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

Prader-Willi SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

Annual Angel Drive Kick-Off!



Abigail, age 12 years

Join the entire PWSA (USA) community and help us kick off the annual Angel Drive!

PWSA (USA) channels the power of **love**, **compassion**, and **hope** into substantive, meaningful programs and initiatives to **save and transform lives**! Through life-changing programs and ground-breaking research, PWSA (USA) has brought increased hope, better health, and enhanced quality of life to thousands of individuals with PWS and their families, helping them thrive in the face of a rare genetic condition. But we need YOU to help us.

Every gift you make to the 2017-2018 Angel Drive campaign makes a real and meaningful impact in the lives of individuals with PWS and their families!


Siena, age 2.5 years

These five pillars serve as the foundation of who we are…
Together, they represent what we can accomplish when we unite as a community to save and transform the lives of those living with Prader-Willi syndrome.

PWSA (USA) receives no reimbursement for the services we provide; we rely solely on the generosity of our supporters to make our work possible. Your gift is an investment with a priceless return!

"Through the years I have depended on the PWSA (USA) family support for all aspects of Maxx's life (he is now 12). This past year, we experienced increasing difficulties with the school system for various reasons. PWSA (USA) was a terrific support and advocate for Maxx. Your staff reviewed Maxx's IEP and made excellent suggestions on how to improve it; a staff member even joined in the IEP meeting by speaker phone…I am so grateful for your help and for the constant presence of such an amazing "rare genetic disease" association. You help in so many ways!"
- Mother of Maxx, who has PWS

"I love PWSA (USA) because this is a place where I feel welcomed and know that my grandson (who has PWS) is welcomed and supported. At PWSA (USA) there is always someone to listen, to help connect new parents to experienced parent mentors, and to provide needed information.
- Grandmother of a young grandson

PWSA (USA)'S FIVE PILLARS OF SUPPORT



Ours is a clear, comprehensive mission; we are a community of individuals, families, and professionals working together to:

- Raise **AWARENESS**
- Provide holistic and comprehensive **FAMILY SUPPORT** services
- Facilitate **RESEARCH** that saves and improves lives
- Provide **EDUCATION** to those serving or working with the PWS community, such as medical professionals, education professionals, and residential providers
- **ADVOCATE** for the needs of the PWS community


Chloe, age 12 months

Gifts to the 2017-2018 Angel Drive go to support critical research to develop new treatments and medications that truly do save and transform lives. Be a PWS community "angel," and make a gift today!

Watch for your Angel letter in the mail or donate online at **https://www.pwsausa.org/angel-drive/**

Your tax-deductible donation is greatly appreciated and helps make our work through the PWSA (USA) Five Pillars of Support possible.

Volume 42, Number 6 ~ November-December 2017 ~ Our 42nd Year of Publication

Dental Problems in Children and Adults with Prader-Willi Syndrome

Compiled and Reviewed by

B. Dorn, R.N., Dr. T. Hughes, D.D.S., and Dr. K. Wachter, D.D.S.

Persons with Prader-Willi syndrome (PWS) of all ages face lifelong challenges in dental health. A few of the more common dental problems include enamel erosion, tooth sensitivity and severe tooth wear. The following information provides information on causes, signs, prevention and treatment options that may be helpful.

Enamel Erosion and Tooth Sensitivity

What is it? Enamel erosion is the wearing down of the protective coating (enamel) of the teeth. When enamel wears down, microscopic channels in the tooth open up and become exposed. Most people with this problem complain of discomfort and pain. However, since persons with PWS have an altered pain response, they may or may not experience and report this sensation.

Common Causes:

- Abnormal salivation (low production of saliva)
- Grinding of the surfaces of teeth
- Health conditions including gastric reflux
- Medications (aspirin, antihistamines and some vitamins)
- Diet high in sugars and acid

Examples of foods and beverages with high acidity: Soft drinks, sport drinks, fruit juices, lemonade, coffee, tomatoes, strawberries. (Citric acid, phosphoric acid, and ascorbic acid are a few ingredients to watch for in foods.)

Signs of this Problem:

- Translucency of the enamel (you can almost see through the tooth)
- Darkening or discoloration of the teeth
- Pain or cold sensitivity (may not always be reported in persons with PWS)

Preventing this Problem:

- Drink water. Limit soft drinks, sport drinks, juices and coffee in moderation. Dilute juices with water.
- Swish mouth out with water or brush teeth after drinking or eating items high in acid.
- Don't sip on beverages for extended periods of time.
- Do not drink or eat high acid beverages/food in the evening after supper.
- Use a straw to keep acids away from teeth.
- Brush with fluoride toothpaste and minimize swallowing. (This condition can occur in children and causes defects in the enamel of the teeth. Ingesting large amounts of fluoride can cause nausea, stomach pain and/or vomiting. It may not be quickly detected in persons with PWS.)
- Get regular dental checkups and cleanings every 6 months.
- Talk to a dentist about daily non-alcohol fluoride mouthwash. (Use as a rinse; do not swallow.) If needed, apply with Q-tip.
- Consult dentist on use of sealants in preventing enamel erosion and tooth decay – even in adults.
- Use toothpaste that helps tooth sensitivity and protects enamel.

Treatment:

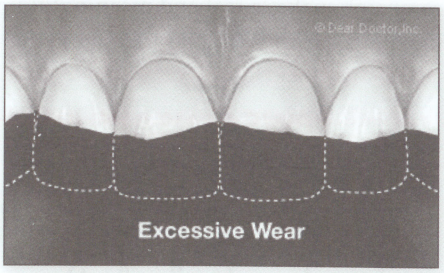
- Once lost, enamel cannot be replaced.
- If a person with PWS is found to have a sudden loss of tooth enamel, testing should be done to determine if a medical condition is present. Treatment should focus on identifying and correcting underlying problem. (May require special diet and medications.)
- A soft diet and avoidance of very hot and/or very cold foods often helps with tooth sensitivity.

Severe Tooth Wear / Grinding / Bruxism

WHAT IS IT? Teeth grinding or recurrent rubbing of the surfaces of teeth can cause damage to the teeth and result in severe wear and other oral complications. This is often seen in both children and adults with PWS. It occurs most commonly at night or while sleeping.

Causes:

- Exact cause is unknown
- Bite abnormalities
- Anxiety and/or stress



Treatment:

- Mouth bite guard – best if individually fitted by a dentist. Used while the person sleeps. May require incentive program for compliance.
- If bite abnormality is identified, referral to an orthodontist is strongly recommended.
- Avoid or cut back on foods and drinks that contain caffeine, such as colas, chocolate, and coffee.
- Discourage chewing on pencils or pens or anything that is not food. Minimize chewing gum. It allows jaw muscles to get used to clenching and makes it more likely to grind teeth.
- Work with person with PWS to learn not to clench or grind his/her teeth. Have him/her practice relaxing

continued on page 3

Dental Problems, continued from page 2

jaw muscles. (Try holding a warm washcloth against cheek in front of earlobe.)

- Include plenty of water; dehydration has been linked to teeth grinding. ■

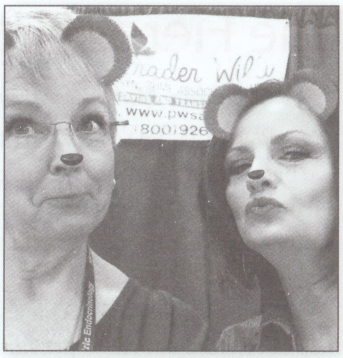
Medical A-Z Updated

By Kathy Clark, R.N., M.S.N. CS-BC, Coordinator of Medical Affairs, PWSA (USA)

We have just expanded the medical information descriptions and hand-outs on the PWSA (USA) website and app. For example, the new dental problems article in this edition can be printed off from our website to share with your dentist, as well as an additional new handout on preventative dental care. This section includes handouts addressing common questions and important medical alerts. We will continue to update these resources which are meant for both parents and professionals. ■



International Meeting of Pediatric Endocrinology



PWSA (USA) staff Kathy Clark and Diane Seely, show that sharing lifesaving information can be informative and also fun.

The International Meeting of Pediatric Endocrinology was held in Washington, D.C. on September 14-17, preceded by an international conference for pediatric endocrinology nurses. Diane Seely and Kathy Clark attended the IMPE to meet and educate physicians from around the world about PWS and the many services offered by PWSA (USA). At our awareness booth in the large exhibitor area, we were at a busy location where physicians had coffee breaks and lunch nearby. Attendees included 4,000+ physicians, nurses, and researchers who came from around the world.

Kathy Clark also attended the International Nurses' meeting, where Christine Derycke, R.N., from Belgium, provided a lecture on PWS in infancy. Kathy distributed guidelines and resources for PWS care at this meeting of over 60 pediatric endocrine nurses.

At the physicians' meeting, Dr. Jennifer Miller was featured at *Meet the Expert*, a lecture offered twice to a packed room of over 200 participants from all over the globe. She also spoke as a part of a panel on *New Therapeutic Options for Treating Genetic Obesity*. There were several PWS posters, a type of professional presentation. These posters may be published later in more detail and may be small studies or student projects. The topics included micronutrients on low fat or low carbohydrate diets; PWS and metabolic syndrome; and comparison of testing methods for diagnosing central adrenal insufficiency in PWS. Once these posters become published (peer reviewed by other experts), we will share the study results.

We were very pleased with the large number of physicians from around the world who stopped at our booth, wanting to talk about PWS and how to provide the best care for their patients. Many young doctors are eager to develop multidisciplinary clinics, showing awareness of the team approach needed for best care. This international meeting, both exhilarating and exhausting, was worth the planning and energy. ■

Let your voices be heard -

New Opportunities to Share your Perspective

If you are the parent or primary caregiver for a person with PWS, we need your help! There are two important surveys that we're asking you to complete. The first (*The Impact of PWS Symptoms on Caregivers*) will help us understand how PWS impacts your life, while the second (*Treatment Preferences in PWS*) will help us communicate your treatment preferences to people not familiar with PWS (e.g., pharmaceutical companies, FDA, etc.) Both surveys are being done as projects of the Prader-Willi Syndrome Clinical Trials Consortium (PWS-CTC), a consortium developed with the goal of accelerating clinical trials for PWS. PWSA (USA) is a partner of the PWS-CTC. The PWS-CTC is committed to engaging the PWS community and incorporating the patient perspective into the development of new therapies for PWS. We believe the voice of the patient community is critical to understanding the unmet medical needs of this population, framing the benefit-risk analysis of new drugs, establishing priorities and value assessments. More information and links to each survey may be found at the PWS-CTC website: https://www.pwsctc.org/projects

Let your voice be heard - please take the time to share your perspective! ■

The Fierce Urgency of Now

By Evan Farrar, M.A., Research Coordinator, PWSA (USA)

As PWSA (USA)'s new part-time Research Coordinator, I've been doing a lot of listening, learning and observing during my first few months on the job. So I felt this is a good time to update our readers on the direction of our research program.

To begin, PWSA (USA) feels a great sense of urgency to help accelerate efforts to provide individuals with PWS more treatment options. The challenges of PWS extend across the life span of a person with PWS. As a result, individuals, families, and caregivers need more treatment options to manage and diminish the challenges facing a person with PWS. While all PWS research is important, our focus is targeted on research that can enhance the quality of life for people with PWS more immediately.

"...this really is YOUR research program."

For this to happen, PWSA (USA)'s Research Program must, and will, do more to develop treatment-based research. We will do this by:

- Devoting more time, energy and resources to support development of new therapeutic interventions.
- Partnering with the PWSA (USA) Scientific Advisory Board (SAB) to increase PWS-related scientific inquiry.
- Creating new opportunities for researchers and scientists to gather to promote collaboration and information sharing.
- Increasing efforts to work collaboratively with external research partners such as pharmaceutical companies, the Foundation for Prader-Willi Research (FPWR), and other organizations.
- Evaluating our current grant-making process to ensure it is optimized to achieve our objective to focus on treatment-based research.
- Encouraging innovative new research models. We believe there are big ideas out there and we want to support them.



Transitioning to research included joining left to right: Stacy Ward, Janalee Heinemann and Evan Farrar in New York. Read Stacy's update on page 10.

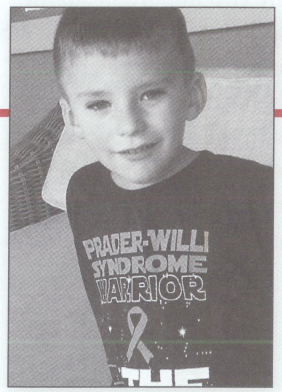
PWSA (USA) occupies a unique space in the PWS research community because we offer both research and family support. Our daily interaction with parents/caregivers, as well as the knowledge gathered about the daily challenges that people with PWS face, benefits our research program in many ways:

- It influences treatment priorities,
- helps us evaluate the relevancy of grant applications, and
- gives us an opportunity to identify emerging treatment needs in the PWS community.

I find the synergy between these programs equips us to play a greater role as a collaborative partner in developing therapeutic interventions for people with PWS.

We are excited about the future of our research program and the opportunity to increase our role in the PWS research community. But none of this would be possible without your ongoing support and dedication to our research program. I extend a thank you for all you do to help us conduct and promote research that will benefit people with PWS and their families/caregivers.

We want to hear from you and invite you to e-mail me personally with any questions or concerns you have about our research program. I also welcome any ideas and comments you might have to improve it. Why? Because this really is YOUR research program and your voice is important. My e-mail address is efarrar@pwsausa.org. I would love to hear from you!



Pax, see page 5

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."

PWSA (USA) CFC ID # is 10088

Click or visit http://www.opm.gov/cfc/index.asp to learn more

Ambassadors for New Parents

By Ken Smith, Executive Director, PWSA (USA)

Many experienced parents of children with Prader-Willi syndrome want to do something to support new moms and dads on the PWS journey. Being a PWSA (USA) Ambassador, a brand new program this year, is a special way to do that. Here is a spotlight on the role of our **Ambassadors** and an interview with our very first one, as an example. Be sure to read below about Catt Putney, our first Parent Mentor Ambassador.

Our Ambassadors serve as representatives for PWSA (USA) at both their local chapters and in the community and do the following:

- help to raise awareness for PWSA (USA)'s many resources and connect families through social media or local events.
- establish and maintain a relationship between PWSA (USA) and their respective matched families.
- establish a relationship with their local NeonataI Intensive Care Unit (NICU) or PWS Clinic.
- deliver our PWSA (USA) Package of Hope and other printed materials to local NICUs.
- assist families by going directly to our website to participate or organize a fundraiser.
- are available to provide local support to parents in their community, if appropriate. ■

Meet Ambassador Catt

By Diane Seely, New Parent Support Coordinator, PWSA (USA)

The following is an email interview profiling Catt Putney, one of PWSA (USA) Ambassadors, and mom of Pax, age 4.

Catt,

We are happy to have you as our FIRST PWSA (USA) Parent Mentor Ambassador. The best way to profile you is to share a bit about you with the PWS community, although many folks already know you – you're Pax's mom, of course! We want folks to know just how much you do for our families! So I have a set of questions here for you to respond to:

D: Tell me how you first got involved with PWSA (USA).

C: We never were really involved until Pax was about two. At the time he was born, there was not a lot of information given by his doctors. We didn't REALLY find out about PWSA (USA) until the 2015 National Conference that we went to after we moved to Florida.



Catt with house guest Clementine, age one year

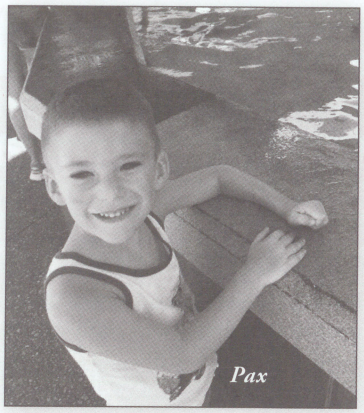
What's your first memory of hearing the words Prader-Willi syndrome?

C: Day Nine we found out he had PWS (UPD). We met with the geneticists, and they completely "sugarcoated" it. Afterwards in the car, we Googled (worst thing to do). I was completely distraught.

D: Tell me about some of the people you've met while volunteering as a PWSA (USA) Parent Mentor.

C: We have been lucky enough to be able to share our home to others who see Dr. Miller. We have met so many amazing families due to the fact we live so close to her office.

D: Tell me about someone who has influenced your decision to work with PWSA (USA).



Pax

C: I was born with Cerebral Palsy (right side), epilepsy and had a stroke at 30. So obviously I have always been an advocate for people with disabilities. My parents embraced CP and did EVERYTHING they could to help (my idols). My minor at Michigan State University was "Perspectives on Disabilities."

D: The interest in volunteering for our PWSA (USA) Parent Mentoring Program seems to be growing. Why do you think that is?

C: I think EVERYONE appreciates support given through PWSA (USA) and thus wants to "Pay it forward." We are all very proud of our kids and want to share "the good times as well as the bad."

D: How would (someone) describe you?

C: I have ALWAYS had a passion to help others (I was even a Cat Behavioral Specialist at the SFSPCA....yes that title exists...lol). My parents taught me to accept my disability (CP). They NEVER let me feel sorry for myself, taught me to embrace who I am and stressed that a disability NEVER defines you as a person. It is because of that I have always been described as outgoing, energetic and extremely open. This makes me who I am.

D: What do you do when you aren't (working, volunteering)?

C: Other than helping with PWSA (USA), we enjoy living the Florida lifestyle. We try to expose our kids to as many new experiences as possible. We enjoy doing activities such as going to the beach, swimming, playgrounds, bouncy houses, boating and just exploring. One of my favorite activities is mommy and Paxton Disney Day Wednesdays (picking a different park every week).

continued on page 6

Family Support Campaign a Great Success!

Thanks to you, our many generous supporters, the 2017 Family Support campaign was a great success! Together you raised $61,293 that will be used to provide life-changing programs and initiatives, such as support for newly diagnosed families and advocacy for school-age children. PWSA (USA)'s Family Support program is the only one of its kind; no other organization is able to serve individuals with PWS and their families as completely. Because families receive services completely free of charge, your support is critical to ensuring we can continue to meet the needs of the PWS community. Your gift is an investment with a priceless return…Thank you!



Average Invested by PWSA (USA) in Family Support Case
$373 per PWS Family



Average Invested by PWSA (USA) in New Diagnosis Case
$665 per PWS Family

To make a gift to the PWSA (USA) Family Support program, please visit: http://www.pwsausa.org/family-support-campaign/ ■

People with Passion and Purpose

Watch for the posting of the two-year progress report covering actions of Prader-Willi Syndrome Association (USA), coming soon on www.pwsausa.org.

The publication combines annual report information of 2016 and 2017, with summaries and photos highlighting efforts and accomplishments in the areas of awareness, family support, and research. The report will also address how your association is working in terms of increasing educational activities and advocacy, and how it is leveraging resources to create maximum benefits for those affected by PWS.

In addition to being available on our website, there will be links to the People with Passion and Purpose report on social media. ■

Ambassador, continued from page 5

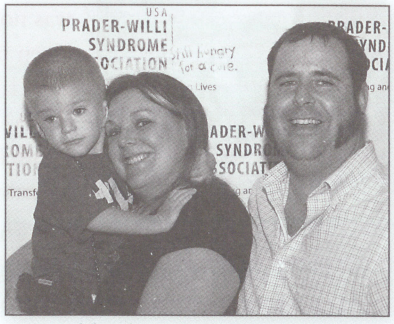
D: What else can you tell me about PWSA (USA)?

C: I think the strength of PWSA (USA) is in the community itself. We are all here to help each other. There are not many people in the world who understand PWS, the obstacles and what we go through day by day. Whether it is meeting up at chapter events, conventions or a quick post on social media, we are all in this together. Sean, Grey, Pax and I are lucky enough to meet people from all over the world to swap stories and hear different perspectives.



D: If you had $30,000 to donate to our organization what would you do with it?

C: While research is SUPER important, I feel education and support are crucial aspects (especially for new parents) and getting those who cannot afford to go to PWSA (USA) events (such as the PWSA (USA) Conference). Also important is expanding materials such as placing the presentations online.



Pax and family at 2015 PWSA (USA) conference

A comment from one of Catt's mentees:

…I love reading all your posts and it gives me hope that this new life we are living with Rose is going to be ok... these first 3 months of navigating the PWS journey has been exhausting, emotionally draining, and filled with worry...You seem to have so much knowledge about so many different things with PWS...amazes me and makes me want to someday be able to devote more of my life and time to advocating for PWS and helping other people, too…thank you for all the posts that are uplifting and giving me strength to keep working hard for Rose. ■

Sustaining Supporter Membership at PWSA (USA)

Save and Transform Lives for as Little as $5.00 a Month!

Your decision to become a Sustaining Supporter Member, or to renew your membership, makes a real and meaningful impact in the PWS community! Because PWSA (USA) receives no reimbursement for the services it provides, your annual membership dues are a direct investment in programs and services that *Save and Transform Lives.*

Become a Sustaining Supporter Member today and help support:

PWSA (USA)'S FIVE PILLARS OF SUPPORT



Membership Has Its Benefits!

- **Satisfaction** Know your contribution has a real and meaningful impact in the lives of individuals with PWS and their families
- **Convenience** Safe, secure annual contributions with the flexibility of making changes at any time
- **Efficiency** Automatic payments mean no postage or paper, and reduced administrative costs putting more of your contribution into PWSA (USA)'s Five Pillars of Support
- **Information** Sustaining supporters receive free issues of PWSA (USA)'s bimonthly newsletter, "The Gathered View" and access to free webinars
- **Savings** Members receive a 20% discount on publications and other merchandise from PWSA (USA)'s online store, as well as discounted admission to the biennial national conference

For more information about Sustaining Supporter Membership, visit http://www.pwsausa.org/membership/ today! ■

A Delicious Way to Support PWSA (USA) Programs



Prader-Willi Syndrome Association (USA) has partnered with Omaha Steaks to raise much needed funding while offering our supporters and their families delicious gourmet and everyday selections at substantial discounts. When you shop for holiday meals, everyday foods, or gift-giving, Omaha Steaks will forward 10% of the sales proceeds to support Prader-Willi Syndrome Association (USA).

Take advantage of the discounts again and again! Choose from three easy ways to shop:

- Online via the website: **http://bit.ly/2h0jjuTpwsaSteaks**
- At any Omaha Steaks Store
- By phone: 1-800-994-7455

Simply use the URL above or alert the Omaha Steaks Specialist you're ordering through our PWSA (USA) campaign; then 10% of all your purchases will be credited to our fund-raising effort.

We greatly appreciate your support with this opportunity, and hope you enjoy several delicious meals from Omaha Steaks! ■



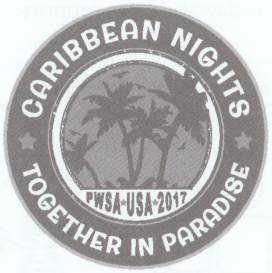
Trivia Night in St. Louis!

Put your thinking caps on and head to Trinity Lutheran Church on Saturday, November 11, 2017 from 6:30 to 10:00 p.m. for a night of trivia and fun! Registration is just $200 for a table of 8, and proceeds benefit individuals with PWS and their families. Attendees are welcome to bring their own food, and both alcoholic and nonalcoholic beverages are permitted. For questions or to register, please contact the St. Louis Prader-Willi Syndrome Association by email at stlpwsa@gmail.com, or by phone at 314-712-9687.

Online registration is also available at: http://bit.ly/2ypkQzHstlPWSA.

Location:
Trinity Lutheran Church
14088 Clayton Road
Chesterfield, MO 63017 ■

Families and Experts Head to Orlando this Month



PWSA (USA)'s *34th* National Convention, with the theme *"Together in Paradise,"* will soon convene, bringing hundreds of members of the PWS community together for the biennial Scientific & Medical, Professional Providers, Chapter Leaders, and General Conferences, as well as many other convention activities.

Watch for photos of children, parents, grandparents, and more on social media November 15-18, and announcements about special presentations and new information that you'll be able to access after Thanksgiving. ■

IPWSO
INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

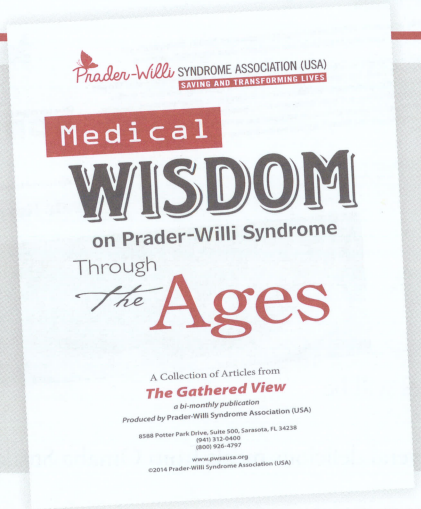
IPWSO Launches New Online Research Resource

By Evan Farrar, Research Coordinator, PWSA (USA)

The International Prader-Willi Syndrome Organisation (IPWSO) recently posted a list of selected PWS research papers and their abstracts on the IPWSO website. The papers were published in peer reviewed academic journals from April to June of 2017. The papers are divided into specific categories: genetics, general PWS, brain imaging; endocrine including GH; sensory and physical, behaviour, cognition, and mental health. The list was compiled by Joyce Whittington and members of the IPWSO Clinical and Scientific Advisory Board chaired by Dan Driscoll, M.D. Dan Driscoll, is also the chair of the PWSA (USA) Clinical Advisory Board. ■

To view this visit:
https://www.ipwso.org/2017-research-papers

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 visit our website, www.pwsausa.org



A Great Publication from PWSA (USA)

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

Medical Wisdom on Prader-Willi Syndrome 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) ■

Great Ideas for the Holidays!

From our 0-5 e-mail group comes a list of 45 non-food related activities and ideas for the holidays.

1. Participate in or host a Turkey Trot

2. Christmas Lights Appreciation Walk



3. Design luminarias to decorate your walkway

4. Go on a hike



5. Pull out or make CDs of Christmas songs to sing and dance to

6. Put on a "Family Dance" with a special family music album

7. Put together puzzles

8. Take gifts to neighbors

9. Sing carols at elderly homes

10. Make a family scrapbook of memories from past holidays/family events

11. Create scrapbook pages for photos you will take during the holidays

12. Play a pick-up game of softball, waffle ball, hockey, kickball – you get the point!

13. Play board games (You can even have a tournament if you like competition!)



14. Decorate ornaments

15. Host an ornament-making party

16. Go caroling!



17. Make homemade holiday cards

18. Collect leaves to make leaf-rubbing cards

19. Watch holiday movies

20. Share your favorite Christmas memories

21. Read Christmas books such as "T'was the Night Before Christmas"

22. Create a Family Tree - make a holiday tree with homemade ornaments using family pictures

23. Go for a hike to try to find wild turkeys

24. Scavenger hunts foraging for greens and such for decorations.

25. Write your own Christmas story; make a book.



26. Fill a count-down calendar with good thoughts for the day. Every day open a good thought. A good opportunity for positive reinforcement for good behaviors

27. Make puzzles out of old Christmas cards, Christmas pictures, etc. (Put velcro on the back for extra OT work pulling and putting them together)

28. Create pine cone gifts by rolling them in lard or sunflower butter and birdseed; wrap and give as gifts.

29. Every year the children each choose a new Christmas book... and when our tree is set up, we take the box of Christmas books out and pile them around the base of the Christmas tree. The children are thrilled by the 'newness' of reading material and gravitate to the books often.

30. We go to the fabric store each year and sew new Christmas pajamas and matching stockings. (We donate the ones from the previous year to the Salvation Army).

31. Skating rink in the back yard (turn on the hose when it is cold enough to freeze)

32. Tobogganing

33. Walks all bundled up, in the evenings after dinner, whenever there is snow falling.

34. Go to the neighborhood rink for a make-shift hockey game.

35. Build a snow family

36. In the snow banks created from the snowplows, we love to dig a snow fort.

37. Snow ball battle with the neighbors (their fort is always right across the street from ours)

38. Make homemade Christmas wreaths



39. Take small gifts, stockings etc., to a local children's hospital

continued on page 10

Counselors Corner

The Achieving a Better Life (ABLE) Act of 2014 allows people with disabilities to open savings accounts where they can save up to $100,000 without losing eligibility for Social Security, Medicaid or SNAP benefits. Eligibility is limited to those with significant disabilities with an age of onset prior to age 26. Some things that you should know about ABLE accounts:

- If you are receiving SSI and/or SSDI, you are automatically eligible for an ABLE account.
- The first $100,000 in an ABLE account is exempted from the SSI resource limit. If an ABLE account exceeds $100,000, SSI benefits will be suspended until the account falls below $100,000.
- Funds in an ABLE account can be used for qualified disability expenses including (but not limited to) housing, transportation, support services and health care expenses.
- If your state has not established an ABLE program, you can open an account in another state if that state's program is accepting out-of-state residents.
- Anyone can contribute to a person's ABLE account, not just the beneficiary.
- Administrative costs for ABLE accounts vary from state to state.

Visit http://www.ablenrc.org/about/what-are-able-accounts to learn more about ABLE accounts.

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

To our cherished family and friends:
A special greeting to express our sincere appreciation for you. We are deeply thankful and extend our best wishes for a happy and healthy holiday season.



Holiday Ideas, continued from page 9

40. Take small gifts, stockings, etc., to a local NICU

41. Pull out old family pictures or videos

42. Visit local attractions (amusement parks, museums, etc.)

43. Make collages from old Christmas cards

44. Ring bells for Salvation Army

45. Host a New Years hat-making party

https://www.pwsausa.org/angel-drive/



Be an Angel. Donate online!

Claire, age 5

Keep Michigan Strong

Twenty four years ago when Dewey Graves, Jr.'s, daughter was diagnosed with PWS at age 11, he was told by the hospital about the local Michigan Chapter. The family went to the Annual Awareness Walk and has continued to walk each year since. The chapter today continues its mission of building awareness in the medical community and also the State government. Dewey has been the chapter president for five years. He has support from National, the previous chapter President, Eric Macks, and the current board of directors; Jennifer Schaupeter (treasurer), Estelle Graves (secretary), Shane DeRidder (webmaster), Carolyn DeRidder (FB and newsletter), Ashley Chapman, and Susan Herman.

Currently, Michigan lists about 250 members. Statistically there may be as many as 600 people with PWS in the State. They use email, Facebook and the website to communicate with the membership. The stated mission is: ***Prader-Willi Syndrome Association of Michigan strives to improve the lives of everyone affected by Prader-Willi Syndrome through Support, Education, Advocacy, and Research.*** National alerts the chapter when a newly diagnosed family reaches out and they are then contacted by the local chapter.

Each year in May, the chapter sponsors an Awareness Walk and fundraiser at Cascades Park, which is in the middle of the state. The chapter has integrated community support for this event with local high school kids, local fire and police departments. The day includes games, races, face painting, lunch, and of course the Walk. The goal each year is to raise $25,000 to support local outreach, send members to camp in Ohio and to the National conference, and sponsor events including a bi-yearly local medical conference. The chapter sponsors an annual family picnic, an annual Zoo day, and two family meetings each year. They are also fortunate to have a weekend dedicated to serving PWS at a camp in Ashley, Ohio each fall. chapter leadership also participates in a Disability Conference ever year with an awareness booth. They reach out to doctors, medical professionals and CMH during this conference. **Join us - we NEED YOU to make a difference and keep the Michigan chapter strong!**

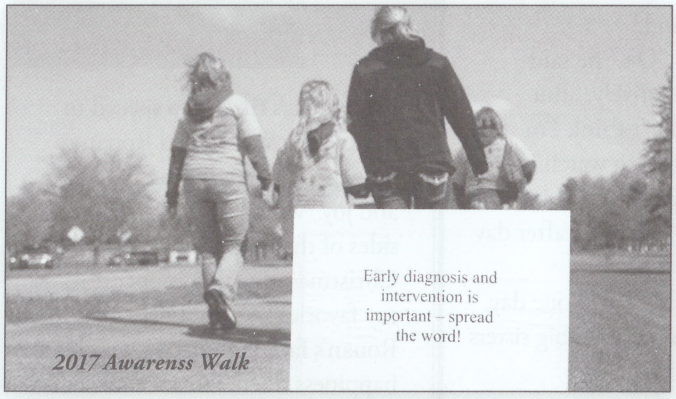
The Michigan chapter website is **https://pwsami.org/**. It is designed and managed by Shane DeRidder is the main communication tool for Michigan PWS families. Dewey and the Board are also reaching out to State government to increase awareness and upgrade some areas that don't meet acceptable PWS standards. Michigan has a few PWS specific homes, but the goal is for more of this specialized housing. For more information, feel free to use the contact information provided on the website. ■

~ Submitted by Dewey F. Graves, edited by Andrea Glass



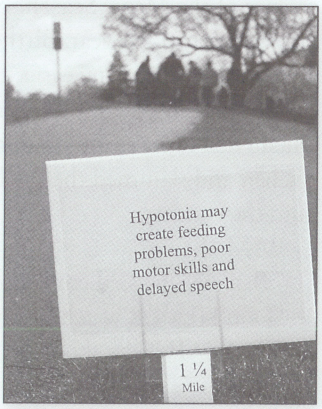
2014 Awarenss Event





2017 Awarenss Walk

To learn more visit:
https://pwsami.org/





I Love Lucy. ...?

By Lisa Peters

My son Nicholas has a gentle spirit and a warm heart. He loves new-born babies, fluffy rabbits and soft, furry kittens, and although he just celebrated his 15th birthday, he thinks and behaves like a child who is much younger.

Sometimes I forget.

This holiday, his new bus driver introduced him to the Peanuts cartoon characters by giving him his first Charlie Brown Christmas DVD. Needless to say, he loved it. The sad bare branch transforming into a colorful glowing Christmas tree, moved his tender heart, fueling his innate altruistic ideology that goodness has the power to transform weakness into strength, sadness into beauty, and hate into love.

He enjoyed the movie so much; he played it over and over again.

Since Nick's birthday arrives shortly after Christmas, I decided to expand upon this genius gift-giving idea. I bought him a collection of Peanuts presents. Things like a Snoopy backpack, a Woodstock lunchbox, a Peanuts puzzle and last but not least, a Charlie Brown Great Pumpkin DVD.



So what if Halloween was months ago? The movie captured the essence of the Magic Season, Nick's favorite time of the year. Birthday gift-giving couldn't get any easier than this.

So, you can imagine my surprise when Nick came storming into the kitchen and slammed the DVD down onto the counter.

BAM...!

"That's it!" he said emphatically.

"I am NEVER watching this movie EVER AGAIN!" he shouted.

"What happened?" I asked, surprised by his overwhelming reaction.

"Did it freeze-up when you were watching it?" I asked, wondering if perhaps it got damaged in shipment by an unusually neglectful Amazon elf?

"NO!" he said, folding his arms across his chest, his silent cue that he is about to go postal.

I got down on one knee and looked in his eyes, now flooded with tears.

"Nicholas, what is it?" I asked.

"I DO NOT LIKE LUCY.....!"

"Why don't you like Lucy?"

"She took Linus's blanket. She is so mean."

"Oh Nicholas," I said, "it gets better if you keep watching it."

"No Mom," he said, "I just can't take it."

"If it makes you feel better, he does get his blanket back," I assured him.

"He does?" Nick asks tentatively.

"He does," I answered.

"No Mom, I just can't watch her be so mean, ever again.

"OK Nick, I understand. But I'll leave it right here on the counter just in case you change your mind."

"Ok," he said tentatively, "But I don't think I'm going to watch it ever again"

And there the movie sat, day after day after day.

"You know Nicholas," I said one day, "Lucy is a big sister. Sometimes big sisters are bossy."

"They are?" he asked.

"Yes, they are, but they are also very helpful. If you watch the movie you will see how Lucy takes care of her little brother Linus. She finds him in the pumpkin patch and gives him back his blanket."

"She does?"

"Yep, she does. I guess if you don't have a big sister it's kind of hard to understand."

"Arrright Mom, I'll try to be brave," he said with a sigh.

It took a few days, and then a few more, until eventually, without a word, the movie disappeared from the counter. I had to laugh when at last I heard an all too familiar piano melody drift loudly from the living room.....

da da da da da da.....dum
da da dum
again and again and again!

■



Ronan

Holidays time is so special to our family. We wanted Ronan to grow up with traditions, wonder and joy. We celebrate with both sides of the family every year. Christmas morning is of course my favorite because I get to see Ronan's face light up with such happiness. Here's to another incredible holiday season.

Ronan received a riding helmet for Hippotherapy and of course he HAD to wear it! ■

~Kathryn Lucero

A Diversion during the Season...

By Denise Servais

Holidays can be difficult to get through when you have a loved one with Prader-Willi syndrome. Food seems to be everywhere! One of the things that seems to work for us is keeping Maya distracted as much as we can. One bright spot for us, and our daughter Maya in particular, is the love that she has for animals. Every Christmas, our family spends time with Maya's Aunt Becky. Becky fosters dogs and always seems to have a house full of dogs when we visit her. Many of these dogs scare easily, are nervous, or have had some kind of trauma in their lives. Maya connects easily with these dogs. It's interesting how these dogs will let Maya do things that the dogs will not let her sisters do (i.e. pet them, give attention). Maya is already looking forward to this coming Christmas to meet her aunt's new foster dogs. ■



Will We Survive the Holidays?

By Janalee Heinemann

*(Note: This article appeared in **1983** for our PWS Missouri newsletter, but in revisiting it, I think a lot of families could still identify with it today.)*

Although the holidays are a source of joy and festive gatherings for many, they can be a difficult time for others. Bereaved parents and widowed people often dread the holidays, and recovering alcoholics must call on inner resources to "get through" the holidays. We families dealing with Prader-Willi syndrome are yet another group of people who look towards the holidays with a combination of eager anticipation – and dread. Will the holidays this year be a fun shared experience with their children, or will they only bring on a few more temper tantrums and five or ten extra pounds?

I'm sure many of our parents can identify with the following holiday scenes:

…"*Chestnuts roasting on an open fire…*" along with the pleasant aroma of baking holiday cookies, candies and turkeys, means that many more "No's" we have to say to our children.

"*To grandmother's house we go…*" means running the risk that the excitement and change in routine, plus relatives who want to be too liberal with the food, will bring on an embarrassing temper tantrum for our child with PWS – or worse yet, a parent tantrum!

"*Follow me in merry measure…*" to all of the fun-filled parties at school and friends' homes, which presents just that many more occasions where our children will be frustratingly aware that they are not able to eat all of the holiday treats that are an inevitable part of any party.

"*Not a creature was stirring, not even a mouse…*" doesn't include our child with PWS! There is no guarantee that the cookies and milk left out for Santa will still be there when he arrives. What parent of a child with PWS hasn't woke up in the night concerned about the noise in the kitchen? A burglar, or Santa coming down the chimney is the least of our worries!

(Our children who have Prader-Willi syndrome can be a joy through the holidays – as long as we do good prevention. If you need holiday tips for Prader-Willi syndrome, you can go to **https://www.pwsausa.org/2015-holiday-tips/**. If you do not have access to the Internet, you can call PWSA (USA) and ask them to send a copy to you.) ■

Holiday Tips

From the PWSA (USA) website

Dear Friends,

The holidays are typically a food fest in our country – and can be a time of stress for our PWS families. With good planning, it is possible to make it a happy holiday for all.

- If you will be with relatives, carefully plan ahead of time and communicate the importance of food control with all involved. Make sure all attending know the "rules of engagement" and agree to cooperate. See that someone at all times is clearly in charge of your child with PWS. Clearly define when you are "changing guards". As Dr Linda Gourash states, "When everyone is in charge – no one is in charge."

- If your child is old enough, rehearse the "rules" before the special day and come to a mutual agreement on what your child will be allowed to eat. You can barter, i.e. "Do you want a little extra turkey and dressing, or do you want a piece of pie as your special treat?"

- It is okay to request that Grandma and other relatives tuck away tempting items during your visit and to discreetly check with you prior to offering your child a treat.

- Make sure you know what everyone is bringing, so there are no surprises on what the choices will be.

- Grandpa and Grandma, or aunt and uncle may want to bring a special gift toy to compensate for the food they have to deny your child.

- Go over with the hostess or your family the plan to contain accessibility to food. This will help prevent your child from sitting near bowls of food, rolls, or condiments. Many people do not consider how many calories children can consume with the extras – sugar, butter, ketchup, etc.

- After eating when people are just visiting make sure food is put away or, if left out, someone is responsible for guarding it.

Your child must have the security of knowing you will be strong in your commitment to keep them protected from food – in spite of themselves. Giving in, even once, means several battles ahead. Consistency is the key. Of course, each family must judge their own situation based on their child's food drive and their own regulations on treats. Some families are raising their children to never have any sweets – no exceptions. Others (like ours) just go by calories and the weight of the child, trying to keep the diet less in quantity with more variation of food. Often, the most important thing is to prevent food sneaking or food demands. There is a large variance in the food drive of children with PWS. Some will ask or beg for more food, but make no significant attempts to sneak food. On the other hand, some will go to great extremes to get food, and are incredibly cleaver at doing so.

HOLIDAY ALERT FOR PRADER-WILLI SYNDROME

There have been several holiday seasons where some of our pre teens, teens and adults with Prader-Willi syndrome have had unexpected deaths due to food binging episodes that led to necrosis of the stomach wall and a perforation (tear) in the stomach. In several of the deaths, the person with PWS was slim, so there was no great concern about weight gain.

They were all in festive group situations, where "everyone was watching" which meant no one was watching. Keep in mind that even if a person with PWS is slim, it does not mean they have total food control. Add too many food temptations around, the lack of feeling full, and the high pain threshold, and you have the potential of filling the stomach dangerously full. Also add to the risk factors that in a study sponsored through PWSA (USA), a significant portion of people with PWS in the study had delayed stomach emptying, and in another recent study sponsored by PWSA (USA), virtually all in the study had an undetected swallowing problem which can lead to choking and/or aspiration.

We know that there are many food binging episodes of our children and adults with PWS – most not having such disastrous results, but we feel obliged to forewarn parents, grandparents, and caregivers of the potential risks. We want this to be a happy holiday season for all of our wonderful children and adults and their families.

Your child must have the security of knowing you will be strong in your commitment to keep them protected from food – in spite of themselves. Giving in, even once, means several battles ahead. Consistency is the key.

Please help us keep them safe!

Sincerely,

Prader-Willi Syndrome Association (USA)

November 24, 2015

* There is a revised Medical Alert booklet available with new important G.I information. You can order the booklet by shopping online; visit http://bit.ly/2xcElu5pwsausamedicalert. A sample can be viewed in the "Medical" section on the website. ■

Prader-Willi SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

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

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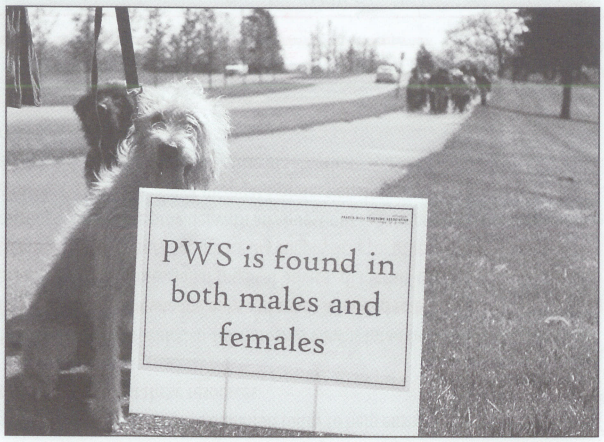
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The Michigan Chapter is On the Move using great mile markers! See page 11

on the MOVE
PRADER-WILLI SYNDROME ASSOCIATION (USA)



See pages 9, 10 and 14 for Holiday Tips and Ideas!

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