

# The *Gathered View*

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

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

## Phase Two Oxytocin Initiative Study Needs YOU!

Great NEWS! Phase 1 of our oxytocin trial in individuals with Prader-Willi syndrome (PWS) is almost complete! Preliminary results appear very exciting and we're anxious to move forward with the Phase 2 study. Support from a pharmaceutical company to sponsor these studies has not been obtained at this time. We feel that it is crucial to move forward as quickly as possible with a Phase 2 trial with a medication that has a high potential to benefit our children. Thus, we are appealing to the PWS community to help raise the necessary funds.

We are so very grateful to the PWSA (USA) for providing the funding to allow us to complete the Phase 1 study and are pleased to announce that PWSA (USA) and TREND are leading fundraising efforts for the next phase of the study. We're working to develop the Phase 2 trial as a multi-center study, include a dose-finding component, and to include a wider age range of participants.

The estimated cost of the Phase 2 study will exceed \$1 million. To ensure that your fundraising goes **directly** to support this oxytocin initiative, the funds need to be directed to PWSA (USA) and designated for the "**Oxytocin Initiative,**" as this is the **only mechanism** by which your funds can be earmarked specifically towards this study. We are tremendously enthusiastic about the potential benefits of oxytocin for individuals with PWS. We hope that the community will come together to support this exciting research initiative for a medication that could directly benefit individuals with PWS and their families.

Please help us get this landmark next study started as soon as possible. Thank you for your support. ■

**Jennifer Miller, M.D.**

Pediatric Endocrinology  
University of Florida  
College of Medicine

**Daniel J Driscoll, M.D., Ph.D.**

Pediatric Genetics and Metabolism  
University of Florida  
College of Medicine

Set up a fundraising page or donate directly to:  
<https://www.firstgiving.com/pwsausa/oxytocin-study>

## 40 Year Flashback

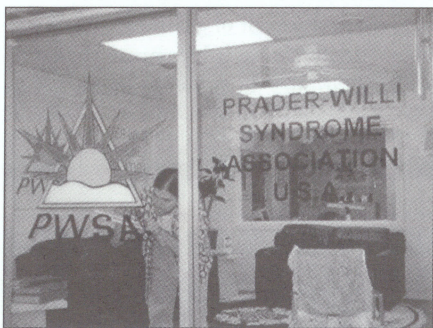
### PWSA (USA) 1994-2000 Flourishes The Evolution Years of Growth Hormone

The Association was growing so much, this period's history is provided in list form.

#### 1994

##### Conference in Atlanta, GA

- The national office moves to St. Louis, MO
- The sunburst logo is unveiled



PWSA (USA) office moves to Sarasota in 1997

- Janalee Heinemann steps down from the PWSA (USA) presidency and Jerry Park steps up
- Further advances in genetics leads to recognition and characterization of the imprinting center on chromosome 15 controlling activity of imprinted genes in the 15q11-q13 region

#### 1995

##### Conference in Seattle, WA

- PWSA (USA) publishes an article on "Growth Hormone and PWS" by Dr. Philip Lee\*
- The 1st National PWS Awareness Day is held

- PWSA (USA) sponsors the 2nd edition of, "Management of Prader-Willi Syndrome" (Springer-Verlag)
- Chromosome testing with fluorescence in situ hybridization (FISH) identifies the chromosome 15q11-q13 deletion

#### 1996

##### Conference in St. Louis, MO

- Dr. Moris Angulo\* reports one of the first systematic studies on GH secretion and the effects of GH therapy on growth velocity and weight gain in children with PWS. It was published in the *Journal of Pediatric Endocrinology and Metabolism*
- PWSA (USA) Scientific Advisory Board approves a policy statement

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Volume 40, Number 4 ~ July-August 2015 ~ Our 40th Year of Publication

## PWSA (USA) saving lives in the ER

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

One of our goals for 2015 is to focus on ways to have more impact with ER situations. We all know that taking a child or an adult with Prader-Willi syndrome to the ER can in and of itself be life-threatening. I certainly know this through my experience of covering most medical crises for over 16 years. Due to the fact that there are over 6,000 rare disorders, we cannot expect every ER physician and staff person to know in depth about every disorder, but we have to find ways to get them the information in a way that they can hear and will believe. We have for years asked every person caring for someone with the syndrome to carry our small Medical Alert booklet wherever they go, and we have an extensive medical section on our PWSA (USA) website – but that is not enough.

We have had the recent good fortune of adding to our volunteer team, Dr. Dan Beaver, a 30-year ER physician, who is the parent of a young adult

with the syndrome and husband of our crisis counselor, Kate. He has been able to look at our concern from the ER perspective. Dan sent me information on *UpToDate* published by Wolters Kluwer, which is often the main site that ER physicians and other physicians/residents worldwide go to get their information. I realized in reading their information on PWS that our G.I. expert, Dr. Ann Scheimann, who is a long-term volunteer member of our PWSA (USA) Clinical Advisory Board (CAB), was the key author of the information on PWS. I emailed Ann and discovered that she had just completed a revision, so Ann wrote to the deputy editor of *UpToDate* and asked that information on our PWSA (USA) website and that of IPWSO, what we do, and our contact information be added – which has been approved.

Add to this the fact that our volunteer Dr. Jim Loker, also a CAB member, parent of a young person with PWS, and husband of our medical liaison, Carolyn, recently spearheaded the completion of the new G.I. algorithm.

It has been published in our May-June 2015 *Gathered View* newsletter and on our website. This algorithm will help direct ER medical staff what to look for and do when GI problems are presented in PWS. Also, our PWSA (USA) members, Rick and Kim Settles, in memory of their son Patrick, were the impetus behind the creation of the new PWS Constipation Medical Alert article which will be extremely helpful for ER physicians.

A new technological way to aid in ER situations is through mobile phone apps. (See Ken Smith's Executive Director View on page 6)

This is not the end to our quest to create more ER support. Saving and Improving the Quality of Lives has been the PWSA (USA) mission for 40 years – and will continue to be our #1 goal. This entire evolution of ER support is a beautiful example of the synchronicity between our PWSA (USA) staff, professional volunteers, and devoted parents. Please help us to be able to continue to provide this kind of essential support through your volunteer and financial donations. ■

### Published:

## Medication Trials for Hyperphagia and Food-Related Behaviors in Prader-Willi Syndrome

Dr. Jennifer Miller, member of PWSA (USA)'s Clinical Advisory Board, wrote a published paper, with editing and assistance from Janalee Heinemann, PWSA (USA) Coordinator of Research and International Affairs, and Dr. Theresa Strong, FPWR Scientific Advisory Board chair. Titled *Medication Trials for Hyperphagia and Food-Related Behaviors in Prader-Willi Syndrome*, this paper has been published in *Diseases* at <http://www.mdpi.com/2079-9721/3/2/78>

### Conclusions:

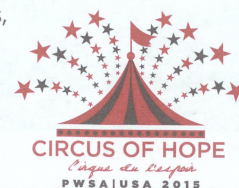
This is a tremendous time of hope for potential treatment of the appetite issues in PWS. Given the fact that the great majority of patients are now diagnosed in infancy, the combination of

early intervention and early growth hormone therapy, along with a medication to decrease the appetite issues, could result in a much improved quality of life, and increased independence, for individuals with Prader-Willi syndrome.

We want to thank Dr. Miller for her long-term dedication to our children and adults with Prader-Willi syndrome and for her long-term commitment to volunteering with PWSA (USA).

Also in this special edition of PWS in *Diseases*, a paper is written by our PWSA (USA) research committee member, Dr. Karen Vogt (an endocrinologist and parent of a child with PWS) and Jill Emerick. The paper is titled "Growth Hormone Therapy In Adults With Prader-Willi Syndrome." <http://www.mdpi.com/2079-9721/3/2/56> ■

Hear Dr. Miller with other presenters, plus meet, learn, and share with other PWS families at the **PWSA (USA) National Conference, November 4-7**. Early Bird discount ends soon!  
**Visit: [www.pwsausa.org/conference](http://www.pwsausa.org/conference)**



## PWSA (USA) 2015 Grant Announcement

Celebrating 40 years as a charitable nonprofit, Prader-Willi Syndrome Association (USA) is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with Prader-Willi syndrome (PWS). PWSA (USA) is seeking to fund projects for a maximum of \$75,000 total per project for a 1-2 year grant support aimed at discovering and developing treatments, cures and technologies benefiting those with Prader-Willi syndrome.

The current focus of PWSA (USA) research is supporting projects that have the potential for immediate and high impact for the PWS community, thus will support research-based translational grants or those showing high promise for translating basic biomedical knowledge to clinical

application. The goal is to fast-track better treatment for the syndrome.

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; thus the following topics will be the focus area for grants accepted in 2015. For this year, research in these areas only will be accepted for this RFA:

- finding solutions to dealing with gastroparesis in PWS
- sleep issues in PWS and how it plays a role in behavior
- dealing with an aging population in PWS
- psychotropic medications - what works and doesn't work with PWS

- pulmonary embolus – the cause of 7% of PWS deaths [PWSA (USA) 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

### Proposal Submission:

Visit the Research section of the website for RFA guidelines: <http://www.pwsausa.org/get-information/researcher/funded-research/research-funding-opportunities> ■

## Dr. Moris Angulo The man with a big heart

The approximately 400 families who take their children that have Prader-Willi syndrome (PWS) to Dr. Moris Angulo know firsthand of his great love for our children and adults with the syndrome. They are his favorite patients, and when he walks down the hall at a New York state chapter conference, Dr. Angulo is like a rock star with children and adults running up to him with their arms out for a big hug. Besides running a very busy clinic, Dr. Angulo has support groups for the parents and hosts a big holiday party for the children and adults with PWS each year.

What most people do not know is that Dr. Angulo's incredible support goes far beyond New York. He helps families from other states in the USA, and families from other countries, especially Spanish-speaking countries. Having grown up poor in small town (El Tránsito) of El Salvador, Dr. Angulo has never forgotten what it feels like to be in desperate need. There were people

that helped him so that he could go on and get his degrees both in genetics and endocrinology – thus he has paid it forward a thousand times over. Dr. Angulo has paid his own expenses to travel to educate parents and physicians in countries such as Cuba, Honduras, Mexico, Chile, and of course El Salvador. He also helps many, many families and physicians via email, and has even hosted some families coming from other countries in his own home. Dr. Angulo has been able to obtain essential medications at times for people in developing countries, and recently, after seeing the only outdated microscope in the entire hospital in Honduras, he was able to convince his own hospital (Winthrop University) to donate a microscope, which he personally delivered.

When I asked Dr. Angulo recently if he ever plans to retire, he said, “*No, not as long as I love my work – and I specially enjoy working with my Pee-Wee's.*” (His affectionate name for the children with PWS) We both spoke recently at the Albany hospital and New York chapter

conference. The evening of the gala, watching all of the children and adults with PWS dancing, I said to Moris, “*Look what a difference you have made in their lives!*” Most of us want to do good in this world, but Dr. Angulo has put that “want” into action and has done good around the world. ■

*Janalee Heinemann*  
IPWSO Vice-President



*Dr. Moris Angulo with Sophia  
(daughter of Yinna Ng)  
at NY conference.*

## PWSA (USA) Medical and Research View – Making a Difference!

40th Flashback, continued from page 1

on “Growth Hormone Treatment and PWS”

- DNA methylation genetic testing and validation in Prader-Willi syndrome along with further diagnostic testing approaches proposed

1997

### Conference in Orlando, FL

- 1997 PWSA (USA) office moves to Sarasota, Florida
- Janalee Heinemann becomes Executive Director\*\*
- Methylation specific PCR testing for Prader-Willi syndrome
- Imprinting mutations identified
- Behavioral findings further characterized in clinical studies in PWS

1998

### Conference in Columbus, Ohio

- Jerry Park steps down from the PWSA (USA) presidency, and Barb Dorn steps up to the role
- A major growth hormone study on children with PWS is published (Aaron Carrel, M.D.\*, Susan Myers, M.D.\* and David Allen, M.D., and Barb Whitman, PhD\*)
- Dr. Martin Ritzen from Sweden reports on the European Growth Hormone Trial
- PWSA (USA) receives a lot of publicity due to being on the national Leeza Gibbons Show
- Janalee Heinemann testifies in a PWS case that received publicity around the world.
- PWSA (USA) Scientific Advisory Board creates a policy statement: Adults With PWS and Decisions Regarding Least Restrictive

Environment and the Right To Eat

- Animal (mouse) models for PWS developed
- Further characterization of psychosis in PWS

1999

### Conference in San Diego, CA

- PWSA (USA) Scientific Advisory Board member, Dr. Philip Lee\*, organizes the first PWS Growth Hormone Symposium held at the conference
- Jim Kane steps down as PWSA (USA) board chair and Ken Smith steps up
- Woman with PWS gives birth

2000

### FDA approves growth hormone for Prader-Willi syndrome

Thanks to Dr. Barb Lippe from Pharmacia, plus years of advocacy by PWSA (USA) and its advisory board members

2000

### Conference in Pittsburgh, PA PWSA (USA) 25th Anniversary celebration

- David Wyatt, with 37 years of experience as a retired hospital chaplain instructor, begins volunteering and supporting the non-medical PWS crises as PWSA (USA) as 1st PWSA (USA)'s crisis counselor
- The PWSA (USA) Clinical Advisory Board is created
- Concerns raised about central adrenal insufficiency in PWS
- Intellectual characteristics compared in PWS with those having the deletion or maternal disomy genetic forms

\*All are past or current members of PWSA (USA) advisory boards

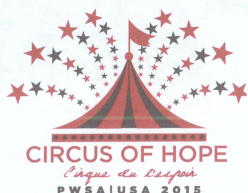
\*\* In the November 1997 newsletter, Janalee wrote: *It never ceases to amaze me how life can take so many turns down unexpected paths. It may not be the path that we thought we were going to take but is one that leads us to the place we should be at that point in time. When Al and I moved to Sarasota after so many years of being enmeshed with the syndrome on a personal, state, and national level, I think we were secretly relieved to “get away from it all.” The national conference got us re-involved in spite of ourselves, and getting to know the Florida chapter members, we begin to realize that whether it’s St. Louis, Florida, or another country, this is “family.” Within our world of Prader-Willi syndrome, there is a deep bond of love that goes beyond the typical relationship. Now, when I pick up the phone and hear the voice of a new parent looking for someone to hear their grief and give them support, or an “old” parent looking for an understanding heart, I know I have come home.* ■



2000 Staff from the Children's Institute



2000 Conference L to R: Frank Moss, Maria, Silva, Janalee Heinemann, Lota Mitchell



## Share Your Expertise - CALL FOR PRESENTATIONS

Prader-Willi Syndrome Association (USA) Provider's Day Conference - Thurs., Nov. 5, 2015

Proposals may be submitted in hard copy to

Mary K. Ziccardi, C/O REM-Ohio, 9775 Rockside Road, Suite 200, Valley View, Ohio 44125

or e-mail form to: [Mary.Ziccardi@thementornetwork.com](mailto:Mary.Ziccardi@thementornetwork.com)

**SUBMISSION DEADLINE: BY 5:00PM ET AUGUST 3, 2015**



**RUN!** IPWSO's Professional Provider and Caregiver Board (PPCB) is pleased to offer all professional providers a day of international learning and sharing!

Wednesday, November 4, the PPCB is hosting an **International Caregiver's Conference**. This very first U.S. opportunity is one day prior to PWSA (USA)'s Provider and General Conferences.

In addition to the Pam Eisen Memorial Lecture (given this year by Janalee Heinemann) and a scientific overview, the day will be spent learning and interacting in facilitated workgroups with colleagues from around the world. Confirmed topics include behavior management, PWS basics, communication, supporting, empowering and training staff, sensory intergration and social competencies.

Plan to arrive one day early and join your international peers to discuss the unique challenges of supporting people with PWS. You will be amazed at the similarities and differences across the globe. Participate and learn with providers and caregivers from all over the world! Contact us to reserve your spot today!

Your registration fee for this day includes a continental breakfast, lunch, an evening dinner party and all supplies and materials need to have an amazing day!

**REGISTER EARLY! SPACE IS LIMITED! Visit: <http://www.pwsausa.org/conference>**

**\*Please note: Provider's and Caregiver's sessions on Wednesday and Thursday are open ONLY to non-related providers and caregivers. ■**

**Step right up, Step right up...  
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



**Early Bird Registration Now Open: [www.pwsausa.org](http://www.pwsausa.org)  
Check out topics and speakers!**

**Research Updates in PWS with Q&A**

*moderated by Dr. Merlin Butler*

- **Oxytocin address** by Dr. Sue Carter
- **Swallowing study** by Dr. Roxann Gross
- **Panel Q&A:** Dr. Jennifer Miller, Dr. Ann Scheimann, Dr. John Cassidy will be available to answer questions.

**Overview of Clinical Trials with Q&A**

*moderated by Dr. Jennifer Miller*

Dr. Miller, Dr. Merlin Butler, Dr. Shawn McCandless (*with reps from the four pharmaceutical company trials underway*) will provide updates in the process and findings.

**Workshops**

- **GI Issues in PWS**, Dr. Ann Scheimann
- **Cardio in PWS**, Dr. Jim Loker
- **Advocating for the Person with PWS in the Emergency Room**, Dr. Dan Beaver
- **A Magic Pill: What Works, What Doesn't, and Why?**, Dr. Jan Forster
- **The PWS Behavior Prototype: Through the Lens of the Polyvagal Theory**, Dr. Steven Porges
- **Wills, Trusts, and Financial Planning**, Steve Leightman
- **Training of Social Competence (Emotional Change of Perspective)**, Dr. Norbert Hödebeck-Stuntebeck
- **What's Food Got to do with It?**, Lauren Martin
- **Establishing Medical Clinics for PWS**, Lisa Thornton & Panel
- **Music for Expression and Growth**, Ellyn Thornton

**Workshops for parents/caregivers by age: Infants and toddlers with PWS:**

- **Managing Behaviors**, Lisa Graziano
- **Speech, Language, and Oral Motor Skill Development**, Katie Hartman
- **GH & other medical considerations (Age 0-12)**, Dr. Jennifer Miller
- **Parenting Success with Less Stress**, Kevin Jackson
- **Therapeutic Interventions**, Janice Agarwal

*Schedule subject to change*



**Children with PWS**

- **All About Schools**, Evan Farrar & SEAB Panel
- **Parenting Tips to Get Behavior on Track**, Kevin Jackson

- **Raising Your Child with PWS, Beyond Protection to Preparation**, Amy McDougall and Jonathan Smith
- **Surviving the Three Ring Circus: Behavior Management Skills for Parents and Caregivers**, Dr. Linda Gourash
- **Teenagers with PWS**
- **Juggling New Issues - Transition Planning**, Kate Beaver and Barb Dorn
- **Psychiatric and Behavior**, Dr. John Cassidy
- **Sexuality and PWS**, Janalee Heinemann and B. J. Goff
- **GH and other medical considerations (Teens-Adults)**, Dr. Jennifer Miller
- **Adults with PWS**
- **What to Do After 22?**, Michelle Holbrook and Lisa Thornton
- **Supported Living**, Mary K Ziccardi & Panel
- **Prader-Willi Syndrome- Adulthood 101**, Elizabeth Roof

*Sharing sessions for parents and grandparents offer plenty of networking opportunities, as well as the General Membership & Chapter Luncheon on Saturday.*



*Explore exhibitor booths and the PWSA (USA) Store for the latest information, publications and specialty items. Thursday evening Meet and Greet, and Friday night Gala Banquet & Dance (highlighted by a performance by YIP/YAP participants) events are great fun for all.*

## Executive Director View

By Ken Smith

PWSA (USA) has TWO exciting announcements about services offered to our families!

We are delighted to announce our **newly revised New Parent Mentoring Program**.

When parents receive the diagnosis of Prader-Willi syndrome, it is devastating. Often, in the beginning there is a period of grieving for the perfect child that was eagerly anticipated, and then almost a feeling of relief to know that having the diagnosis takes the guesswork out of the equation. It means that there is – HOPE – and a strong community that is right there with you to empower you with information, guidance and support. This is also part of the process; at PWSA (USA) we have an extensive collection of educational literature, counseling, research and, especially for new parents, our parent mentoring program.

Our **New Parent Mentoring Program** is an extension of our Family Support Program and will include two new positions: Lori Moline as New Parent Support Specialist and Diane Seely as New Parent Support Coordinator. Lori and Diane are committed to ensuring that all newly diagnosed families are contacted within a 24-48 hour period and to provide them with support and up-to-date material in our **Package of Hope** – which we have been providing to families for well over the last decade. In addition, they will pair new parents with a mentor; each of our parent mentors are selected with the family's specific needs in mind to guide them throughout the child's lifetime. Lori and Diane will be the bridge between our parent mentors and our families by supporting mentors, creating and populating three sharing and support Facebook groups – one for parents of birth to

three, one for parents of three to five, and one for parent mentors' support.

Both Diane and Lori are experienced, knowledgeable, sensitive women who are full of energy and optimism about the future of our children. Thank you both for taking on these important jobs! *See their pictures and stories below.*

The second exciting announcement is that an **iPhone app for PWSA (USA)** will be available for download to our community this summer! In today's world, the majority of the population uses their cell phone to do pretty much everything. We stand by our beliefs in that we **Save and Transform Lives** by making our valuable information accessible via our app on your phone. You will have the freedom to browse any and all information that is already on our website with the ease of using your phone. Having information readily available during times of need is so important! We have made sure that you will have quick access to that information with our user friendly interface. When you open our app, you will see an easy-to-navigate menu with topics to thumb through such as medical, research, family support, new diagnosis, local chapter information, and many more. Plus, you will be able to update your membership with PWSA (USA) through the app and make donations to continue helping us provide the vital, needed services to the PWS community.

*Our sincerest gratitude to Kim and Rick Settles for their generous gift in memory of their son Patrick, making this all possible. App coming this summer!* ■



**Diane Seely** says: It is an honor and a pleasure to serve our community. Prior to my position at PWSA (USA) as New

Parent Support Coordinator, I served on the board of the PWSA (USA) Ohio Chapter for two years. In 2011, my husband Rob and I established *Reagan's Reach*, a non-profit in honor of our son. Rob has also been a Board Member for almost two years for PWSA (USA). I am a mother of five children; my first four children are grown and live outside of the home.

My youngest daughter just graduated from Bowling Green State University and my youngest boy, Reagan, is 12 years old. Reagan was diagnosed with PWS at four weeks old. He is absolutely the light of my life! *(See Reagan's picture in From the Home Front on the next page.)*



**Lori Moline** says: Many years ago I left a healthcare workplace to become a stay-at-home, homeschooling mom, and have spent most of the last 25+ years educating and caring for my very large, active family of six boys

and two girls. Thirteen years ago, we were blessed with a beautiful, floppy, quiet little baby girl, our daughter Sophie Pearl with PWS, the youngest of the crew, and I was introduced to the world of special needs parenting and Prader-Willi syndrome. I was concerned about her profound hypotonia at birth and sought out a neurologist at the Mayo Clinic; she was diagnosed there when she was about seven weeks old. I began researching like mad, staying up late and poring over any scrap of information that I could find online. I ran into PWSA (USA) on one of those info-binges and called; they put me in contact with Carolyn Loker. Carolyn and I only spoke once when Sophie was a baby,

**continued on page 7**

## Executive Director View

Moline, from page 6

but she was so encouraging and so informative. I have always held what she did for me that day so close to my heart. As time passed, children grew, and my life began to simplify, I reached out to help my fellow PWS parents as the lead admin on the Prader-Willi Syndrome Open Forum Facebook group, where I have been blessed to serve the PWS community for the past three years. What a thrill it is now to work with Carolyn and Diane and everyone else at PWSA (USA), facilitating the same kind of support and encouragement for our new parents that meant so much to me all those years ago!! I believe all of these life experiences and more have led me to be uniquely suited for this exciting new position with PWSA (USA). I am honored to be a part of re-inventing the Parent Mentoring Program in a fresh, new format, and reaching out in new ways to bring care and support to our newly diagnosed families, and their precious children! ■

**The 2015 Online Giving Challenge will take place on September 1st this year! Many exciting opportunities will be announced as we get closer- be sure to keep an eye out for any updates. The challenge is only open for 24 hours so get ready! Matching funds, prize money and many more chances to make a big difference for PWS will be available. Stay tuned!**

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](http://www.pwsausa.org)

## From the Home Front

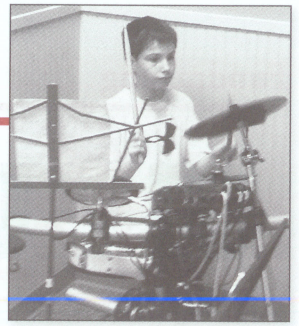
By Diane Seely, mother to Reagan

If you would have asked me 12 years ago what I thought the future would hold for my son Reagan; I might have told you that he will struggle with the most basic milestones. That his accomplishments will be few and far between. That was when he was just 4 pounds and in the NICU. I have found that to be further from the truth; his future is more his to decide than mine or his diagnosis. He struggles but not without triumphs. He met his milestones on his own terms. He is a fighter and goes after what he wants; I could not be more proud. When I think back to my pregnancy, I had visions of my son playing little league baseball. However, this boy has his own dreams.

This is proof that PWS cannot steal dreams from our children.

A picture is worth a thousand words, but I wish you could hear him playing this song. It's "Stand" by Rascal Flatts. ■

*'Cause when push comes to shove  
You taste what you're made of  
You might bend till you break  
'Cause it's all you can take  
On your knees, you look up  
Decide you've had enough  
You get mad, you get strong  
Wipe your hands, shake it off  
Then you stand, then you stand*



## NEW! School Handout from PWSA (USA) Adults with PWS Advisory Board

During PWSA (USA)'s Adults with PWS Advisory Board January meeting, we spent time with the group discussing their school experiences. The conversation with this bright and engaging group was fascinating and informative. We celebrated successes at school and also the challenges they faced. Many of those challenges still exist for students with PWS today. Because what Advisory Board members had to say is so important, and very helpful information for school professionals, with their permission we created a brand new handout called, "Supporting Students with PWS: Information and Advice for School Professionals" from the PWSA (USA) Adults with PWS Advisory Board. Topics covered include:

- What works best for students with PWS
- What kind of accommodations can help
- What school professionals should know to better serve students with PWS

This is the first handout for schools that contains information exclusively from the perspective of people who've lived the experience of being students with PWS. Therefore, it is an important contribution to literature we provide schools because it is based on the first-hand experience of Advisory Board members. We recommend it to parents and school professionals. You can obtain a copy of the handout in two ways:

If you are subscribed to the PWSA (USA) school e-letter, "School Times," it will be included in our next issue. To subscribe to "School Times" e-mail me at [efarrar@pwsausa.org](mailto:efarrar@pwsausa.org) **Note: We encourage all parents of school age children with PWS, and school professionals who serve them, to subscribe to "School Times" which is the only publication dedicated exclusively to PWS school-related issues.**

You may also e-mail me directly to receive a copy. To request a copy by mail, contact our office at 800-926-4797.

I want to say a very special thanks to the Advisory Board members who provided information for this handout: Shawn Cooper, Brooke Fuller, Conor Heybach, Kate Kane, Lauren Lange, and Abbott Philson. Without their willingness to share openly and honestly about their school experiences, this important new resource would not be available to help a new generation of students with PWS. ■

~ Evan Farrar, M.A., PWSA (USA) Family Support Counselor



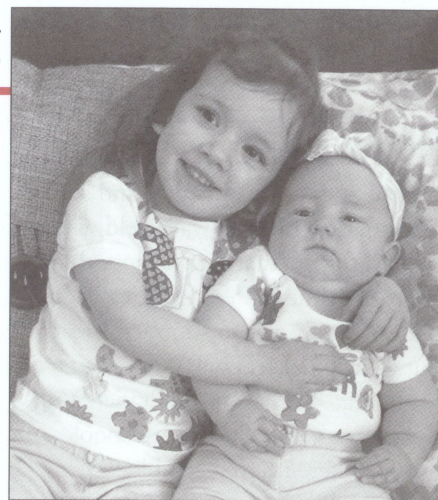
## eWalk Family Spotlight

By Wendy Barron, Hopewell Junction, NY

Alanna Jo Barron came into our world on 12/20/14 at 11:11 pm. Instantly, we knew something wasn't "right". Alanna was incredibly floppy and unable to feed. The next morning the decision was made to move her to the NICU where an NG tube was placed. Our entire world came crashing down. A geneticist was consulted and he immediately thought Prader-Willi syndrome. At just 2.5 weeks old, the same day of her Mic-key button surgery, we were given the confirmation of her diagnosis. Even being in the medical field I had never heard of PWS. Staying off of the Internet was impossible; everything seemed so doom and gloom. I received a call shortly after we were given our diagnosis from a friend I had grown up with. Their baby girl had just been diagnosed with PWS as well. Stunned that they both had the same rare syndrome, we found strength and security in each other. We are so grateful in a really strange way that our families will always have each other.

Once we both signed up with PWSA (USA), so many doors have opened! Social media support groups, parent contacts, webinars, and tons of information that is much more accurate than what is on the Internet. Finding a treatment, and potentially a cure, is a huge driving force and continues to give us hope! While we bounce from doctor to doctor with appointments 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! I have no doubt our community will find treatment options to help our kids!

Miss Alanna continues to do well despite her battles! She is becoming more active everyday and trying hard to learn to bottle feed. She is such a sweet, happy baby! This road will be tough but we are having more good days than bad now. Watching Alanna, now 4 months old, with her big sister Kenley, who is almost 3, is such a blessing. Kenley gives her big hugs and says, "I love my Alanna". What could be better than that?" ■



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

Want to be a part of the new and exciting virtual walk fundraiser eWalk? Check it out! It's been amazing to see our proactive community registering for eWalk, thus raising awareness/money for PWS. If you haven't registered for your own eWalk fundraising page yet, you still have time and be part of eWalk! We encourage all to join this movement.

To register and create your own easy to set up eWalk page, please go to [www.ewalk4pwsa.org](http://www.ewalk4pwsa.org). Contact Donny Moore if you have questions: 941-487-6729 or at [dmoore@pwsausa.org](mailto:dmoore@pwsausa.org). ■

## Michigan OTM Success is Shared

The Michigan Chapter hosted their OTM Walk on May 9. Not only reaching their 2015 goal of \$7,000, they more than DOUBLED their income from last year by bringing in over \$16,000! How? Read on.

PWSA Michigan President Dewey Graves wrote: "Leanne and I were speaking on the phone recently. She commented that Michigan did very well this year. We surpassed our goal easily by a large margin. I agreed we had a great year. Leanne asked how we did it. I started thinking about: the Chapter Board- wondering what we did or who could I point to who had a great impact on the walk success. The board meetings, planning and strategizing over the next walk! But what pushed the walk over the top?"

Was it the walk itself? Held at the beautiful Cascade Park in Jackson County, with its beautiful pavilion, ample parking, paved walkways with lots of awareness to be had. Maybe it was the great sack lunch...turkey dogs, chips, sliced apples,

and snack! Or was it the T-Shirt that every walker got, or the backpack and ink pen? How about the obstacle course we do for the kids or the medals handed out after the event? The only way to explain it: the people themselves! Our FirstGiving Page (online donation platform) was up well before the walk. Everyone joined together, created teams on the page, and started fundraising efforts. So many different families and individuals became involved! We had families host Awareness fundraising parties through their FirstGiving pages. Others sent emails to family & friends asking for a small donation. Individuals called ME and asked when the donation page would open so they can make their donation!

So how did Michigan surpass this year's goal? It was easy; Michiganders are generous, sincere, caring, thoughtful and concerned about the awareness of Prader-Willi syndrome and the well-being of those affected by it. I want to THANK YOU all for your support!" ■

Dewey W. Graves Jr., PWSA-MI President



### Meet the Candidates: PWSA (USA) 2015-2018 Board of Directors

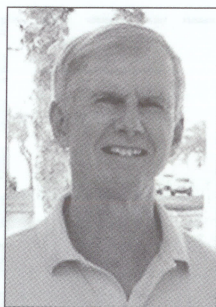


**Dr. Leon D. Caldwell**, proud father of Kahlil, age 11, diagnosed with PWS at age 7, is interested in broadening the accessibility of PWSA (USA) to culturally diverse families and promoting racial/ethnic inclusion in PWS research. He says, "The PWSA board is an excellent match for my personal and professional interests in supporting a viable and inclusive advocacy

organization."

Currently a Senior Research Director at ThinkShift, a Washington, D.C. social innovation collaborative of the DeBruce Foundation, Leon has held positions as Senior Research Associate at The Annie E. Casey Foundation in Baltimore, MD.; founding Director of the Center for the Advancement of Youth Development ([www.advancingyouth.org](http://www.advancingyouth.org)) housed at Rhodes College; and Lead Evaluator of the JustCare Family Network, a mental health system of care implementation in Shelby County, TN. Leon has developed several national and local initiatives aimed at addressing the needs of vulnerable populations and community capacity building for finding solutions to challenges. In Memphis he facilitated two National Think Tanks for African-American Progress (2008, 2009), launched the Memphis Area Fatherhood Coalition (MAF-C) with community partners, and conducted over 100 empowerment evaluation trainings, teacher in-services, parent and youth focused workshops. Caldwell's change theory is that by building the capacity of youth service providers, more effective youth and family interventions to better serve youth can be created.

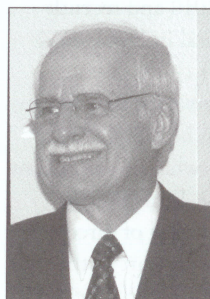
Leon has focused much of his community-based participatory research efforts at improving the quality and outcomes of African-American families, particularly men and boys. He earned a doctorate in Counseling Psychology from Penn State and a Master's Degree in Education and Bachelor's Degree in Economics from Lehigh University. Prior to moving to Memphis, he was an Associate Professor of Educational Psychology at the University of Nebraska, Lincoln, where he founded the Family Potential Center and the Educational Psychology in Ghana Study Abroad Program. He has taught at the University of Memphis; the University of California, Irvine; North Star High School in Lincoln, NE; and the University of Ghana Winneba. ■



**Thomas Conway, Esq., Albany, New York** – Mr. Conway is a retired attorney who spent his legal career working in the public interest. His most recent position before retiring was General Counsel to the New York State Department of Health. Prior to joining the Department of Health, Mr. Conway served for 20 years as an Assistant Attorney General in the Bureau of Consumer Frauds and Protection. He also

worked as a staff attorney in the Harlem Neighborhood Office of the Civil Division of the Legal Aid Society in New York City, and as Director of Litigation for the Public Utility Law Project. Mr.

Conway's grandchild was diagnosed with PWS at birth, and he has volunteered at PWSA (USA) national headquarters for the past two winters. He has worked on several projects for the Association, including as an editor of the recently published book, *Medical Wisdom Through the Ages*. If elected to the Board, Mr. Conway hopes to concentrate on advocacy issues and work closely with the Special Education Advisory Board. ■



**James L. Koerber** - Jim and his wife Rita have four adult children and five grandchildren living in California and New Jersey. Their youngest daughter Alison has Prader-Willi syndrome. She is 38 and lives in a care home in Chula Vista, CA. Jim got involved with the Prader-Willi Syndrome Association (PWSA) shortly after Alison was diagnosed at age nine. He served on the Board of Directors and as President of the

Prader-Willi California Foundation. He was elected to the PWSA (USA) National Board in 1997, but had to resign when he and Rita moved to Indonesia in 1998.

Jim earned a B.S. in mechanical engineering technology from Purdue University and an MBA in management from Golden Gate University. On July 1, 2007, he retired from Chevron Corporation after almost 41 years and moved from London, England to their 80-acre farm in Corydon, Indiana. During his career at Chevron, he held a number of technical and management positions in the U.S. as well as international. Even with his work and travel, he maintained a strong connection with the Prader-Willi Syndrome Association. Since his retirement, he spends more time being a grandfather, showing his restored 1926 Model T Ford, lowering his golf handicap, and participating in community activities.

One of his first community activities after retirement was to provide leadership for the re-establishing of the PWSA Chapter in Indiana. He served as President from 2008-13. He also served as Chairperson of the Catholic Community Pastoral Council from 2008-13. He is currently serving as the Chairperson of the Society of St. Vincent de Paul and is an active member of the Entrepreneurial Committee of Main Street Corydon, the Chevron Retirees Association and the Flaget Alumni Association.

His broad leadership experience and his desire to make PWSA (USA) the best organization it can be to serve those affected by Prader-Willi syndrome, are the reasons Jim serves on the board. ■



**Thomas D. Noonan, Fort Worth, TX** – Tom is a Director of Business Development at Rimkus Consulting Group. He earned a B.S. in Business Administration in 1984 from Bowling Green State University. He was previously a Board Member for Haag Engineering and is currently a

continued on page 10

## Organization News

Candidates, continued from page 9

board member and the President of the Texas Chapter of the Prader-Willi Syndrome Association. He and his wife Tracey, an interior designer, have been married for 6 years; his step-son, Grant, is 18 years old and was diagnosed with PWS at age three (UPD). Grant, currently living at home, recently graduated from Keller High School and will be attending a transition program for the next three years through Keller ISD. Grant was admitted to The Children's Institute in Pittsburgh back in 2010 and recently was admitted to Healthbridge Children's Hospital in Houston. Tom has wanted to be involved with a children's charity for as long as he can remember, but he wanted to be involved in a charity where his involvement made a difference. When he met his wife Tracey and learned about PWS, he knew this is what he was meant to do. Tom believes with his experience with the Texas Prader-Willi Association, experience being on another board of directors, being a step-parent to a child with PWS, and being part of the treatments provided at two separate PWS specific centers, he feels he would be a good asset to the Prader-Willi Syndrome Association (USA) Board of Directors. ■



**Marguerite Rupnow** has been in the human services field and Oconomowoc Residential Programs since 1987. Involved in children's programming for eight years and over seven years working with adults who were dually diagnosed, Marguerite assumed the position as Director of Operations for Prader-Willi Homes of Oconomowoc in 2002. With 28 years of management experience, Marguerite continues to be involved in

the development of program, group home, leadership and staff training. Marguerite holds a M.B.A. with concentration in Health Care from Concordia University of Wisconsin.

As the agency director of the largest organization providing community-based living for individuals with PWS in the U.S., she has unique insight into the variety of challenges faced by the families and individuals living with PWS across the spectrum. She understands the complexities of large-scale projects, strategic planning, teamwork, leadership, business acumen, and work in a variety of situations and settings. On a personal level she appreciates the struggles a parent with a child with special needs

is faced with on a daily basis. Her affiliations and experiences are with PWSA-WI, PWSA (USA), IPWSO, numerous organizations and various church and school committees.

Marguerite has participated in organizing the YAP program for the last two national conferences and the upcoming conference in November of 2015, was on the committee for organizing the 2008 PWSA (USA) conference in WI, and has been a speaker at provider conferences locally, nationally and internationally since 2004. She was involved in writing the International Best Practices book for supporting individuals with PWS.

Having worked with individuals with PWS for almost 30 years, and solely since 2002, she is amazed, honored and blessed to work with this syndrome. She lives in the area with her husband and sons Jabin and Jonah. She enjoys reading, gardening, camping and being a soccer mom. ■



**Michelle M. Torbert** - Michelle and her husband Tommy have been married for 29 years and live in Homestead, FL. They have 4 "boys" ranging from 20-25 years of age, and the princess Leslie, who has Prader-Willi syndrome. Leslie will be 18 in August.

From 2007-2015 Michelle served as president of the PWSA (USA) Florida Chapter and is currently a member of their board of directors. She has been a member of PWSA (USA)'s board of directors since 2009 and is currently Board Chair. Michelle also serves as co-chair for the PWSA (USA) National Conferences and as a Parent Mentor.

Michelle and her husband established the "Casting for a Cause" fishing tournament in 2008 and have currently raised over \$700,000 for PWSA (USA) and the Florida chapter. The tournament grows every year and always includes Leslie's participation. She loves to fish and fishes with her daddy.

Prior to having children, Michelle worked as a police officer for the City of Homestead from 1981-1991. She and her husband then formed Torbert Produce, Inc., and the family is now in the farming and produce business. Michelle has also served on many local community boards including the Red Cross, Homestead Hospital Pineapple Gala, Little Angels Foundation, Palmer Trinity School and others. She is also active in her church.

Michelle would like to serve another term on the PWSA (USA) board of directors and continue to help and serve the families who have children with Prader-Willi syndrome. ■

Clip along dotted line and mail

### OFFICIAL BALLOT Voting Instructions: See page 11

Leon Caldwell, Ph.D.    Tom Conway    Jim Koerber    Tom Noonan    Marguerite Rupnow    Michelle Torbert

Corrections to the 2014 Annual Membership Meeting Minutes: \_\_\_\_\_

No Corrections Necessary (if neither box is checked, we will assume you have no corrections to the minutes)

## PWSA (USA) 2015-2018 Board of Directors Approval of 2014 Annual Membership Meeting Minutes

### Voting Instructions:

1. Review the candidates' statements printed on the Slate of Candidates. Read the 2014 Annual Membership Meeting Minutes.
2. Cast your vote on the Official Ballot **located on the bottom of page 10**. Note any corrections necessary to the Annual Membership Meeting Minutes. Clip out and insert the ballot into the Official Ballot Envelope.
3. Print and sign your name on the Official Ballot Envelope. Affix postage. Mail it to PWSA (USA) postmarked no later than August 21, 2015.
4. If you receive *The Gathered View* only in an electronic form and were not provided with an Official Ballot Envelope, **please mail your ballot to: Julie Doherty, Secretary, PWSA (USA) 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238-5471**. In the return address portion of the envelope, print your name and address and the following statement: I am/We are a PWSA (USA) Member in Good Standing Eligible to Vote. Place your signature below this statement.  
**Deadlines:** The deadline for voting is August 21, 2015. Ballots postmarked after August 21 will not be counted.  
**Confidentiality:** Your vote will be kept confidential. PWSA (USA) staff will verify voter eligibility and separate the Official Ballot from the Ballot Envelope before the Ballots are tallied.

**Voting Criteria:** Voting members must be Members in Good Standing with PWSA (USA). Membership dues must be current and paid in full or a dues waiver granted.

**Member Types Eligible to Vote:** Each membership type, whether individual, family or professional, is entitled to one vote.

Cast your vote for the 2015-2018 Board of Directors. Vote for a maximum of six (6) of the candidates listed on ballot at bottom of page 10. ■

## DRAFT- PWSA (USA) Telephonic General Membership Meeting

### Monday, October 27, 2014

Michelle Torbert, PWSA (USA) Board Chairperson, called the meeting to order at 8:01 p.m.

Outgoing board members, Michelle Holbrook and David Agarwal, were thanked for their service. Newly elected board members, Denise Westenfield and Tammie Penta, as well as re-elected board member Dan Driscoll were welcomed.

**Conference 2015: Wednesday, November 4th**, through Saturday, November 7th, 2015 at the Lake Buena Vista Palace in Orlando, Florida. Plans are well underway.

**Executive Director:** Ken Smith noted he is one month shy of completing his first year as ED. It has been a challenging and rewarding year. He thanked the members of the board, but especially the executive committee members, for their support. Almost 1,200 calls have been received this year on our family support line from individuals removed from school, recently incarcerated, or in severe medical crisis. All states are represented in these calls, including Alaska and

Hawaii. Sixty percent of our staff time and approximately \$44,000 has been spent on family support and service, including transportation to The Children's Institute and the Houston facility. Approximately 119 new diagnoses were received, most under the age of one, including international families. That is roughly 25 more than this time last year. The New Parent Mentoring program, through Cindy Beles, welcomes these new families, sends them the Packet of Hope and connects them to their local state chapter. Rob and Diane Seely are working with the mentoring program, as well as Dr. Jennifer Miller. Ken introduced Jack Hannings, new Director of Fund Development, whose first day was today. He has been employed in nonprofit fundraising for over 35 years. Ben Karp, Communications Specialist, recently resigned, to do volunteer work in south Amrrica. Fundraising is far below what it has been. Jack will be addressing that. Ken noted the board has several very active committees, the most active being the chapter relations

committee headed by Crystal Boser. They had a productive and meaningful meeting two weeks ago in Orlando, attended by state leaders in person and via the Internet. We hope this will be the beginning of strengthening the relationship with our chapters. Ken invited everyone to reach out to him by phone or email with any questions or concerns. The new web site was launched four months ago and is a work in progress. Online membership management and other tools will be available as we move forward. The Angel Fund campaign will begin in the next couple of weeks with electronic and postal mailings.

**Research Committee:** Janalee Heinemann advised the grants have just been reviewed and a decision on which to fund should be available by the end of the year. The newest and biggest developments involve the clinical drug trials and our work with the FDA. It's the first time in the history of the organization that so many pharmaceutical companies are interested in the PWS population

continued on page 12

## Organization News

Meeting, continued from page 11

for drug studies. Drug companies are seeing that PWS is a window to the obese population. Zafgen is the strongest moving trial right now and a couple other medications have been approved by FDA to deal with weight and appetite and some behaviors as well. This is a huge opportunity we have not had in the past. Nondrug alternatives are also in the works. Everyone is encouraged to receive The Gathered View because so much of this information is found there. Physicians in Saudi Arabia and Italy ALLEGEDLY have had success with bariatric surgery. Currently our physicians are still opposed to it since there are too many risks, and the weight comes back. This topic, among others, will be discussed next week at the Obesity Conference in Boston. Gene therapy is a long way off and may not be useful to our population

since PWS is not a single gene disorder. The researchers are reporting some dramatic results on the swallowing study and that will be in our upcoming GV. Dr. Scheimann's study, sponsored by PWSA, concerning gastroparesis and constipation is yielding much valuable information. The world of genetics is exploding. Noninvasive prenatal testing is months away from being available in the US, and PWS will be included as one of those disorders identified in the testing. It was noted that no parent is ever denied membership in the association and receipt of the newsletter based on an inability to pay.

**Finance Committee:** Steve Leightman reported our financial situation is strong, but we also have challenges. Membership has grown significantly over the years, as Ken noted, and this has caused a strain on resources to serve the increasing

number of families. We currently have a deficit, but have funds in reserve to cover this. A myth has been circulating that most of the funds we raise is used for overhead and personnel costs. In actuality, between 75% and 80% of every dollar raised goes to provide programs and services to our families. That is thanks to the dedicated and hard working office staff that work diligently to control costs.

Participants' phone lines were unmuted to allow for questions. Several callers identified themselves. Tammie Penta noted a training was just completed with 25 adult care facility staff in Arizona. A secondary training will take place next week.

Julie Doherty moved to adjourn the meeting, and the motion was seconded by Tammie Penta. Meeting adjourned at 8:30 p.m. ■

Respectfully submitted,  
Julie L. Doherty, Secretary

## Fundraising Congratulations!

Many thanks to our dedicated PWS community members that made the following events so successful! Your hard work and commitment to PWSA (USA) is appreciated beyond measure! Funds raised will support many different programs for those affected by PWS on a local and national level.

**Wisconsin "On The Move" May 9th Walk: \$18,500**

*Hosted by the Wisconsin chapter at Roosevelt Park*

**Michigan "On The Move" May 9th Walk: \$16,000**

*Hosted by the Michigan chapter at Cascade Falls Park*

**Minnesota May 15th Golf Scramble: \$35,000**

*Hosted by the Minnesota Chapter at Oak Glen Golf Course*

**Utah Fitness Fun-Raiser: \$21,000**

*Hosted by the Utah Chapter at Olympic Park*

**Connecticut Walk and Roll: \$43,000**

*Hosted by the Connecticut Chapter at Middletown High School*

**Illinois' I Heart Momma May 24th 5k: \$4,500**

*Hosted by the Illinois Chapter at Hickory Creek Forest Preserve*

**Hunter Lens June 6th Golf Tournament: \$20,500**

*Hosted by the Lens Family at The Back Nine Golf Club*

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](mailto:lgilliland@pwsausa.org) or 941-487-6743. ■

## iHOLA!

*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.*

iHola! 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 necesitan informacion y ayuda. Les quiero directar a [www.pwsausa.org](http://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](mailto:ninaroberto@verizon.net). ¡Hablamos pronto! ■

## Join Our Family!

**PWSA (USA) Member Benefits include:**

- 20% discount on merchandise
- Conference registration discount
- *Gathered View* newsletter
- Members only online access
- Be a part of the advocacy community

Join our family! Purchase a membership today at [www.pwsausa.org](http://www.pwsausa.org) and click on Membership

# Spotlight on Minnesota

By Andrea Glass

The PWS MN Association is as old as PWSA (USA) and coincides with the fact that the first official national office of PWSA (USA) was also in Minnesota. The first and fourth National conferences were held in MN. The 2001 National/International conference was hosted by MN with 1250 attendees.

The PWS MN chapter has continued to be very active both locally and nationally. The chapter has built a powerhouse of knowledge on PWS and has provided educational publications, videos, presentations, crisis counseling and consultations for a membership of approximately 120 individuals, families and providers.

Minnesota continues to have a strong commitment to PWSA USA. Many of the Minnesota members currently serve or have served on National boards and committees, including, Jim Gardner [past Treasurer of PWSA (USA)] and Carol Hearn [past President of PWSA (USA)]. Denise Westenfield, Treasurer of PWS MN, currently serves on the PWSA USA board. Joan Gardner is currently the PWSA (USA) parent delegate to IPWSO (International Prader-Willi Syndrome Organisation).

A primary objective of the Chapter is to connect parents with children or adults who have PWS with each other and assist them in finding appropriate resources. They have built a directory which includes the sex and year of birth people who have PWS and live in Minnesota so that interested parents can network with others who have comparable aged children. Two events are pre-planned each year, including a picnic and winter party, primarily for adults and older teens that have PWS. There has also been age specific gatherings for families with younger children.

To further help the families affected by PWS, in 1989 Jim Gardner and Neil Shapiro advocated to the state legislature for a Health and Human Services Bill that specifies service entitlements for people with PWS. The bill particularly addressed the need for adult living situations. To ensure future services, Denise Westenfield participates in the PACER Advocacy Group at the MN state capitol. PACER (Parent Advocated for Educational Rights) is a tremendous resource which we use for our families as needed. In addition, members of our association attend school or case management meetings when families ask for help.

The PWS MN has had many outreach presentations to the MN medical community over the years. The four pediatric hospitals have been provided with the new PWS textbook for their reference libraries. Both Joan Gardner and Elaine Beuchner have presented, as well as adults with the syndrome. They have also produced an educational training video for group home providers. There is an



informal sharing of physician names (based on family experience). Dissatisfaction by some families with one PWS clinic program caused a second children's hospital to build a program. There are now two sources of PWS health care professionals for children who have PWS in the State. These health professionals have been given contact information for the Chapter.

There are several good providers of group homes in the State. Laura Baker, which started as an ICMFR, has a dedicated PWS program. Oakwood, the first successful residential facility dedicated to PWS in the U.S. It lasted 20 years when in 2001 residents were moved to 3-4 person group homes in accordance with the new philosophy of HHS for "least restrictive environment". These are technically called adult foster care homes. AME Community Services has 9 PWS homes, Stepping Out had 5-6 homes, and various other agencies have one or two. The Chapter has a close relationship with the AME and Stepping Out providers who members of PWS MN and serve on the board of directors.

The Chapter has been active fundraisers for many years. The Doris Luhman golf tournament in Cokato, MN ran for five seasons. For the past four years, the Minnesota Prader-Willi Golf scramble has been organized by Kristi Rickenbach.

Current officers are: Kristi Rickenbach (President), Jim Gardner (Vice President), Denise Westenfield (Treasurer), and Erin Bale (Secretary). If you would like further information please refer to the links at <http://www.pwsausa.org/chapters/minnesota>. ■

*"The test of our progress is not whether we add more to the abundance of those who have much. It is whether we provide enough for those who have little."*

*Franklin D. Roosevelt*

*Contributed by Clint Hurdle*

## From the Home Front

### Going Back to School

By Denise Servais

Summer's end has always brought me many mixed emotions- some relief the kids are going back to school (no more hearing, "I'm bored."), anticipation about what the new school year will bring, and some sadness that my kids are getting older. However, the biggest feeling I get is anxiety, especially when it comes to dealing with Maya. Maya is my 11-year-old daughter with PWS. Maya will be going into 6th grade this year and a new school. She will be mainstreamed but will spend her core classes in an autism class. Given some of Maya's behavioral challenges, I requested the district put her into this class as the teachers are specially trained to deal with her behaviors and her unique way of learning. Plus, it is a smaller class size which Maya needs. (note: I did push for an autism label, but that is another story).

I used to drive myself crazy worrying about what the new school year will be like for Maya (and me, too!). Every year, it is a new teacher, new paraprofessionals, new staff, etc. To me, our school district appeared rather slow when it came to training and educating the staff on Maya's needs. This drove me crazy. I realized that I probably wouldn't feel so helpless until

I started to become more assertive and knowledgeable. It's not that the IEP team didn't care, but they are busy, and my child is not the only one on their caseload. In fact, as many schools around the country are making budget cuts, special education caseloads are increasing and staff is getting cut.

To alleviate some anxiety, I created a list of things to do.

A few months before the end of the school year, I request an IEP meeting before the new school year begins (even if we already had one during the school year). I do occasionally get some push back from the staff as they are busy, but it is my right to call an IEP meeting. I put everything in writing so that I have a paper trail. This will also establish a timeline that the school must follow in response to my request. I also request who I would like to attend the meeting. I contact an advocate to help me with the process. In Minnesota, we have PACER and ARC, plus advocates at no cost. Advocates vary with skill level and interpersonal skills, so if there is one that I don't feel comfortable with, I request a new one. And of course, if I find one I like, I will keep that advocate as long as I can. There are many sources of information and support like this in each state. We are all fortunate to have a strong organization in PWSA (USA)



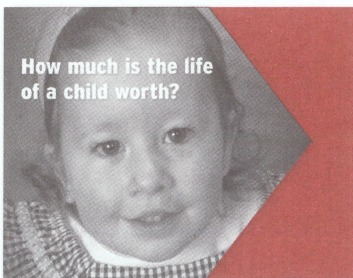
Left to right: Maya (11), Mallory (6), and Maddie (13)

that is able to assist if we need it.

I review information on special education laws so I know my rights. The more I know, the better advocate I will be. Websites like Wrightslaw.com are helpful.

I download articles from the PWSA (USA) website and make copies for each person on the IEP team (even if they have already received one in the past). If you go to PWSA (USA)'s website, under the Get Information tab, there is a tab for professionals that include therapists and school professionals. I found that some teachers read them and some don't, so I personally go over key points during the meeting. Many of Maya's IEP teams have commented on how helpful these articles are. I also hand each member a description of what I feel are Maya's abilities, strengths, weaknesses, and interests, and review it with them. ■

## Celebrate! \$155,393



As of June 15, the 2014/2015 Angel Card campaign exceeded its \$150,000 Goal!

This is a +33% increase over the 2013-14 campaign by +\$38,850

Thank you to our wonderful community for helping our families.

Activities and news within our organization, plus vital information regarding research and support, needs to be shared with our readers. We struggle with limited space in *The Gathered View*. To our donors – for whom we are eternally grateful: **THANK YOU**. We will continue to acknowledge and communicate with you on a personal level. Your support and dedication to PWSA (USA), as well as the individuals, families and all those involved with PWS that we serve, we are humbled by your gifts.

Sara Dwyer, Editor

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

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 info@pwsausa.org  
 www.pwsausa.org

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.

## Staff and Key Contacts

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### The Gathered View (ISSN 1077-9965)

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**missmayim** FOLLOWING

30.7k likes 5d

missmayim Help save the lives of children with Prader Willi Syndrome, the most common genetic cause of childhood obesity. Donate to PWS(USA)'s eWalk: [www.ewalk4pwsa.org](http://www.ewalk4pwsa.org) #ewalk4pws #pwsa

view all 233 comments

cgeracif Thank you for helping support our daughter Mackenzie! It means the world to all of us to raise awareness

kelseyroetman Thank you so much for raising awareness for PWS. Not only for that but bringing the whole PWS community together on one picture so we are able to share stories and support one another!!

Jollifwood Our daughter and family have been living with PWS for 27 years. THANK YOU with all that I am for continuing to raise awareness to our unique and complex syndrome. YOU ROCK!!!

♡ Add a comment...

dr.blalik Things like that , makes me love you more ♡

antonio.reginel.7 You are pretty

dena902 Thanks so much mayim my 17 yr old son Tony has Pws thanks for showing you care

instamatewill Love u mayim

daisy.figgy @javier2795

mooneygirls2 Love this so @kristina7876 🍷🍷

rachras I love this!

kelseyroetman Thank you raising awareness for PWS that but bringing the whole community together on or we are able to share stori one another!!

bakerman1234 Just had our walk today in support of my son Declan...great turnout!! @missmayim

Jlemar999 Awesome! @chelsea\_derrick

traci88 @\_\_bea\_\_ Is this not the most awesome celebrity post ever?!

\_\_bea\_\_ @traci88 I think I've read somewhere she is a big advocate for pws. I don't watch the show but it is amazing. I wish more celebrities focused on issues at home vs over seas. 🍷

traci88 @\_\_bea\_\_ Yes she is. She has done amazing things for the PWS community from small to massive. I Adore @missmayim

reggae4life\_ @missmayim thank you for supporting the #praderwillicommunity. I have a 5 1/2 year old daughter with PWS-UPD and words can't express what it means to know you are supporting joining in on the cause! Thank you so much!!!

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Mayim Bialik, actress from the hit comedy TV show, "The Big Bang Theory" is working with PWSA (USA) to raise awareness and donations for Prader-Willi syndrome! Outside of her acting career, Mayim has her Doctoral degree in Neuroscience and wrote her dissertation on PWS. We are grateful to Mayim as she has joined our efforts to Save and Transform Lives! Please join Mayim and our community that are helping us raise important funds for PWS. ■