

The Gathered View

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

Dear Janalee,

*A partial collection compiled and edited by
Sara Dwyer, Editor, The Gathered View*

I just wanted to personally say “farewell” to you ... Your “lifetime” contribution has been amazing – not only your education in the field and the spreading of knowledge, but most importantly the genuine love and support you have given so many people – those with PWS, their families and friends and professionals involved with PWS.

...I can only wish you and Al, Matt and all your children, the very best for the future. You are an amazing woman, Janalee, and an inspiration to us all.

God bless and thank you.

Georgina Loughnan, Australia,
IPWSO board member

May this next chapter of your life be full of joy. I always drew from your dedication. You can be very proud of what you helped to build and create.

Fondly,

Ronnie Levine, Josilyn’s grandmother

Congratulations on your retirement and thank you for all you have done to help those with PWS and their families. Everyone wants to make a difference and you did. Thank you.

Brian Wynne

*Below: PWSA (USA) Board of Directors Meeting
April 22, 2017 Orlando, Florida, and in
celebration of Janalee Heinemann*



Yes, she has meant so much for so many of us (PWSA (USA), families, parents, health care providers and givers, physicians and investigators engaged in the care, treatment and study of PWS). She will never be replaced.

Merlin Butler, M.D., Ph.D.



Merlin Butler

*Live in peace
with the knowledge of
how you have touched
the lives of millions
of people.*

~Mike Jallick

...you certainly have a place in heaven for all you have done for our children.

Tammie Penta

NO WAY you are 72 years old! You look SO young, and are very much young at heart! I want to personally thank you for all that you have done over many years to support, educate, and advocate for those with PWS and their families.

I will always consider you the rock star of PWS!

Elisabeth M. Dykens, Ph.D.

I met Janalee in 1998 when I was elected IPWSO President. Since then we worked together hard side by side to help and assist people worldwide. She taught me that the heart is not just a muscle.

Giorgio Fornasier (Italy), Past President and retired Executive Director, IPWSO

I’m still choosing to live in partial denial that you are retiring. The void will be enormous, and only those of us who’ve worked with you for many years understand the many formal/informal work roles you’ve taken on, truly understand the magnitude of that void.

What most are not aware of is the many acts of kindness and support behind the scenes you’ve offered to staff going through a difficult time. Mary K. and I talk about this dimension of your work often. It is a reflection of the good heart and soul you have which has been at the core of the generous agency PWSA (USA) has become over the years. You will be so missed...

Evan Farrar

Thank you so much for all of your hard work and dedication to PWSA (USA) and to our community ... for always reaching out to me and acknowledging my Dad’s legacy. You have no idea how much this means to me and my family.

Erin Bale

Words can’t express all that we owe you and all the thanks we have in our hearts. It is impossible to calculate the relieved suffering and lives saved because of you. I can’t even imagine 37 years of service. You are truly wonderful.

All the best in your next adventures!

Lisa Thornton



Giorgio and Janalee

Executive Director View

It's May. It's spring! We made it through the winter! So why should we all be thinking about November? Because the PWSA (USA) national convention, the biggest event of the year for the Prader-Willi community, will take place November 15-18, 2017, in Orlando.

Jackie Mallow and Michelle Torbert, our intrepid chairs who are repeating their roles from earlier conferences, are right now planning and working with their committees to bring you "Caribbean Nights – Together in Paradise".

There will be a few differences. Maybe the first one you should know about is that it is no longer to be called a "conference". Instead, it is a CONVENTION, with many smaller conferences within it, such as the Parent Conference, Chapter Leaders Conference, the Providers Conference and the Scientific Conference. After 33 years of calling it "conference," it is going to take a bit of adjustment to switch to "convention" for the 34th one.

Another difference from last time will be the hotel. The Caribe Royale isn't a big-chain hotel, and it has been so accommodating to the needs of our community – including getting the cost down to an affordable rate.

Also worth noting is that we will be able for the first time to award CME credits to medical professionals attending the Scientific Conference. Credit and many thanks go to Dr. Jim



Loker for bringing this about.

But what will be the same are the world expert speakers, addressing what Michelle Torbert calls "hot topics of interest," what affects your child today and in the future, and current research. The Parent Conference will provide those who attend with so many *FACTS* about PWS that they need as they deal with its challenges, *FUN* for all ages whether it be splashing in the hotel's beautiful pool or enjoying a tropical drink beside it, and *FRIENDS* who often understand more than your family does and with whom you may bond for a lifetime.

And what else will be the same are top-notch programs for our children with PWS, from infancy into adulthood, and their siblings. Older brothers and sisters, too, may find friends who understand their experience as none of their school friends can. Parents get to enjoy their Gala dinner while their children

enjoy their own Gala dinner. Then everyone loves all the dancing afterwards – with or without a partner.

Attending convention can truly be a top-of-the-mountain experience, a never-to-be-forgotten experience, indeed, a life-changing experience. Jackie Mallow says, "You are not alone on your island – come join us on our Caribbean Island in Orlando!" ■

"The secret ingredient to success in anything we do is to find the purpose and passion in it."

Sara Dwyer

Advocacy Alert Network Seeks Members

The **PWSA (USA) Advocacy Committee** is seeking interested persons to participate in the newly created Advocacy Alert Network. Persons who join the Network will be notified by Committee members of pending legislative issues affecting PWS and be provided with a model email or letter that can be used to contact legislators regarding the issue. In this way, we hope to increase our voice on significant legislative matters affecting the PWS community. The time commitment required for this important endeavor is not great, and anyone who is interested in becoming part of the Network is urged to join. If you are able to participate, or if you have any questions about this project, please contact Tom Conway (TConway@pwsausa.org). ■

Dear Janalee,

Please, say it isn't so.

From the time I heard those first awful words, "Your son has Prader-Willi syndrome"

There has always been you.

The strong, intelligent shaman-like woman guiding and organizing the efforts of the brave few.

And somehow everything and everyone was better.

As PWSA (USA) grew, you reached out even further assisting those from other countries,

Teaching the world that love has no borders.

I believe that we, as human beings, have an obligation to make the world better.

You, my friend, have touched the lives of thousands, if not hundreds of thousands of families.

Making their lives better, safer, fuller, hopeful, and more meaningful.

You have taught, inspired, educated and comforted.

You are, I believe, one of those earthly angels placed here by God to guide and support those in need.

I have never met you, Janalee, but I share a bond with you that goes beyond what I am able to express in words.

I wish you the best always.

I send you peace, light, happiness, love, and am here if ever you need me.

Love, Lisa Peters

Reviewed by Jennifer Miller, M.D.

Coenzyme Q10 Supplements

By Moris Angulo, M.D. and Kathy Clark, M.S.N., R.N., P.N.P.-Coordinator of Medical Affairs, PWSA (USA)

What is CoQ10?

Coenzyme Q10 (CoQ10) is an important vitamin-like substance that is vital to the “powerhouse” of cells – the mitochondria - for energy. It is created in the body but is also present in foods.

CoQ10 is now a very popular supplement with a wide range of claimed benefits. Its role in muscle energy is clearly proven, but taking additional supplements has shown varied results in a variety of conditions. For example, CoQ10 may be recommended to a heart patient who is on medications that can decrease natural CoQ10 levels. With muscle energy so diminished in PWS, it was hoped that CoQ10 supplementation would be a boost, a low-risk supplement worth trying. With many parents reporting positive results, many PWS specialists now routinely suggest CoQ10, not as essential or due to a deficiency, but as a supplement that may be worth a try.

Are people with PWS deficient in CoQ10?

There is no clear evidence of a CoQ10 deficiency in PWS. There has not been a research trial which shows the benefits of CoQ10 in PWS by comparing treated children to those who did not take CoQ10. Lacking that evidence, PWSA (USA) cannot provide scientific information in terms of dosing and the right formula of CoQ10 for children and adults with PWS, or state that it is an essential medication for people with PWS.

Is CoQ10 supplementation effective in persons with PWS?

We know from communications with parents and physicians who have used this product that the response to CoQ10 can vary - from substantial changes in energy to no effect at all. We are aware of no known adverse side effects if taken in an appropriate dose.

There are not clear dosing guidelines for CoQ10 especially in childhood, and suggested doses are not standardized across brands. The information we have on the effectiveness of CoQ10 is all “anecdotal” data (i.e., from parents commenting on their personal experiences with their child).

CoQ10 supplementation is not a substitute for growth hormone treatment which has clearly been shown to have multiple benefits for individuals with PWS, and is the only FDA approved treatment for PWS.

How can I choose the most effective brand of CoQ10?

Over-the-counter supplements and vitamins are easy to obtain, but may not be effective because the ingredients must

be in the right formulation for the body to absorb. Vitamins can be hydrophilic (dissolve in water) or lipophilic (dissolve in fat), so other ingredients may need to be added to improve absorption. For example, vitamin D may be an ingredient in a typical dry vitamin tablet, but without additional fat, it is not well absorbed by the body. CoQ10 is a lipophilic cofactor and requires fat for absorption. Powder-based CoQ10 supplements do not contain fat and are poorly absorbed. To overcome this, most CoQ10 supplements are available in softgels with vitamin E and other lipids (fats) to help the body absorb the CoQ10. While the addition of fats improves absorption, a CoQ10 supplement that is both water and fat-soluble can provide even better absorption.

What are safe doses of this supplement?

Unlike multivitamins, there is not an official recommended starting supplemental dose of CoQ10. Each manufacturer may suggest different doses and package the supplement in different strengths. Most manufacturers suggest starting doses between 1-30 mg/per kg/per day for infants, and no more than 180-200 mg per day for older children. In non PWS older children and adults who have had low blood levels of CoQ10, 60-100 mg per day is sufficient to raise the blood level to the normal range.

CoQ10 softgels typically come in 60- or 100-mg doses. These gel caps can be sliced open, and the contents squeezed out. Tiny softgels may be a choking hazard for some individuals, but there are also liquid preparations. CoQ10 can be purchased over-the-counter at most pharmacies or can be purchased on line.

Blood tests of CoQ10 need special handling and results are difficult to interpret. Some physicians still recommend a CoQ10 level before treatment and may want to monitor blood levels.

Be sure to give your health care providers a complete list of supplements and the doses that your child is receiving at each visit. ■

Dear Janalee,

*You have helped more people than you can possibly imagine...
Melanie Silverman*

CHUCKLE
CORNER

One day my husband caught Maya, 13, attempting to open the freezer door.

He said, "What are you doing?" She said, "I was just looking for my cell phone. I guess it's not in the freezer!"

- Denise Servais, Lake Elmo, MN

A review by Kathy Clark, MSN, PNP, Medical Coordinator PWSA (USA)

Causes of Death in Prader-Willi syndrome: Prader-Willi Syndrome Association (USA) 40-year Mortality Survey

By Merlin G. Butler, Ann M. Manzardo, Janalee Heinemann, Carolyn Loker, and James Loker: Genetics in Medicine (2016).

While we celebrate exciting new discoveries and therapies for PWS, we also continue to expand our understanding of the significant challenges. Knowledge is power – even when the topic is distressful and sad. This study was sponsored by PWSA (USA) and is the largest published summary on mortality worldwide.

As a part of the bereavement support program, PWSA (USA) has gathered information since 1973 on deaths as reported by families. This data was first summarized in 2005 in a paper written by the mortality committee. In 2016, a publication by Dr. Butler and colleagues extensively reviewed the data from 1973-2015, with a priority of describing more specifically the causes of death.

The article states that 486 families reported a death to PWSA (USA) making this the largest study of death in Prader-Willi syndrome. These individuals were between the ages of two months and 67 years. 70% of these deaths occurred in adulthood. Of the 486, 312 had a cause of death provided and 36% died “of unknown cause.” Not all records provided enough detail; for example, listing “obesity” as a cause of death (7%).

Respiratory (breathing) failure was the most common cause of death (31%) in PWS in both adults and children. Heart issues were the second leading cause at 16%, primarily in adults due to obesity-related right heart failure rather than to coronary disease. These are not surprising findings when uncontrolled weight has long been the greatest challenge in the syndrome.

A surprising 10% of deaths were due to GI problems, and GI-related deaths occurred at all ages. This finding is the reason we have become very vigilant about gastric problems – obstructions, motility, perforations. Prior to analyzing this information, physicians were unaware of how common or lethal gastric problems could be for persons with PWS.

With this new knowledge, we have developed the GI Chart to provide to doctors and emergency rooms, included in the pocket-sized red Medical Alert handbook.

Choking was more common in males, in part due to rapid eating when sneaking food but is also complicated by lack of saliva and the ineffective swallowing we know is often part of the syndrome. Another surprising finding was the 7% incidence of pulmonary embolism. We are now paying more attention to the problems of blood clots and why those might be so common.

In looking at the trends over time, lifespan has increased through the decades for women, but curiously not so for the men. Men were more likely to have behaviors such as binge eating, leading to choking or stomach perforation. Accidental and/or hyperphagia-related deaths appear to disproportionately impact younger males, possibly owing to impulsive characteristics or higher activity levels.

Deaths in childhood are more likely due to respiratory failure, aspiration, infection and choking rather than obesity related factors. Cardiac disease, pulmonary embolism, accidents, sepsis,

and obesity-related complications were primarily seen in adolescents and adults.

The article noted that early diagnosis and prevention of obesity are key factors in preventing premature death in PWS. These include close monitoring and supervision of food access and quantity of food to avoid choking and stomach rupture. Not included in the article was that 80% of the 147 individuals with known height and weight were obese at the time of death.

PWSA (USA) will continue to collect this important information. We offer our thanks, gratitude and deepest sympathy to the families who have suffered the loss of a loved one. Their courage in contacting us is deeply appreciated. ■

*Early diagnosis and
prevention of obesity
are key factors
in preventing
premature death
in PWS.*

Dear Janalee,

...I can remember when you and Al first joined. Your involvement over the years was certainly a blessing to the PWSA (USA)...
Claire Ledoux, from CT.

I just cannot thank you enough for all you have done for PWS.
All my best to you and Family and a hug.
Susanne Blichfeldt, M.D., Denmark

...don't know what I would have done without you...
Beverly Strongitharm

New Research Grants Funded by PWSA (USA)

By Evan Farrar, M.A., Research Coordinator and Family Support Counselor, PWSA (USA)

PWSA (USA) recently approved a grant to provide annual Support for the PWS-EMO Rare Disease Clinical Research Network (RDCRN) in the amount of \$25,000. The grant runs from 2017-2018 and is coordinated by the Data Management Coordinating Center (DMCC). PWSA (USA) provided a similar grant to the DMCC in 2016 to make sure that over a decade of research data was not lost when NIH funding for the RDCRN expired. The 2016 grant helped produce an immense amount of PWS-related research publications and presentations. In 2017-2018 the DMCC will be involved in several projects that will continue to drive research in areas such as creating an electronic nutritional phase checklist to help investigators correctly interpret nutritional phases in PWS.

PWSA (USA) recently approved a grant of \$10,000 to support the International Consortium to Advance Clinical Trials for PWS in 2017. Launched in 2015, this collaborative and international consortium was created to gather patient organizations like PWSA (USA), academia, and pharmaceutical companies to advance current and future clinical trials for PWS and facilitate the decision-making process for regulatory agencies. Supporting the consortium is in keeping with PWSA (USA)'s mission, and long standing commitment, to encourage collaborative and relevant research for the PWS community.

Counselors Corner

Supreme Court Rules in Favor of Students with Disabilities

By Thomas Conway, Esq., Advocacy Committee Chair, PWSA (USA)

On March 22, 2017, the United States Supreme Court issued an important ruling expanding the rights of special education students.

The case before the Supreme Court, *Endrew F. v. Douglas County School District*, involved a student with autism who was making little progress in his public school. The student's individualized educational plan (IEP) largely included the same educational goals and objectives from year to year, despite the fact that he was not making progress toward those goals. Endrew's parents removed him from the school and placed him in a private school where he made significant academic and social improvement. The parents requested reimbursement of the cost of the private school tuition from the school district, but the district denied the request.

The lower courts ruled in favor of the school district, holding that the **Individuals with Disabilities Education Act** (IDEA) does not guarantee students any particular level of education. The lower courts held that the law requires only that school districts provide students with disabilities an educational program that is "merely more than *de minimis*." This "merely more than *de minimis*" standard had been adopted by most mid-level federal appeals courts and

was the standard by which the appropriate level of special education benefits was being measured throughout most of the country.

In a unanimous decision written by Chief Justice Roberts, the Supreme Court rejected the "merely more than *de minimis*" standard. Chief Justice Roberts stated: "When all is said and done, a student offered an educational program providing 'merely more than *de minimis*' progress from year to year can hardly be said to have been offered an education at all." Quoting favorably from an earlier Supreme Court decision, Chief Justice Roberts expressed the Court's view that: "For children with disabilities, receiving instruction that aims so low would be tantamount to 'sitting idly...awaiting the time when they were old enough to drop out.'"

Chief Justice Roberts stated that "every child should have the chance to meet challenging objectives" and concluded by holding that the IDEA requires that students with disabilities be provided "an educational program reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances."

The Court noted that it would not attempt to elaborate on what appropriate progress will look like from case to case and that in creating a student's IEP, deference will continue to be given to the expertise and judgment of school authorities. However, the new heightened standard by which an IEP, and a student's progress, must now be measured is an important victory for all students with disabilities and will empower parents nationwide as they advocate for their children in schools. ■

Don't miss this life-changing experience! Attend the PWSA (USA) Biennial National Convention/Conference: November 14-18, 2017



This one-of-a-kind gathering is where research, support services, and families come together with the common goal of improving the lives of individuals with Prader-Willi syndrome and their families. This amazing event:

- Offers programs tailored for parents, people of all ages with Prader-Willi syndrome, medical and professional providers, many of whom will travel from all over the world to attend
- Shares the latest in medical and scientific research
- Provides high-quality professional care for persons with PWS is provided, so that family members can focus on receiving the latest information; and
- Allows the experience of networking with others who understand topics related to PWS, which is priceless for participants.

The PWSA (USA) Caribbean Nights – Together in Paradise Convention Has It All!

A comprehensive, full agenda of meetings, times to connect, specialized programs, information, relaxation, and fun events:

- | | |
|-------------------------------------|-----------------------------------|
| ■ General Conference | ■ New Parent Mentor Meeting |
| ■ Exhibit Hall | ■ Medical & Scientific Conference |
| ■ Evening Gala | ■ Young Infant Program (YIP) |
| ■ YAP Gala | ■ Chapter Leaders Meetings |
| ■ Sibling Program | ■ PWSA (USA) Bookstore |
| ■ Youth & Young Adult Program (YAP) | |
| ■ Professional Providers Conference | |

Enjoy discounted room rates at the Caribe Royale Hotel in Orlando during this special gathering of the PWS community.

See you in six months at ***Together in Paradise*** Convention! ■

**The General Conference takes place
Friday & Saturday, November 17-18.**

Find more information and register at

<http://www.pwsausa.org/2017-pwsa-usa-national-convention-registration/>

*Photos from the 2015
PWSA (USA) National
Conference.*



Adults with PWS Advisory Board Selects first Co-chairs at 2017 Annual Meeting

By *Conor Heybach and Brooke Fuller, Co-chairs*

There have been several exciting things happening in the Adults with Prader-Willi Advisory Board. The Adults with Prader-Willi Advisory Board is proud to announce that we have elected Brooke Fuller and Conor Heybach as our very first co-chairs. The co-chairs will be responsible for running and planning the board's annual meeting during their one year term. Our responsibility is to make sure that all members of the board views have been heard. We also have the responsibility to report back to the PWSA (USA) national board about what we have discussed at our board meeting and give any advice we have for the PWSA (USA) national office in continuing to assist families with PWS loved ones. Every advisory board member will have an opportunity to serve as a co-chair. **With the new model of having co-chairs from within the advisory board, we are now the first board in the history of PWSA (USA) led by people with PWS.**

At our annual meeting in January, the board took the following actions:

- Approved creation of a semi-annual Adults with PWS Advisory Board e-letter.
- Approved having co-chairs work with the coordinator of the national convention of PWSA (USA) to give feedback and assist with planning for the convention to represent the views and concerns of advisory board members.
- Approved creating ways to raise funds specifically for the board to assist advisory board members to travel to the board's annual meeting in Sarasota and other special projects.
- Approved and created the content for a resource on employment for people with PWS and employers.
- Approved creation of a page for the advisory board on the PWSA (USA) website.



As Co-Chairs for the Advisory Board, we will work with national staff at PWSA (USA) to implement the decisions of the Board.

*left to right:
Brooke Fuller and Conor
Heybach*



Left to right front: Shawn Cooper, Kate Kane, Andy Mauer, Brooke Fuller, Abbott Philson, Conor Heybach. Back row: Lauren Lange, Trevor Ryan.



**Want to be a part of the world's
largest PWS advocacy community?**

**Become a member today! Go to:
www.pwsausa.org and click on Membership**

PWSA (USA) Member Benefits include:

- 20% discount on merchandise
- *Gathered View* newsletter
- Members only online access
- Free Webinar registration

Dear Janalee,

It has been our great pleasure to have worked closely with you over these last 20 years. We have continued to be impressed by your tireless devotion to "the cause." You have been an inspiration to many people and a shining beacon to the Prader-Willi families across the USA and around the world. You will be sorely missed!

All our best for you and Al! Dan & Marilyn Driscoll

May is Prader-Willi Syndrome Awareness Month...

Awareness Leads to Action, and Action Leads to Progress that Helps Our Cause...

By **Steve Queior**, Development Director, PWSA (USA)

Many *Gathered View* readers are very aware of a broad range of facts about the syndrome, and with your vital help PWSA (USA) is continuing to share more information with others across the country and beyond... key points including that Prader-Willi syndrome:

- Creates constant feelings of hunger
- Causes weight gain while consuming considerably fewer calories than the average person
- Is triggered by the genetic mutation of the 15th chromosome
- Displays other symptoms including medical, psychological, and developmental challenges
- Occurs in approximately 1 in 15,000 births

As more of our friends and neighbors, educators, medical professionals, governmental officials, and others are more aware, more positive **Actions** will be taken.

As the largest education, support, research, and advocacy organization for people and families living with the Prader-Willi syndrome, your PWSA (USA) is all about building on enhanced awareness with increased actions that save and transform lives. Consider the following actions taken by PWSA (USA) over just 12 months:

- More than 2,000 families were directly assisted
- Almost 200 families with new diagnoses were provided family/medical/crisis support
- Over \$585,000 was raised to fund the Oxytocin Phase 2 Study
- More than 10,200 free educational materials were provided to families

While many of the actions are coordinated by the board, committees, and professional staff of your association, it is what all of you do around the country that will take our results to the next level of positive impact.

"What you do makes a difference, and you get to decide what kind of difference you want to make."

- Jane Goodhall

Actions You Can Take:

For many, becoming a member, or renewing your membership, in the PWSA (USA) is a great first step. You can see the many benefits of membership at www.pwsausa.org.

org, ranging from receiving the *Gathered View* for free and discounts on publications and merchandise, to access to the "Members Only" section of the website and reduced pricing for webinars and conference attendance.

Membership drives even more actions though, as it adds power to our public policy and advocacy efforts on behalf of the PWS community. And, very importantly, memberships strengthen the fulfillment of our mission by providing critical funding for our family support and research efforts.

We all benefit from the involvement of others, whether you think of it as "many hands lighten the load," or "there is strength in numbers." Demonstrating action by being a volunteer - working with others from PWSA (USA) - has additional benefits, ranging from gaining knowledge that can help you to making fast and lasting friendships.

Many have learned that it is a "win-win" partnership when you decide to:

- Be a volunteer
- Support a fund-raising event
- Attend chapter, regional, and national meetings
- Host a fun fund-raising and friend-raising event
- Raise your voice for our cause
- Make a positive impact in a many simple ways, including:

Supporting the eWalk Virtual Fundraiser –

eWalk is Prader-Willi Syndrome Association (USA)'s online virtual walk that allows anyone, from anywhere, to participate and help raise vital funds. Remember, PWSA (USA) is the only organization that provides PWS new diagnosis support, research, family/crisis support, medical support, advocacy, and education. For more information, please visit the website at www.pwsausa.org and click on "2017 eWalk."

Awareness and Actions...

Your Involvement Accelerates All Our Progress:

Together we can and will address the challenges related to Prader-Willi syndrome and improve the quality of life for all of those impacted by it.

As always, your board of directors, committee volunteers, and staff thank you very much for your involvement and support!

"Today, give yourself permission to be outrageously kind, irrationally warm, and improbably generous. I promise it will be a blast."

- Sasha Dichter

Dear Janalee,

It is a rare and beautiful thing to look at someone's life and realize that they were the catalyst for something great. Truly this would not have happened without you; it was that lucky, blessed convergence of all the right elements in time and place.

Kathy Clark

Thank You Sprouts!

Sprouts Farmers Market is THE fastest growing grocery chain in the country, and is all about healthy food/healthy lifestyle. That relevance with PWS turned into this donation presented at their recent local opening (and second store!) in Florida. ■

Mason, age 18 months



left to right, James Collins, store manager;
Steve Queior, PWSA (USA); James
Gibson, regional marketing specialist.



A BIG Thank You!

Wingate
University
and Dr.

Dawn Norwood helped raise over \$2,625 as well as TONS of awareness for PWS! Dawn's godson, Mason (above) has PWS and she is passionate about making an impact.

We are off to a great start this year! You can help by hosting a fundraiser in your area. We will be here to assist you in putting together a successful event. To get started, please contact Leanne Gilliland at lgilliland@pwsausa.org or 941-487-6743. ■

Some of our upcoming Awareness/ Fundraising Events: Join Us!

5/13 Oconomowoc, WI: Wisconsin *"On The Move"* Walk: Hosted by the WI Chapter

<https://www.firstgiving.com/pwsaofwi/7th-annual-on-the-move-walk-a-thon>

5/13 Lakeville, MA: 8th Annual Hunter Lens Golf Tournament: Hosted by the Lens Family

<http://www.firstgiving.com/pwsausa/8th-annual-hunter-lens-golf-tournament>

5/19 Stillwater, MN: Minnesota Golf Scramble: Hosted by the MN Chapter

<https://pwsaofmgolf.eventbrite.com>

5/20 Lehi, UT: Fitness Fun-Raiser: Hosted by the UT Chapter

<http://www.firstgiving.com/pwsausa/utah-fitness-fun-raiser>

5/20 Durham, CT: Walk and Roll for PWS: Hosted by PWS Families United

<https://www.eventbrite.com/e/2017-walk-and-roll-for-pws-registration-32368304470>

6/3 Paducah, KY: Paducah *"On The Move"* Walk: Hosted by The Thweatt Family

<http://www.firstgiving.com/pwsausa/kentucky-on-the-move>

6/17 Tucson, AZ: Tucson *"On The Move"* Walk: Hosted by The Garcia Family

<http://www.firstgiving.com/pwsausa/tucson>

9/30 Meridian, ID: Idaho *"On The Move"* Walk: Hosted by The ID Chapter

<http://www.firstgiving.com/pwsausa/2017-IDAHO-OTM>

Dear Janalee,

Well done thy good and faithful servant! Many will be forever grateful for your love, support and mentoring. Thank you for *"standing in the gap"* on behalf of the children and families challenged with PWS.

Our family will be eternally thankful for you. God bless you and those you love.

Love,
Clint Hurdle

On March 24th PWSA (USA) hosted the 3rd Annual "Clint Hurdle Hot Stove Dinner" at the Courtyard Marriott in Bradenton, Florida. With the help of team manager Clint Hurdle, The Pittsburgh Pirates, our local community and our awesome PWS families, the night was an outstanding success! 165 individuals attended, helping us raise tons of awareness and over \$64,000! This event continues to grow each year and we are so thankful for everyone's support and generosity.



Hurdle Hot Stove Event A Big Success!

Funds from the evening will allow PWSA (USA) to continue saving and transforming lives by providing vital support services, research, awareness, education and advocacy. Many thanks to all! ■

New Mexico

By Andrea Glass

The New Mexico chapter was officially launched in September 2016. The first board meeting elected: President: Kathryn Lucero, Vice President: Katina West, Secretary: Jeanine Cordoba, Treasurer: Tracey Foreich, Committee Head: Penny Chavez, Community Outreach Coordinator: Melissa Hodges, Technical Advisor: Kerstan Cole and general board members Brooke Stone and Aaron Martinez. The chapter was started with much grateful support from the National office and case management assistance from ARCA's Prader-Willi Syndrome Project.

As a newly formed chapter, they have reached out to the 65 members known to National that reside in New Mexico to alert them to their efforts. Statistically, there may be as many as 200 individuals with PWS in New Mexico. The Board is currently devising a strategy to reach out to the rural areas and the newly diagnosed. They are currently making packets to give to the hospitals with information about the Chapter, PWSA (USA), and ARCA's Prader-Willi Syndrome Project. There are also plans to have an awareness table at the Project's June 2017 conference, a Fall fundraiser, and a soon to be launched Facebook page. The Facebook page will be information-based and open for the community to learn of events and fundraising in our state. The fundraiser ideas so far include a walk, and a paint and wine night.

The chapter vision is to raise awareness about Prader-Willi syndrome in our state by having family and community events and also fundraisers. We want to reach out to not only larger cities like Albuquerque, Santa Fe and Las Cruces but all over our state in the smaller more rural communities, which is not currently being done at this time. We want to meet the needs of as many New Mexicans as possible with Prader-Willi syndrome.

The PWS community is fortunate to have a social service organization like ARCA's Prader-Willi Syndrome

*I reached out
to PWSA (USA)
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others diagnosed with
Prader-Willi syndrome.*

Project who has been a helpful advocate for services throughout New Mexico. Each year ARCA goes to a Town Hall event to discuss issues pertaining to the PWS population; families of those with PWS also participate. The key person at ARCA is Penny Chavez. She is available to attend IEP meetings with families, and assists with getting individuals a DD waiver for residential supports. Individuals spend on average 10 years on this waiting list. ARCA also provides a medical network for our PWS population that helps with services throughout the state.

There are not any PWS specified

group homes in New Mexico. However, with the assistance of ARCA, they will accommodate 100% of a PWS individual's needs. Penny indicates that the state participates in a Know Your Rights Campaign which allows individuals to live where they want. The specific needs are met by the specific group home. The Prader-Willi Syndrome Project assures that the person with PWS is safe in whatever home they decide to live in.

A note from Kathryn Lucero, New Mexico chapter president: My son Ronan was diagnosed with Prader-Willi syndrome when he was 4 weeks during our stay in the NICU in 2014. We felt so alone and there were not many resources available in our state. I did find ARCA's Prader-Willi Syndrome Project, which is funded by the state of New Mexico. This agency has case management and is able to help families with some state resources. I reached out to PWSA (USA) to get involved as much as I could to help my son and others diagnosed with Prader-Willi syndrome. You can feel so alone at times and I want families to know there are resources available not only in our state but nationally as well.

I am very excited to see what our Chapter can do for individuals and families in the state of NM and to strengthen our partnership with ARCA's Prader-Willi Syndrome Project. I strongly believe that those that are newly diagnosed and those that have had Prader-Willi for years will have many resources and a strong team to advocate for them. Please email us with any questions or concerns at PWSANM@gmail.com ■



Federal Employees! The Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all."

Visit their Web site at <http://www.opm.gov/cfc/index.asp> to learn more. **PWSA (USA) CFC ID # is 10088**

Register PWSA (USA) as your charity of choice when shopping on Amazon and they will donate a percent of the price of your eligible **AmazonSmile** purchases to Prader-Willi Syndrome Association (USA) when you shop on **AmazonSmile**. To get started: <https://smile.amazon.com/ch/41-1306908> ■



A Population-Based Profile of Prader-Willi Syndrome in Ireland

On March 9th the Irish Minister for Health, Simon Harris, launched a detailed report based on research commissioned by the Prader-Willi Syndrome Association Ireland (PWSAI). The primary aim of the research was to map the support needs of families with a person with PWS throughout the life stages and to make recommendations regarding support provision.



Members of PWSAI with Minister Simon Harris

The Findings

The research showed both positive and negatives. One positive is that the age of diagnosis has been steadily decreasing in recent years with children born between 2012 and 2016 receiving their diagnosis within 4 weeks on average compared to 19 weeks for those born between 1999 and 2003. The research also showed a significant decrease in the age at which children with PWS commence using Growth Hormone Therapy. Children aged from 0-4 who were reported on in the study commenced using growth hormone at 1.7 years on average compared to 3.6 years for children aged 5-12 years.

The statistics in relation to the education and employment of people with PWS were less encouraging. They showed that the majority of adults with PWS in Ireland have left school without any educational qualifications and that only one adult with PWS reported on in the study is currently in paid employment.

The report highlighted gaps in services too. Sixteen respondents reported that their family member with PWS would require full time residential care within 5 years. A majority of respondents across all age groups also indicated that they required respite, but in most cases this was not available. Among families with adults with PWS living at home only 25% reported receiving any respite.

As well as showing the many medical, psychiatric and behavioural challenges faced by people with PWS, the research also highlighted that PWS takes a heavy financial, physical and emotional toll on families and has a negative impact on siblings and family relationships. The gendered distribution of



Minister Simon Harris

PWS in Ireland

The Republic of Ireland has a population of 4.7 million including about 100 people who have been diagnosed with PWS. Most of these are known to the PWSAI and 61 families in which there is a person with PWS participated in this research.

Two PWS-specific multidisciplinary clinics led by paediatric endocrinologists operate in Ireland and Growth Hormone Therapy, which was first licensed for use for people with PWS in Ireland in 2001, is now widely available.

The first and only PWS-specific group home in Ireland was opened in 2003.

PWSAI was established in the 1980s as a support group for people with PWS and their families. In 2002 it became a limited company and gained charity status. PWSAI has no paid staff and is run entirely by family members of people with PWS.

care was also highlighted by the research - 50 of the 61 survey respondents were mothers of people with PWS, 3 were siblings and 8 were fathers.

Two professors from Trinity College Dublin (a psychiatrist and an endocrinologist) generously gave of their time and expertise to oversee this research. As part of the survey design they included questions and scales that had been developed around the world.

PWSAI was fortunate to have received funding for the research from the Galway Cycle and relied on its own members and supporters for most of the work associated with promoting and instigating the project.

While it is too soon to say if this research will lead to improved services for people with PWS in Ireland, the media coverage generated as a result of the research has already succeeded in shining a spotlight on the lives of people with PWS and their families.

If you are interested in reading the full research report, visit <https://pwsai.ie/events/pwsai-national-survey-launch-2017> PWSAI is active on Facebook and Twitter and any queries about the research can be sent to info@pwsai.ie ■

Editor's Note:

Reprinted with permission from the IPWSO blog. Many thanks to Marguerite Hughes (the mum of a 13-year-old with PWS from Ireland) who is a member of the IPWSO board and, until last year, a member of the board of the Irish PWS association, and IPWSO.

An Amazing and New Experience

By Denise Servais

Have you ever had an experience that was so unbelievable that you couldn't stop thinking about it? I had one of those experiences recently. My daughter, Maya (13) with PWS was a participant in the Miss Amazing pageant. Miss Amazing is a national organization whose mission it is to provide girls with disabilities opportunities to build confidence and self-esteem. I was a little nervous about how Maya would handle a long day but she really wanted to participate.

Maya handled the day very well with practicing her speech and presenting her formal dress on stage, as well as interviewing with the judges. She was flexible with the change in her meal schedule. During the pageant, I was so impressed that she was able to stand on the stage in front of an audience and give a short speech about herself. The event was beautiful and it was clear a lot of planning had been put into this event. So far so good and we were almost toward the end. All the participants were called up as princesses to get their crown and trophy, and then one girl from each age group was chosen to be Queen. When every girl in Maya's age group was recognized, they called the

name of the girl to become Queen. My daughter's name was not called. That's ok, I thought, we had prepared Maya for this.

It wasn't ok with Maya. She immediately threw herself down on the floor in the middle of the stage and yelled, "I want to be Queen!" Volunteers rushed in to try to pry her off the floor so the pageant could continue. When it looked like they weren't going to be successful, I made my husband go onto the stage. As my husband escorted Maya off the stage she ran toward the Emcee's podium and grabbed a sash that would be given to a Queen. A collective, "Oh" was heard from the audience. I saw the look of disbelief on the Emcee's face who was a well known morning radio host.

After several minutes, I left my seat to find my daughter sobbing backstage clutching the sash. Knowing that the last Queen was going to be called soon, the sash would be needed. As I tried to coax the sash out of my daughter's hand she continued to sob and scream, "I'm not giving it back, it's mine!" Fearing that she would be heard from the stage, my husband and I were able to usher her outside. This made her furious as she now began to try to run back into the

venue and threaten to go back on stage and declare herself Queen. I tried to hold her to stop her as she attempted to kick and scream. As my husband got the car, I tried to remain calm and think of the techniques I had learned from the PWS conferences! We must have been a sight to see as cars slowed down to take a look at us.

Later that night and the following next day, I could only think of how embarrassed and upset I was. I developed a migraine and spent much of the day in bed. Later the following day, I saw an email in my box from one of the pageant judges. I was afraid to open it fearing that she would say how much the Servais family ruined a beautiful pageant. Instead, she wrote that she felt bad and wanted me to know that we were part of an audience that night who understood. She even extended an invitation for Maya to come back next year. She said that this is one of those life lessons that is important to learn. Hmm, so what life lesson did I learn? I guess I learned that perhaps I over reacted. But more importantly, I learned that even though we may never find the crystal ball that can tell us what will happen, we can always find people who care and will support us no matter what. ■

Carry PWSA (USA) Wherever You Go!

By Evan Farrar, M.A., Research Coordinator and Family Support Counselor, PWSA (USA)

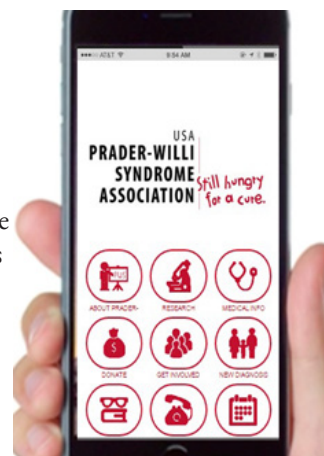
Are you carrying PWSA (USA) in your pocket? If not, why not? Because now you can by downloading the **FREE** PWSA (USA) app for your smart phone. With this app, you will have immediate access to all the important information you need on the PWSA (USA) Web site with a touch of your phone screen. Forget a handout you wanted to share with a teacher or doctor? No problem. It's all on your phone! Through this app you can:

- show your child's doctor important medical information during an appointment.
- watch a school video with your child's IEP Team.
- read the latest news on research and other topics of interest.
- provide ER staff with key medical alerts during emergencies.

- conveniently explore family support and other resources available to you.

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

So what are you waiting for? Start carrying PWSA (USA) wherever you go by downloading today the PWSA (USA) app available for Android and iPhones.

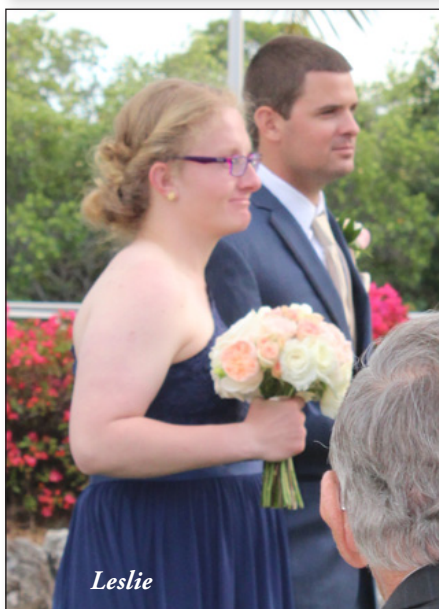


Siblings of Sisters with PWS Find Support...and Love



It was approximately 2007 when Beverly and Doug DeLemos attended their first PWS conference in Florida. Though their daughter Abby was diagnosed at age 3, they had never taken the step to attend a conference until she was 16. They came with their 18-year-old daughter Holly and their 12-year-old daughter Libby. As the years progressed, they faithfully attended both the spring and fall Florida conferences and Libby began to volunteer in the childcare program. She met the four Torbert boys (Thomas, Eric, David and Alex), sons of Michelle and Tommy Torbert, and older brothers to Leslie, with PWS. All the siblings became friends and would socialize during the conference weekends.

When Libby and David were in high school, they began a long-distance dating relationship – Libby lived in Orlando and David lived in Homestead, about a four-hour drive apart. They saw each other as they could over holidays and long weekends. This relationship continued as they both entered college. It was great that they didn't have to explain their sisters to their significant other and they found humor in saying, oh, yeah, my sister does that, too! The love for their sisters increased their bond to each other and they both shared a love for this very special population. The Torbert boys volunteered with the YAP and Sibling Programs at the PWSA (USA) National Conferences on four to five occasions and Libby did as well for



two to three of those events. They enjoyed the support and camaraderie of the other siblings they met.

In the fall of 2015, David and Libby became engaged and were married March 4, 2017. Abby served as maid of honor and Leslie was a bridesmaid. Two of the bridesmaids, Terann and Lynn Mayo, also have a younger sister with the syndrome and they met through the Florida PWS conferences to form their very special friendship with Libby. All of the groomsmen grew up with Leslie, participated in the annual *Casting for a Cause Fishing Tournament*, and helped out at conference events as well. Interacting with the PWS population developed a strong sense of compassion and empathy in these young men.

Two years ago, after Michelle had been president of the Florida chapter for eight years and was ready to step down, she was able to convince Beverly to step up to that role – keeping things all in the family!

When your state chapter holds an event, or with the National Convention coming up in November, please consider attending – not only for the support you will receive, the support your child with PWS will receive, but also for the support and acceptance your other children will receive by meeting and forming friendships with other siblings. Who knows, maybe there will be another love story to tell... ■

~ Julie Doherty, aunt to David and Leslie Torbert

A Parent Mentor Moment

By Jennifer Gibbons, Mesa, AZ

This month, nine years ago, I learned I was going to become a mom. I had waited 15 years and been through multiple miscarriages and a failed adoption. I was thrilled. I was terrified. I had 31 days to prepare for my daughter, who was already here—she was two months old. Oh, and this sweet baby has Prader-Willi syndrome.

I reached out to National and the Arizona chapter to learn more about PWS. We met a teenage boy who was so charming and told us he really hoped we got the baby (we hadn't been selected at that point). I talked to moms who helped me understand the syndrome and what questions to ask.

Then we were selected to parent Ella! The first "CONGRATULATIONS" came from Tonya Coupaud. That was her complete message... "Congratulations". It was exactly what I needed to hear. Congratulations on becoming a mother. Congratulations on this beautiful blessing of a daughter. *Congratulations.*

That simple message stayed with me. There were many more congratulations as time passed. But hers was first, it was simple and it was the balm my heart needed after learning about the scary parts of PWS. *CONGRATULATIONS.*

Six years later, as I worked through some of the challenges and need to advocate for Ella. I received another very important message. I had been working on maintaining our long-term care through the state (similar to Katie Beckett waiver or any

title 19 insurance in any state). It was hard work as PWS is not a covered condition in Arizona. I gathered information from countless sources. I compiled, researched, advocated, prayed, cried, and worked really hard. I called Lilli Hiatt and asked her opinion about the situation. I explained what I thought the best action would be, and why I had come to that conclusion. She encouragingly responded...

"YOU GOT THIS!"

Many times, as I continue to advocate for Ella, I think of these messages.

Congratulations: these blessings are yours because of this amazing girl.

You got this: because you are the parent who once the work and research is done, you will know what is best for YOUR CHILD. As I work on situations that require my advocacy, I believe I have found the best solution for Ella, when I hear that encouraging "YOU GOT THIS" in my head, I know I am on the right path for my girl.

So today, no matter what you are working on for your child with PWS, I would like to send you two messages...

CONGRATULATIONS!

YOU GOT THIS! ■

Editor's Note: The Parent Mentor Program at PWSA (USA) was developed to assist families in their journey. Here is one family's reflection. To learn more, visit: <http://www.pwsausa.org/parent-mentoring-program/>

Congratulations. That simple message stayed with me. There were many more congratulations as time passed. But hers was first, it was simple and it was the balm my heart needed.

From The Gathered View writers:

Dear Janalee,

...because of leaders like you, families like mine reap the benefits of joining an already strong organization. The good work that you have done will have a positive impact on families for many years to come. Denise Servais and daughter Maya



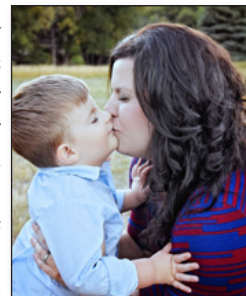
The first time I went to a National conference I met the woman behind the name Janalee. I was completely amazed at your incredible focus on improving the lives of individuals and families affected by PWS in the U.S., AND throughout the world. PWSA (USA) flourished during your time, expanding on family counseling, research, fundraising, and ties with the international community, all so important in our lives. Most of all, you leave a highly qualified staff to fill your shoes and continue with the mission; thank you.

Andrea Glass and son Ian



Ronan was almost 2 when I went to my first conference. I listened to the speakers taking in everything I could and remember being inspired, knowing I would be okay after hearing your presentation. You spoke with so much passion in your voice for the PWS community. Thank you for ALL you have done and the hope you have given to parents.

Kathryn, Armando & Ronan Lucero



PWSA (USA), using your talents, intelligence and compassion to nurture its growth and the PWS family.

Thank you! Lota Mitchell and daughter Julie

37 years ago we met at that PWSA national conference at a meeting of social workers attending, you and me! Since then, we've worked together on many projects, like the first brochures. You've been the constant for

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 Gathered View (ISSN 10 77-9965)

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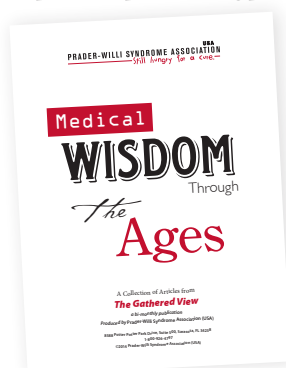
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Another great publication from PWSA (USA)

<http://www.pwsausa.org/product/medical-wisdom-of-pws-through-the-ages/>



Medical Wisdom of PWS Through the Ages

Authored by medical professionals, this highly-prized collection of nearly 200 pages features relevant medical articles on unique issues of the syndrome from our newsletter, *The Gathered View*.

\$25.00 (2014)

e-News...

Reminder – stay informed and current with PWSA (USA)'s free e-News. Sign up by clicking on our Web site: www.pwsausa.org and watch for the next update!

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Dear Janalee,

You are the keystone who shared, guided and indoctrinated me in the world of PWS. With former GV editor Lota Mitchell, we became a great team! Because of you I discovered my purpose: ensuring those who read our works have an opportunity to change and transform lives in many ways. Meeting the families at conference was life-changing. This association is strong, collaborative, passionate because of you. Thank you for lighting that spark to my passion. I'm honored to carry the torch in your honor.



left to right: Lota, Sara, Janalee

Sara Dwyer, *The Gathered View* editor