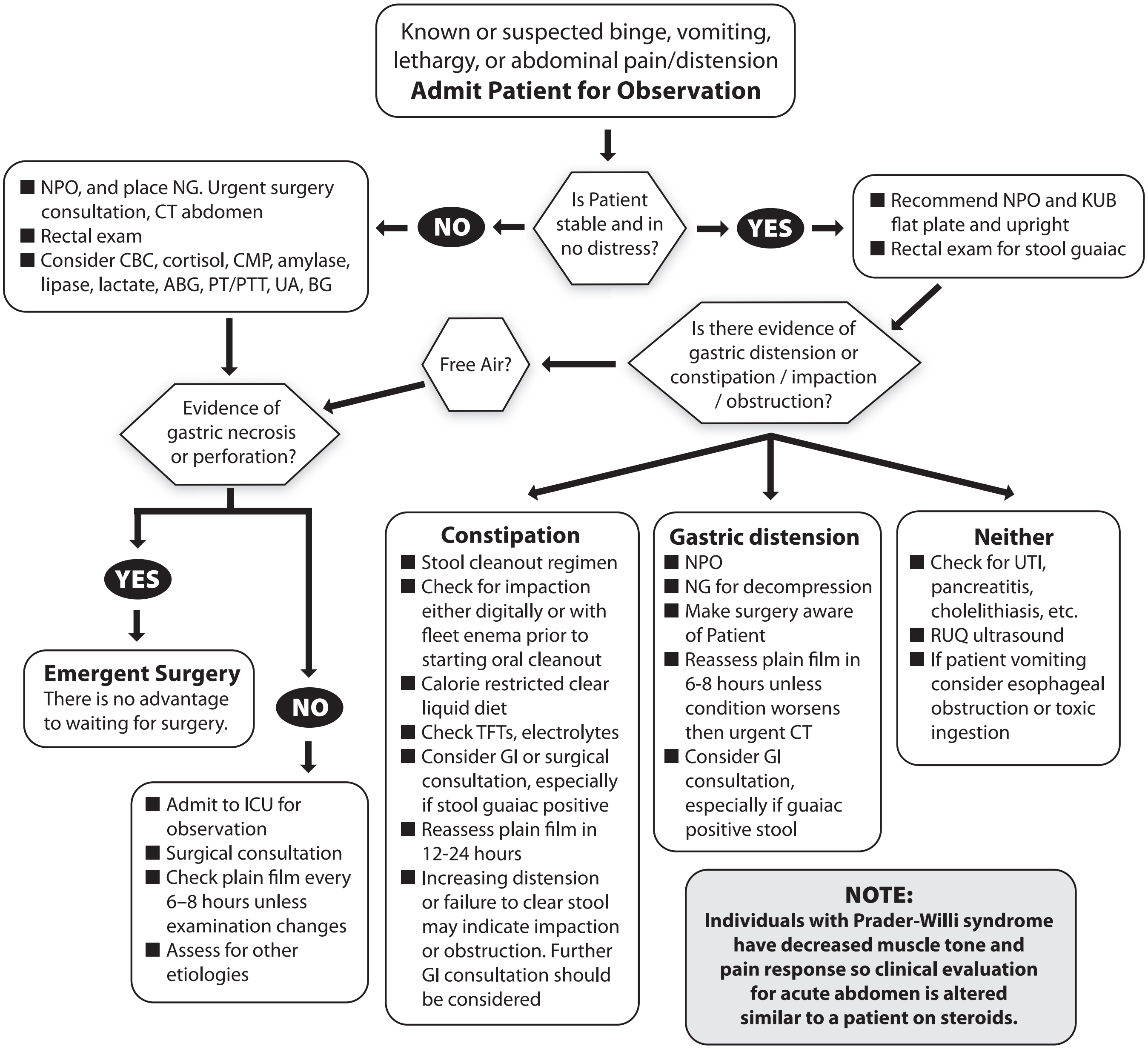
PWSA (USA) Clinical Advisory Board Members

Constipation is a common problem in individuals with Prader-Willi syndrome (PWS). It takes longer for food to move through the GI system in Prader-Willi syndrome.* This slower passage of food can lead to serious issues similar to the ones seen related to the stomach (see MEDICAL ALERT BOOKLET UNDER SEVERE GASTRIC DISTRESS and GASTROPARESIS). Outpatient methods used to clear constipation in non-PWS patients may be ineffective due to poor fluid intake and hypotonia. Inpatient regimens frequently use large volumes of fluid which may cause problems. Reliance on these methods may lead to life-threatening conditions such as necrosis and perforation of the colon and subsequent sepsis. Due to decreased muscle tone and altered pain response, individuals with PWS may not have the same clinical exam that a non PWS patient would have. A heavier reliance on imaging may be necessary. Individuals with PWS may be at higher risk for impaction. Rectal examination and enema may be required in addition to oral cleanout regimen. This may also be problematic in some leading to rectal picking.

Patients with PWS having constipation and receiving repeated regimens of oral PEG (polyethylene glycol) solutions for bowel cleansing should be monitored closely for abdominal distention and retention. **Failure of standard constipation protocols to clear the stool in a timely manner, especially in the face of increasing abdominal distension, vomiting, decreased appetite, stoppage of food consumption and/or abdominal pain warrants surgical or GI consultation. Emergent surgical or colonoscopic intervention may be necessary.** ■

*__Kuhlmann, et al. (2014)__ *A descriptive study of colorectal function in adults with Prader-Willi Syndrome: high prevalence of constipation.* BMC Gastroenterology, Apr 4; Vol 14: page 63*

Evaluation of Individuals with Prader-Willi Syndrome with GI Complaints



Known or suspected binge, vomiting, lethargy, or abdominal pain/distension

Admit Patient for Observation

Is Patient stable and in no distress?

NO

- NPO, and place NG. Urgent surgery consultation, CT abdomen
- Rectal exam
- Consider CBC, cortisol, CMP, amylase, lipase, lactate, ABG, PT/PTT, UA, BG

Evidence of gastric necrosis or perforation?

YES

Emergent Surgery
There is no advantage to waiting for surgery.

NO

- Admit to ICU for observation
- Surgical consultation
- Check plain film every 6–8 hours unless examination changes
- Assess for other etiologies

YES

- Recommend NPO and KUB flat plate and upright
- Rectal exam for stool guaiac

Is there evidence of gastric distension or constipation / impaction / obstruction?

Free Air?

Constipation

- Stool cleanout regimen
- Check for impaction either digitally or with fleet enema prior to starting oral cleanout
- Calorie restricted clear liquid diet
- Check TFTs, electrolytes
- Consider GI or surgical consultation, especially if stool guaiac positive
- Reassess plain film in 12-24 hours
- Increasing distension or failure to clear stool may indicate impaction or obstruction. Further GI consultation should be considered

Gastric distension

- NPO
- NG for decompression
- Make surgery aware of Patient
- Reassess plain film in 6-8 hours unless condition worsens then urgent CT
- Consider GI consultation, especially if guaiac positive stool

Neither

- Check for UTI, pancreatitis, cholelithiasis, etc.
- RUQ ultrasound
- If patient vomiting consider esophageal obstruction or toxic ingestion

NOTE:
Individuals with Prader-Willi syndrome have decreased muscle tone and pain response so clinical evaluation for acute abdomen is altered similar to a patient on steroids.

PRADER-WILLI SYNDROME ASSOCIATION USA
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Credits: James Loker, M.D., Pediatric Cardiologist • Ann Scheimann, M.D., M.B.A., Gastroenterologist
PWSA (USA) Clinical Advisory Board Members

www.pwsausa.org

Fear will make you settle. Faith will take you further than you deserve to go.
*So feed your **Faith** and do away with fear*
if you want to unlock the door which holds your dreams and aspirations.

40 Year Flashback, *continued from page 1*

we had. There were very few in the medical field who were familiar with the syndrome.

Marge Wett was our first executive director, working from her own kitchen table with no salary and no funds with which to work (including postage) other than contributions from families and friends.

The first "Gathered View" was created and edited by Shirley Neason in July of 1975. To us, the creation of the newsletter and the later formation of the annual conference enabled us to understand that there were other families "out there" facing the same problems and frustrations that we were facing.

When Andy was nine years old, we received the diagnosis of Prader-Willi syndrome. Having been dealing with the unknown for so long, we were at first relieved to have received a diagnosis, but the basic question remained "what is it?" No one had an answer (not even the medical profession) so we started our own Journey of dealing with the syndrome by instinct and hoped we were dealing with it in the right way.

Knowing that we were not alone was the most important part of our lives during the 70s and 80s. We were all so grateful for the newsletter, for Gene and Fausta Deterling who had created PWSA, and for the conferences where we had a chance to meet and talk with parents from all around the United States and later from all around the world. In spite of all the problems and frustrations and encountered, there was a positive side to Prader-Willi syndrome – the wonderful friends we have made over all these years. We are a family!

It was a time of trial and error for us as parents and for the association and a time of fundraising for a cause that was totally unknown and, in fact, a cause that was not popular – obesity, especially in fundraising. This fact was echoed by several psychologists.

The association continued to grow in the early 80s and although the frustration remained due to the continued lack of helpful information, we were encouraged. Recently, I was asked to describe a life with a child with Prader-Willi syndrome. After some thought, my reply was "I felt like a pioneer traveling into the unknown and trying to find answers. It was certainly an adventure! In those early days instinct was our only guide". ■

My First Conference, *continued from page 1*

Margaret Miller, Julie Mitchell, Mathieu Parent, Lori Prettyman, David Burleigh, and many others. I really feel that they and their parents are part of my family. Because of the many conferences I have attended, my PWSA family has grown and become very important to me and I know they will always be there for me. ■

Andy Maurer with Dr. Prader at a special conference in 1984.

Status of PWSA (USA) Research Grants

As most of you are aware, PWSA (USA) has a long history of funding research, and also programs that accelerate and enhance research on Prader-Willi syndrome – such as the programs we sponsored in 2014 at Obesity Week. We are pleased to announce the funding of the following research grant:

Reducing the Risk of Prandial Aspiration and Choking in Persons with PWS –

Principal investigator: Roxann Gross, Ph.D.

In the past, the increased risk of choking to death in PWS was thought to be primarily caused by gorging and rapid eating behaviors. Thanks to an initial grant from PWSA (USA), research data was obtained revealing the real problem was swallowing problems and poor esophageal function. The most striking finding was discovering the presence of often large amounts of food remaining in the throat and the esophagus after swallowing. Alarmingly, 97% of those studied had no sensation or awareness that the food "didn't go down".

The purpose of this new study will be to provide the medical community with evidence-based recommendations for the evaluation and treatment of dysphasia in persons with PWS. Once completed, this research will significantly advance the understanding of how swallowing problems in PWS can be treated. This work is highly relevant to the current research mission of PWSA (USA) because the results will have a direct and immediate impact on care.

Two more grants have been sent back to the investigator for revisions and resubmission. PWSA (USA) will also be putting out a new request for grant submissions in May. The research committee decided we would put an emphasis on the topics of:

- finding solutions to dealing with gastroparesis in PWS
- sleep issues in PWS and how it plays a role in behavior
- aging in PWS

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Executive Director View

Annual Meeting of the PWSA (USA) Advisory Board

By Ken Smith

Executive Director, PWSA (USA)

Andy

Shawn

Kate

In the March/April issue of *The Gathered View,* we shared profiles of four of our eight members of the PWS Advisory Board: Trevor Ryan, Brooke Fuller, Lauren Lange, and Conor Heybach. Now read about Shawn Cooper, Kate Kane and Andy Maurer. The eighth member, Abbott Philson, will appear in the next issue of *The Gathered View.*

This board is comprised of adults with the syndrome; they are all people with proud parents. Parents of little ones with the syndrome can look to them for inspiration so that their children can grow up to live meaningful lives, and contribute to the society in which we all live.

Evan Farrar, Mary K. Ziccardi, and I are the advisor/mentors to this board and are always impressed with its members.

Stewart A. Maurer III, better known as Andy, born in 1959, was diagnosed with PWS in 1969 at the U. of Minnesota. He attended many schools across the country due to his father's career moves, graduating from high school in 1979. He completed five computer courses at Midlands Technical College in Columbia, South Carolina. Andy attended the first PWSA conference in 1979 and most of the conferences thereafter. He had the opportunity to speak at the 25th Anniversary Celebration of PWSA (USA) in 2000 (see his cover story). Featured in an article about PWS in People Magazine in 2005, he also appeared on CNN and other local news channels. In 1988 he received a Vital Service Award from the ARC ATLANTA for his volunteer work at the North Fulton County Training Center. He participates in Special Olympics -- bowling, bocce and equestrian sports. He went to the 2003 Special Olympics World Games in Dublin, Ireland, competing in equestrian events and earning a bronze medal. In 1996 Andy moved into a four-person group home provided by the Babcock Center, Inc. He serves on the Board of Dreamriders (a therapeutic riding program) and is currently President of the Babcock Center BETA (Becoming Empowered Through Advocacy) group. Andy is glad to be on the PWSA advisory board so that he might be helpful in putting together information that will help others with the syndrome to make their lives more meaningful and productive. He loves getting together with his friends on the board.

Shawn Cooper, born in 1973, was diagnosed with PWS at age 11 ½. She and her family attended their first of many national conferences in 1975. Shawn received her Special Ed H. S. Diploma in 1993 and, shortly after receiving a Medicaid Waiver, moved into the first group home for persons with PWS in the state of Georgia. After several living arrangements, she moved into her "Forever home" in 2012, a supported living environment staffed by enAble, a non-profit organization with a 35-plus year history of serving adults with disabilities. An active member of the Advisory Board since its inception over 10 years ago, she has held a number of part-time jobs; been the subject of numerous magazine, newspaper, and television specials, helping to bring awareness of PWS; and participated in several international studies on PWS. Today Shawn, 41, is thriving. She has recently reached her goal weight and is actively engaged in exercise (treadmill and strength training), sports (tennis, bowling, and softball), and community activities (church, dances, parties, crafts, etc.) She has received a "Train the Trainer" certificate for self-advocacy in the state of Georgia and attends the "People Planning Together" annual conference. Shawn worked part-time at TJ Maxx during the Holiday season and volunteers at the Humane Society and the Drake Closet, a women's boutique to support homeless women and children. She provides sign language at the annual church program for Noah's Ark and was selected to give

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Grants, *continued from page 4*

- psychotropic medications – what works and doesn't work with PWS
- pulmonary embolus – the cause of 7% of PWS deaths (PWSA current study of death)
- developing a better hyperphagia scale for today's population – including those who have controlled hyperphagia
- motor tics/tardive dyskinesia – reducing the risk; minimizing the impact
- biomarkers for health risk factors in PWS
- postoperative issues and management

At PWSA (USA) we work to integrate what we have learned about the needs of our families through our support programs with research that we think will make an important and practical difference in our children's lives. **Saving lives today – enhancing lives for tomorrow!** ■

Executive Director View

Continued. *from page 5*

the invocation at enAble's 2013 *Dare to Dream Gala*. Shawn enjoys traveling to her family home in Louisiana, where she is able to connect with family and friends in the PWSA (USA) Louisiana chapter.

Hi, my name is **Kate Kane.** I am 33 years old and live in Oconomowoc, Wisconsin with my housemates in the Margaret Ruth home. Since moving here over ten years ago from my family home in Maryland, I have enjoyed the support of the PWHO program. Recently, PWHO started a new day program, "DayRise", which offers me lots of interesting and different activities to fill my day. I enjoy reading, horseback riding, listening to music, playing games on my iPad and all kinds of animals. My collection of "Life is Good" and "Black Dog" clothes, coffee mugs and Tervis cups is ever growing! Although I have struggled with some of the typical issues of PWS, including scoliosis surgery, medication changes and even a stay with Ken Smith in Pittsburgh, I am proud of the life I have built for myself. Early on, I learned the benefits of helping people with my mom in the Pets on Wheels Program. My accomplishments include my high school diploma, being nominated by the members of the Maryland Athletic Club as a "Person of Inspiration" for dedication and work as a swimmer, and being featured on the Good Morning America and 20/20 shows to promote awareness about PWS. I hope that my life, easy smile, good humor and generous spirit will inspire other people with PWS to reach for the stars as they build their own lives. ■

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

From the Home Front

Max Sznaj, Eagle Scout

Max started scouting in first grade with his dad by his side as a leader all the way. He worked hard up all the ranks. He had a few bumps in the road with being in the hospital for six weeks in Pittsburgh and having scoliosis surgery. He still wanted to do his scout work and stay in scouting; PWS wasn't stopping him. He has earned several medals for hikes, the highest religious medal and 47 merit badges.

> *When it came time for his Eagle Project, he became very excited about giving back to a program that helped him so much.*

When it came time for his Eagle Project, he became very excited about giving back to a program that helped him so much. That program was *Manes and Motions* therapeutic horseback riding, which he has done since he was little. He remembered one of his side walkers, Jason, was a Boy Scout and they always talked scouting. Then Jason did his Eagle project at *Manes and Motions* and Max was pretty impressed. Now it was Max's turn. And it was good timing. *Manes and Motions* had just fulfilled the dreams of its founder Mrs. Massi with an indoor riding arena. Max really loved her because she was such a kind, loving person. Since the new arena was opening in the fall, Max was asked if he could spruce up the horse barn with a nice cleaning and fresh paint. After writing a proposal and getting it approved, he began the job. Now Max had to raise money for all the supplies and get volunteers to help him get the job done. That ended up being the easy part of the project. With *Manes and Motions,* organizing a good time to paint had to be taken into consideration; he was painting the horses' home! The weekend was selected, cleaning supplies and paint purchased and volunteers invited to come whenever they could. Cleaning and painting 12 horse stalls and the ceiling of a barn seemed like such a huge project that we thought would take a good three days. To our amazement, it took only one and a half days; what a testament to how many people Max has touched! He had over 60 volunteers (two coming all the way from Philly to Connecticut), for a total of 270 hours worked all for him. What an honor.

December 22, 2014 was the Board of Review, and he learned he passed. *Manes and Motions* helped Max in so many ways; he became a better rider and a better Scout. Max continues his scouting and will soon be an adult leader. Inspiration came from Mrs. Massi and Jason – now let Max's story inspire you. ■

~Margaret Sznaj

Step right up, Step right up.
Come see the greatest show on Earth!

Cirque du l'espoir
Circus of Hope

2015 PWSA (USA) National Conference
November 4-7, 2015

Buena Vista Palace at Lake Buena Vista, FL

CIRCUS OF HOPE
Cirque du l'espoir
PWSA|USA 2015

What an amazing conference this will be! PWSA (USA) is celebrating its 40th year as the largest support, research and advocacy organization for people and families with Prader-Willi syndrome in the United States. This conference will reflect on what we've accomplished and expound on what is ahead. Each age group will have a different set of topics scheduled within a track where the most up to date information will be presented by our leading experts. Families and Professionals will be able to work together with the goal to increase your knowledge and resources. **We are also hosting the International Professional Providers and Caregivers Conference on November 3rd at the beginning of the conference week.**

Early Bird Registration Now Open: visit our website for more details: www.pwsausa.org

Here is what the week will look like:

Tuesday, November 3

- **International Professional Providers and Caregivers Board Meeting**

Wednesday, November 4

- **IPWSO Professional Providers & Caregivers**
- **Chapter Leaders Day 1** is for the director, president, vice-president of each chapter organization.
- **Clinical Advisory Board Meeting & Dinner**
- **Scientific Advisory Board Meeting**

Thursday, November 5

- **The 29th Annual Scientific Day** is for PWS-related research professionals to present their research findings to their colleagues. Parents and other professionals are welcome to attend and observe; however, a summary of this day will be presented to the parents during the General Conference. For details see page 9.
- **Professional Providers Day** is for professionals providing supports within an education, vocational or residential setting.
- **Chapter Leaders Day 2** is for the director, president, vice-president of each chapter organization.
- **Welcome Reception** Please join other families that evening from 5:00 – 9:00PM as we meet and greet and register for the conference. There will be games and activities for the children. Young and old love to get a chance to see Mickey and/or Minnie, who usually make a grand appearance!

Friday-Saturday, November 6 & 7

Experience two full days of presentations, information, workshops, practical suggestions and a time to spend the day with other parents who walk in your shoes every day, during the age-specific four tracks that support the needs and interests of parents and caregivers of children and adults with PWS. We have assembled the "Top Acts" of professionals who will present the latest in research and support programs, such as education advocacy, behavioral, medical and therapeutic interventions, in addition to legal, financial, advocacy, supported living and family considerations.

Simultaneously, there will be separate sessions to care for and entertain our children and adults with PWS. A separate "sibling only" session will address the needs and celebrate the accomplishments of this important part of the family structure. Our programs, designed for our children and adults with PWS (as well as siblings), are second to none and not to be missed.

For 2015, we are fortunate to have the Latter Day Saints Church missionaries joining us, working in our programs as volunteers. Under the supervision of professional staff, our children will receive attentive and loving care.

Here are just a few of the many comments we received from parents and attendees after the 2013 conference:

"Best meeting we have attended", "Conference was impressive, informative, educational, emotionally gratifying and amazing", "YAP dance was a blast",

"A feeling of support and camaraderie- knowledge of things I can do right now".

And if that is not enough, don't forget the Grand GALA dinner and YAP GALA dinner and dance for our kiddos on Friday evening. This is a great time for our families and professionals to come together in celebration of the great strides we have collectively made over the last 40 years! ■

Experience a conference where you will learn how to successfully care for your child/adult with PWS from an organization who passionately has the heart, drive, knowledge, and experience, and who "get it".

PWSA (USA) –
We Save and
Transform Lives!

A Family Affair -

By Janalee Heinemann, M.S.W.
Coordinator of Research and
International Affairs

NOTE: Although I wrote this article 26 years ago, many things in family dynamics – and the importance of conference – never change, so we thought we would unearth it from the PWSA (USA)archives for this new generation to enjoy.

It sounded like a great idea; at least something we should try once, the great family vacation. What we call a "real" vacation has very specific criteria, the first of which is "no kids." Sun, water and no mental or physical exertion are also high priorities. Thus it must have been a moment of mutual temporary insanity when we agreed we would take three kids to the 1988 PWSA National Conference, stay in one motel room and share one bathroom for five days.

The first monumental feat was pulling out of the driveway. This in itself took hours of hard labor and strategically packing the car so there was enough room left for five bodies and oxygen. At the last house check, we looked at: six-year-old Mikey (grandson) leaping excitedly around the room, 14-year-old Sarah (with her headphones glued to her ears) sulking on the steps, and 15-year-old Matt checking the house for the 15th time for his rock collection book, repeating in an uptight voice, "I can't find…" Al turned to me and said, "Do we really know what we are doing – is it too late to change our mind?" I just gave a sigh of resignation and responded, "Probably not."

Fortunately, all three slept halfway there. During the second half of the trip Matt decided to prove to us that he should be able to get a driver's license. He did this by reading and explaining all the road signs for the rest of the trip. About 15 miles out of Louisville Matt declared that he would make friends at the conference but that he wasn't going to have a "Prader-Willi girlfriend" because, "they can't have babies, you know."

Although two years ago one of Matt's laments was that he couldn't have babies, he has managed to block this out. He now declares that "when I grow up I going to date a older woman (16-19) because she can have babies. She get my food and do all the cooking." When Al told him he was too young and needed to finish school, Matt said, "I have it all figured out. I go to school in the morning and work in afternoon, I good at art you know."

Matt quickly forgot his vow regarding girlfriends with PWS immediately on our arrival when slim, red-haired Joyce Abell put her arm around him and gave him a book on computers. Then Ricky Lacy came up, introduced himself, and shook Matt's hand. Kentucky, being the friendly chapter we know them to be, has also bred friendly children. They all helped us unload the van and within an hour Matt had declared Joyce his girlfriend. Later he looked up at me quizzically and asked, "Is Joyce Prader-Willi, Mom?" I replied, "Well, yes she is. Isn't she pretty though?" Matt had to admit she was.

I wish we could say Matt's issues of acceptance of himself and others with the syndrome ended there but by the next morning Matt had met some of the "normal" sibling counselors and was enamored by their beauty and what they represented to him. Throughout the rest of the conference Matt vacillated between feeling like the best of the kids with PWS to hovering in the shadows of the teenage siblings. Matt beamed frequently when people told him how good he looked and when Lota Mitchell, board chairperson, asked him if he knew he was the most famous kid with PWS in the nation. Matt acknowledged that indeed he knew that and signed his autograph for her. On the other hand, when Sarah was going to the sibling group he asked, "Why I can't come? What they talk about? They think I too stupid to have conversation?" Later, at the dance, when we walked in, Matt was smiling and dancing with a slim, young woman with PWS. When I went to take his picture he immediately stopped dancing and grabbed two attractive teen siblings to have his picture taken with. Matt is not entirely alone with his self-image dilemma. Curtis Deterling, another 15-year-old with PWS also proudly showed me the addresses of the same two "normal" girls. Matt pulled me aside and confidently whispered that they liked him better. The boys' struggle can sadly be summed up with the following example. When we introduced Curtis to Sarah he asked her, "Are you Prader-Willi?" When she said no, he apologized profusely for even thinking that she might have PWS—like himself.

The conference was, unexpectedly, the most significant for Sarah. At 14, her biggest goal is to be one of the "in crowd" and there is nothing "in" about having a brother with PWS. Recently she had been showing signs of shame and intolerance with Matt. In Kentucky, though, Sarah suddenly found a new community of "blood brothers and sisters" and a new sense of acceptance of Matt. Along with other siblings her own age, Sarah told of her concerns and frustrations. The sibs all slipped each other snacks, shared funny stories, and formed special relationships. Sarah also received many positive comments of recognition for the sibling book that she and I wrote half her lifetime ago. It suddenly became okay to be a part of a Prader-Willi family again.

We included our 6-year-old grandson, Mikey, in our local PWS activities and retreats and brought him to the conference with us because he, too, must adapt to the syndrome. We feel it can't hurt Mikey to

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Save the Date and please plan to attend the

28TH ANNUAL PWSA (USA) SCIENTIFIC DAY CONFERENCE

Thursday, November 5, 2015

Buena Vista Palace at Lake Buena Vista, Orlando, FL

You are cordially invited by 2015 chairperson Merlin G. Butler, M.D., Ph.D., from the University of Kansas Medical Center, Departments of Psychiatry & Behavioral Sciences and Pediatrics, to attend this year's Prader-Willi Syndrome Association (USA) Scientific Day Conference.

Dr. Butler has contributed significantly to the medical literature with over 400 published research articles and multiple book chapters, many related to Prader-Willi syndrome (PWS) research. His research led to the first observation of the chromosome 15 deletion contributed by the father, recognition of genomic imprinting as a cause of PWS and development of diagnostic criteria.

Request for Abstracts

PWSA (USA) is requesting abstract presentations of recent research studies on the subject of Prader-Willi syndrome for the Scientific Day Conference. Both oral and poster presentations will be accepted. To be considered for presentation, please send an e-mail to Kerry Headley, PWSA (USA) Scientific Day Coordinator at kheadley@columbus.rr.com with a copy to Dr. Merlin Butler at mbutler4@kumc.edu no later than Friday, August 24, 2015 expressing your desire to present either an oral presentation or a poster. You will be sent detailed instructions regarding submission format and dates once your intent to submit has been verified.

Travel Awards

PWSA (USA) is pleased to announce the availability of travel awards through the Headley Family Scholarship for a limited number of trainees and junior faculty selected to present at the PWSA (USA) Scientific Day Conference. Eligible investigators include undergraduate and graduate students, postdoctoral and clinical fellows, and junior faculty (assistant professor or below). These awards will provide selected investigators with $500 in reimbursement for travel and lodging expenses. Details regarding award funding and the application process will be made available on the PWSA (USA) website and/or by contacting Kerry Headley at kheadley@columbus.rr.com. One poster (or presentation) will be selected as Best Submission and the investigator will be awarded a $1,000 prize.

Program Emphasis

Special emphasis will be placed on discussion or progress in clinical trials in PWS. Abstracts will cover a broad range of topics and PWS issues including genetics, gastroenterology, endocrine, metabolic, psychiatric and behavior issues or imaging studies.

Keynote Speaker

Dr. C. Sue Carter, Ph.D., Director of the Kinsey Institute at Indiana University, is our keynote speaker. She is an expert in neuropeptide influences on behavior, specifically Oxytocin.

Registration

Registration for the Scientific Day Conference held on Thursday, November 5 is $125 which includes a continental breakfast and lunch.

Following the Scientific Day Conference

Please consider joining us for the General Conference on November 6 and 7 directly after the Scientific Day Conference. The theme of this year's General Conference is **Circus of Hope**.

At the General Conference, experts will present on a large variety of important topics related to PWS with interaction encouraged not only by professionals, but also by the hundreds of parents and people attending the meeting including those with the syndrome from newborn to adulthood. **Celebrating its 40th anniversary, the Prader-Willi Syndrome Association (USA) is now 2,000+ members strong and has served over 7,500 children and adults with PWS.** PWSA (USA) has provided support for families, created educational materials for distribution and has funded research and encouraged collaboration among researchers, clinicians and families. PWSA (USA) has established Scientific and Clinical Advisory Boards consisting of key professionals, physicians and scientific investigators, many as pioneers in the field to address research, investigations and treatment including growth hormone in this syndrome. ■

Not submitting an abstract but want to make sure you continue to get notification of the details of this conference, RFAs for grants, etc., Send an e-mail to Kerry Headley: kheadley@columbus.rr.com

Chapter Spotlight

Pennsylvania

Edited by Andrea Glass


Patients from the Prader-Willi Unit at The Children's Institute, also attended the baseball clinic.

The Pennsylvania chapter began with the multi-state MidAtlantic group, formed in 1972 in eastern PA. Next came a support group in western PA for the Tri-State area to include western PA, Ohio, and West Virginia. As it became apparent that the laws of PA and Ohio differed, this group divided again. The PA support group, inactive for several years, was revived in 1997 and became an official chapter. Now, the chapter has the support of past officers, National, and The Children's Institute of Pittsburgh, a 200+ member list, with individuals with PWS ranging in age from two to mid-forties.

The Chapter vision is ***"for the PA Chapter to be a source of support, education and advocacy for individuals with PWS and to their parents/caregivers, and providers."***

For several years, the Chapter sponsored an annual family outing to a Pittsburgh Pirate baseball game. In 2014 an all-day event included breakfast at PNC Park, a baseball clinic, where Clint Hurdle and his coaches instructed our kids, and a "Just Ducky" land/water tour of Pittsburgh. Chapter members feel fortunate that Clint Hurdle and his family are on the National and PA PWS team. *"Since Clint has been the Pirate Manager, he has held a "Meet and Greet" with our families prior to our annual Pirate game outing. He knows our kids by name, and they all adore him. We are so thankful to him and Karla for all that they do for us, and for the community."*

Several statewide mini-conferences throughout the state have filled in when there was no National Conference. Most recently, a weekend event last November included entertainment for the children, a banquet with DJ and dancing, and a Sunday bowling party. Speakers included Ken Smith, Executive Director, PWSA (USA); Dr. Linda Gourash, Developmental and Behavioral Pediatrician; and Keynote Speakers, sisters Gina Gallagher and Patricia Terrasi, authors of ***Shut up About Your Perfect Kid***. The Chapter was host to the 2000 National Conference with 1500+ attendees including a YIP/YAP attendance of 300. Bi-yearly Chapter meetings typically have a speaker and time for sharing.

The Chapter hosts an annual golf outing fundraiser – the 16th is scheduled for June 1. Each year this outing has over 120 golfers and additional sponsors. Proceeds go towards helping families attend conferences and funding Chapter mini-conferences, and raises PWS awareness in the community.

For the past four years, the Chapter has provided "Welcome Boxes" for the new patients in the PWS Unit at The Children's Institute. The plastic boxes and the items for the boxes are provided by the Chapter and taken to the Unit. Patients then assemble the boxes as part of their OT. A letter explains that the boxes are from the PA Chapter and encourages parents and caregivers of the patients to contact us if they need anything (including companionship and support) while they are in Pittsburgh.

The Chapter provides many resources to its members, including a network of physicians that know about PWS, and school resources, coordinating a knowledge base for school districts. Future goals for the Chapter include work at the legislative level in PA to achieve automatic inclusion for those with PWS in statewide disability services.

The current officers are Maria Silva, President; Deb Fabio, Treasurer; Bonnie Azzara, Secretary. They can be contacted at pwsapa@hotmail.com ■

Family Affair, *continued from page 8*

learn to be comfortable around people who may appear unusual to others. Locks in the kitchen, not being able to eat snack foods in front of Matt, and not leaving leftover food around, is all a part of life for Mikey. All of these things he learned at a very young age. Now at age 6, Mikey is becoming more aware that some things are unusual about Matt. He recently asked, "Matt, why do you always ask questions?" and "Matt, why do you always worry about your things so much?" One of the special positive aspects of the National Conference is that it truly is geared for all ages. Mikey, along with Sarah and Matt, danced every dance on Friday night. He found a 7-year-old girlfriend, Sayward, whose room number he promptly wrote on a piece of paper (the result of being around teenagers.)

Adding a fourth generation to our "Kentucky experience", Al's parents from Iowa surprised us with a two-day visit at the conference. When discussing the impact of PWS, we usually focus on the immediate family, but the effect of PWS encircles a much larger group of people in varying degrees. The extended family involvement of the Kentucky Chapter in assisting with the conference was heartwarming. The people brought into the PWS circle of awareness and support grows each year. So, on the way home, as we all basked in the warm glow of the conference, Al and I were breathing a sigh of relief that our "group adventure" had gone far better than our most optimistic expectations. The only hitch was when the kids all said they had so much fun that they wanted to go next time! Al and I cringed, looked at each other with pained faces, and said in unison, "Three kids? All the way to Canada?" ■

YOU can make a difference for the lives with Prader-Willi syndrome

Have you heard about our new and exciting virtual walk fundraiser **eWalk**? If you haven't, you have to check it out! It's been amazing to see our community be proactive by registering for eWalk and raising awareness/money for PWS. If you haven't registered for your own eWalk fundraising page yet, you still have time to register and be part of eWalk! We encourage everyone to join the eWalk movement. Here is what some of the many people have to say about why eWalk is so great:

While we bounce from doctor's appointment to doctor's appointment and specialist to specialist it's even more of a push to help in whatever way we can to fund research and support other families. The eWalk has been a great way for us to do just that! eWalk has also become a great way for us to include family and friends who have been searching for a way to help! We are so grateful for our PWS community and the love and support our family and friends continue to pour over us!

Wendy Armelin-Barron

"I registered for the eWalk simply because it is simple. We live in an area where there are not many Prader-Willi events, unless we drive for 2 or more hours, and many of my friends and family are even further away. The eWalk is a great way for everyone to participate, no matter the distance."

Emily Gabaldon

My sister Ellise has PWS. She is my older and only sibling and I couldn't ask for a better one. I'm so proud to say that she is almost at her ideal weight from working hard at her diet and exercising! I decided to set up a eWalk fundraising page in honor of my sister because she is my hero and has done so much for me and others that I want to honor her.

Heather Schlarbaum

To register and create your own easy to set up eWalk page, please go to www.ewalk4pwsa.org. Please contact Donny Moore if you have any questions at 941-487-6729 or at dmoore@pwsausa.org ■

On March 20, PWSA (USA) and Clint Hurdle, manager of the Pittsburgh Pirates came together to host the first "Hot Stove Dinner Event" at the Courtyard Marriott in Bradenton, FL. The night featured a lovely dinner, auction and the inside scoop on the upcoming Pittsburgh Pirates baseball season present by Clint Hurdle himself. The local community, PWS community as well as many individuals from Pittsburgh came together to make the night an outstanding success raising $41,500! PWSA (USA) sends a big thank you to Clint Hurdle, the Pittsburgh Pirates, our sponsors, many generous donors and all those who attended. Funds from the evening will allow PWSA (USA) to continue saving and transforming lives.

Completed Events:

Many thanks to our dedicated community members that made the following events so successful! Your hard work and commitment to PWSA (USA) is appreciated beyond measure!

GiveRare Day: $21,540 - One day online fundraiser event for PWSA (USA)

Kid's for Kid's Dancing for a Cure: $3,650 - Hosted by All Stars Dance Center in honor of fellow dancer, Audrey Kellerman

What to Wear When You're On the Move: $5,700 Hosted by Vail Farm Elementary School in honor of fellow student, Hudson Slocum

2015 Florida On the Move Walk: $14,600 - Hosted by the Florida Chapter as part of the annual OTM Campaign

If you are interested in hosting a fundraiser in your area to help us reach our goal of 40 events in our 40th year, please contact Leanne Gilliland at lgilliland@pwsausa.org or 941-487-6743. ■

Special Announcement:

PWSA (USA) Creates Special Education Advisory Board!

At PWSA (USA) there is nothing more important to our mission than helping parents and school professionals to work effectively together to support students with PWS. Because of this commitment, PWSA (USA) is a special education advocacy leader in the rare genetic disease community. Our services include:

- Written and video resources to help school professionals understand the support needs of students with PWS.
- Strategies for how to effectively handle PWS specific challenges such as food security in the school setting and providing positive behavioral support.
- Family Support Counselors to interact directly with IEP teams to offer information about PWS and advocate for the needs of student with PWS – and help parents with strategies they can employ to create effective collaborative relationships with school professionals.
- Utilization of national PWS educational experts to help resolve the most challenging school crisis situations.
- The Wyatt Special Education Advocacy Training program whose goal is to train parent advocates within the PWS community. Our first training was held in 2013.

But the reality is the challenge is growing. As schools across the country continue to face funding shortages, as parents rightfully expect appropriate and quality educational experiences for their children with PWS, and as our understanding of the needs of students with PWS continues to grow – we can't stay stagnate in our vision for the future.

So, I am very proud to announce the next step in PWSA (USA)'s commitment to students with PWS – the creation of the PWSA (USA) Special Education Advisory Board (SEAB). Qualifications to serve on the SEAB include:

- A demonstrated commitment to helping students with PWS, their families, and the professionals who serve them.
- A recognized expertise in the field of special education advocacy and PWS.
- A demonstrated ability to work collaboratively with the Family Support staff at PWSA (USA) to benefit children with PWS and their families.

Our inaugural SEAB board members meet these qualifications and more. They are:

- **Mary K. Ziccardi** PWSA (USA) National Educational Consultant
- **BJ Goff** PWSA (USA) National Educational Consultant
- **Tammie Penta** PWSA (USA) Wyatt Advocate and PWSA (USA) Board Member
- **Jennifer Bolander** PWSA (USA) Wyatt Advocate and COOPA Advocate in Training
- **Tanya Johnson** FPWR-Canada Special Education Advocate and Special Education Teacher
- **Amy McTighe** In-Patient Teacher at the Center for PWS at the Children's Institute

Tammie, Tanya, and Jennifer are also parents of a child with PWS.

The SEAB will:

- Advise PWSA (USA) on special education issues.
- Develop and review special education resources as needed.
- Offer guidance on special education support services – including the Wyatt Special Education Advocacy program.
- Communicate to the PWSA (USA) Board and the larger PWS community the importance of special education advocacy for students with PWS.
- Provide contributions to the PWSA (USA) special education advocacy e-letter - *School Times.*
- Serve as a resource to PWSA (USA) Family Support Counselors on special education issues.

Please join us in welcoming these outstanding members of the SEAB to their important new role. With their help, and your support, we look forward to continuing to make a difference in the lives of students with PWS in schools across the country. ■

~ Evan Farrar, PWSA (USA) Family Support and Crisis Intervention Counselor

CHUCKLE CORNER

Wanted!

Do you have a funny story? I mean a really funny story you would like to share with our families? We would love to make people smile with your submission:
Please email your story with your name, town and state (for the credit) to:
pwsaeditor@pwsausa.org

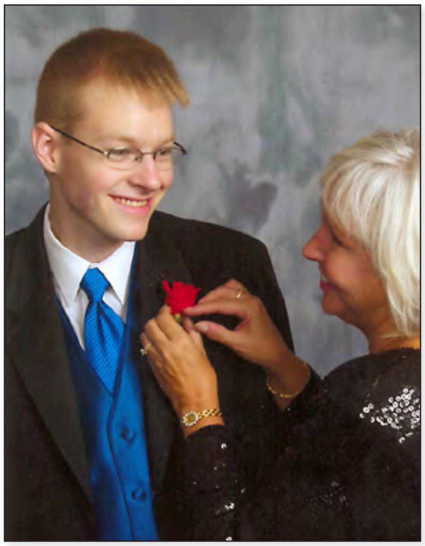
Thank you!

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. ■

WE REMEMBER
Patrick Settles



Our son Patrick was a sweet, gentle, and very happy soul. His energy and love for life was contagious. He was happy and thankful for the simple things in life.

Patrick was born with a disability (Prader-Willi Syndrome), but that did not slow his progress to become a better person. He enjoyed boating, swimming and working out at the YMCA. He participated in Special Olympics Basketball and Bowling. He gave blood and platelets regularly to American Red Cross. Patrick would tell everyone how he helped save another life.

Due to his insatiable appetite, he would appreciate all the times he could go out and eat. His favorite food was spaghetti and meatballs. His passion for sharks was blessed by Make a Wish Foundation. In spring of 2010 they gave him a shark fishing adventure in Palm Beach Florida. His face expressed a smile of total amazement when he caught a 450 pound bull shark. Upon his 21st birthday he celebrated by drinking a Land Shark beer.

Patrick was defined by his unconditional love for others and his circle of friends. An outgoing, lovable person who enjoyed meeting people, he always saw the good in them. He loved Holidays and Family gatherings. One of his favorite times was Halloween because of all the scary movies that came out.

Our Family knows that Patrick's spirit will continue to move us all and inspire everyone to live an active and happy life. We will miss him dearly! ■

(Through his parents, Patrick will continue to help save lives. He died from a G.I. crisis and his parents have resolved to do all they can to help prevent such deaths in the future. They were the impetus behind the 2 G.I. articles in this edition of The Gathered View. *Also, in memory of Patrick, they are sponsoring a PWSA (USA) iPhone app which will enable parents and medical staff to immediately look up necessary medical information wherever they are. They want to especially thank Dr Stephen P. Wright, Medical Director, Kosair Children's Hospital, for initiating the constipation alert article and spearheading an educational video on this issue that will be available in the future through PWSA (USA). We are very grateful and humbled that Rick and Kim were able to move beyond their grief to benefit all with PWS. ~ Janalee)*

¡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 February-March 2015. 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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e-News...

Reminder – stay informed and stay current with PWSA (USA)'s free e-News. Sign up today at www.pwsausa.org and watch for the next update full of great info.

CHAPTER VIEW

PWSA of OHIO has lots on their calendar. The PWSA of Ohio Conference with Dr. Jennifer Miller will be August 8 in Columbus. http://pwsaohio.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

The Gathered View (ISSN 1077-9965)
Sara Dwyer, Editor
Lota Mitchell
Andrea Glass
Denise Servais

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PWSA|USA 2015

Register NOW!

Celebrate 40 years of saving and transforming lives at the 2015 PWSA (USA) National Conference, **November 4-7** at the Buena Vista Palace at Lake Buena Vista, FL. www.pwsausa.org/conference

Our Super Heroes: Empowered by Hope

A collection of family stories from the PWSA (USA) publication, *The Gathered View*

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

New Publication! ***20% discount for members***

Our Super Heroes: Empowered by Hope

Is your child a Super Hero? Enjoy this heartwarming collection of stories from *The Gathered View.*

Compiled by Diane Seely, Carolyn Loker, Melanie Keller, Janet Li and Karen Vogt, you will read shared stories from some of our wonderful families that will embrace and support you through your journey.

One of the biggest gifts from PWS is the community; the fact is you are NOT alone in this. We have a community that celebrates every victory, and applauds even the smallest successes!

This booklet can be purchased now for $7.50 (20% discount for members!) by ordering from our website, http://www.pwsausa.org/shop/publications, also via the downloadable order form found on the website, or email: sales@pwsausa.org Watch for more new publications! ■

Come One, Come All, to the Greatest Show on Earth!

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"Best meeting we have attended" – "Conference was impressive, informative, educational, emotionally gratifying and amazing" – "YAP dance was a blast"

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