

## The Georgia View

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### EDUCATIONAL SEMINAR COMING THIS SPRING

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PWSA-GA will be hosting an educational seminar on April 27, 2019. This multi-disciplined event will highlight several of the current leaders in many areas of interest for individuals with PWS. Families, caregivers and others who play a major role in the lives of a person with PWS would find this seminar helpful and informative. Featured speakers include:

1. Dr. Jessica Duis - Geneticist from Vanderbilt
2. Hailee Hunt-Hawkins - Research Coordinator from Vanderbilt
3. Bailey Koch - Founder of Atlanta Pediatric Nutrition
4. Debbie Lange - Executive Director of PWSA-GA
5. Drew Early - Atlanta Attorney at Shewmaker and Shewmaker
6. Lisa Matesevac - PATH for PWS Study coordinator and PWSA-GA Board member

Lunch will be provided. A "Save the Date" was distributed to the membership via an email, and more details will be included in the invitation going out mid March. We hope you will join us for this informative event!

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## PENCIL US IN

### UPCOMING EVENTS

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**March 24**

**Young Moms' Gathering**, Focusing on moms of PWS with children under 12. Contact Andrea Warren [Andrea@rstwarren.com](mailto:Andrea@rstwarren.com) for details.

**April 27**

**Educational Seminar (see description above)**

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### Vice President’s Message

True confessions . . . sometimes I’m not a good listener. I’m getting better, but sometimes I revert to my old ways of selective hearing and it drives my family crazy. I have realized on more than one occasion how detrimental this can be. Just recently, I was completely tuned out while my daughter with PWS was going on and on about a guy that she is going to marry and how they are going to buy a house at the beach. After 5-10 minutes, I suddenly realized that she was asking me a question! I hear “Dad? . . . Dad? . . . Right Dad?” To which I mindlessly replied, “Sure thing.” And just like that, I agreed to everything she just said, including buying a beach house and providing grocery money so they can go to the store and buy “healthy” food for all their kids. The lesson for me is to learn to be a good listener.

At PWSAGA, you will find people who care about you and will listen to your story. It’s also a place where you will discover new resources and connect with people who know how to advocate for new opportunities. We strongly support research that will enhance the quality of life for those affected by Prader-Willi Syndrome. We invite you to join us as we work together to help our loved ones with PWS reach their greatest potential.

Father, vice president, and potentially-a-better listener,

Neal Spradlin

# PATH for PWS

## Paving the way for Advances in Treatments & Health for PWS

PATH for PWS is a study to help us better understand serious medical events in PWS over a 4-year period, as well as evaluate how PWS related behaviors change over time. The data from this study is intended to inform the development and clinical trial design of potential new treatments.

**There is no therapy provided as part of this study.**

**Q: Is my information protected?**

A: YES. All information entered into the PATH for PWS study is contained in the Global PWS Registry. The Registry is secure and is powered by the National Organization for Rare Disorders' (NORD) IAMRARE™ Registry Program. The information you provide will be 'de-identified' to remove identifying information, and aggregated with responses from other participants prior to being analyzed.

**Q: Who is supporting the PATH for PWS study?**

A: The PATH for PWS study is supported by PWSA(USA), FPWR and other international Prader-Willi Syndrome organizations. This natural history study is being funded by Zafgen with the goal being to understand the medical complications individuals with PWS experience, and what factors increase or decrease risk. This will help us understand and track changes in PWS over time.

**Q: There are many surveys in the Global PWS Registry. Do I have to complete all of them for this study?**

A: NO. There are 14 required surveys in the PATH for PWS study, and they are marked with an asterisk. Five of the surveys will be updated by you every 6 months. You can find a list of the required surveys by visiting [www.PATHforPWS.com](http://www.PATHforPWS.com).

**Q: How long will it take to complete all the surveys required for this study?**

A: We estimated that the initial set of required surveys may take approximately 2-3 hours to complete, but most parents are reporting that they complete the surveys in 1.5-2 hours. The time required varies depending on the complexity of the medical history, as well as the amount of information entered about serious medical events experienced by the participant in the last 6 months. Please note that the surveys do not need to be completed all at once. It can be broken down into manageable parts. You can save partially completed surveys online and come back later to complete and submit the surveys.

**Q: Will I be compensated for my time in completing the surveys?**

A: YES. You will receive a \$100 Amazon e-gift card upon completion of the initial surveys and an additional \$50 Amazon e-gift card every 6 months when you update the 5 required surveys.

**Q: I completed all the required surveys, but I haven't received my gift card yet. When will I get it?**

A: Processing of the Amazon e-gift cards can take up to 2 weeks. However, if it has been longer than 2 weeks and you have not received your gift card, please email [info@PATHforPWS.com](mailto:info@PATHforPWS.com) and Lisa Matesevac, PATH Study Coordinator, will assist you.

There will be several Prader-Willi Syndrome conferences this year including on the state, national and international levels. In order to keep our membership abreast of all the happenings, the flyer information for each has been gathered here. Please contact the hosting organization for further information or questions you might have.

## 10th International Prader-Willi Syndrome Conference

13 to 17 November 2019  
Cojimar Conference Centre  
Havana, Cuba

Join us and our partners the Cuban Human Genetics Society in Cuba this November to:  
share knowledge about Prader-Willi syndrome  
network, learn and collaborate  
hear great speakers

### Conference programme:

Clinical and scientific conference: 14 to 15 November  
Professional providers and caregivers conference: 14 to 15 November  
Parents and families conference: 16 to 17 November  
Activities for people with PWS: 16 to 17 November  
IPWSO General Assembly: late afternoon 17 November  
Conference conducted in English with Spanish translation during many sessions

### Key social events:

Welcome reception: evening of 13 November  
Cuban dancing show: evening of 14 November  
Gala dinner: evening of 15 November  
President's event: evening of 16 November

### Any questions?

For questions about any aspect of the conference please contact the conference office on [office@ipwso.org](mailto:office@ipwso.org). More information will appear soon on the dedicated conference [website](#).

Registration, call for abstracts and conference accommodation advice coming soon!  
meet scientists, doctors, carers and families from around the world

## **2019 PWSGA Meetings and Events Calendar**

**(rev 2/12/19)**

Here's a copy of our chapter's working calendar. As you can see, we have several different events planned, but we have not ironed out all the details yet. Sometimes it is just hard to get all our ducks in a row (or even in the same pond)! But we want you, our members, to be aware of the dates so that you can make plans to attend some or all of our events this year! As we firm up dates and times, we will be communicating this information through emails and through the newsletter. We hope that at least one of our programs will fit into your family's busy schedule. We would love to see you!

<b>February 28</b>	<b>PWSAGA Newsletter distributed</b>
<b>March 24</b>	<b>Young Moms' Gathering</b>
<b>April 27</b>	<b>Board Meeting</b>
<b>April 27</b>	<b>Educational Seminar</b>
<b>May</b>	<b>PWSAGA Newsletter distributed</b>
<b>June</b>	<b>Annual Family Picnic/Outing</b>
<b>August</b>	<b>PWSAGA Newsletter distributed</b>
<b>September 28-29</b>	<b>Fall Family Retreat @ Stone Mountain</b>
<b>October 25-26</b>	<b>National Convention in Orlando</b>
<b>November 13-17</b>	<b>International PWS Conference in Havana, Cuba</b>
<b>November</b>	<b>PWSAGA Newsletter distributed</b>



**Special Olympics**  
Georgia

## PWSAGA and the Special Olympics

If you are thinking of ways for your loved one with PWS to stay active, find new friends, and be a part of something great, Special Olympics Georgia is the place for them. There are many different sports which vary by county and by season including swimming, bowling, track and field (athletics), flag football, rhythmic/artistic gymnastics, roller skating, softball, soccer, table tennis, tennis, floor hockey, golf, powerlifting, equestrian sports, bocce ball, cycling, and volleyball that they can take part in (as well as ice skating, alpine skiing and sailing at the regional level). They don't have to be a great athlete, just be willing to participate. In addition to sporting events, many county level special olympic organizations also provide social activities such as monthly bowling outings and end of the season waterpark parties.



Many of our PWSAGA kids and adults have participated in Special Olympics in the past and continue to do so. In 2018, we had PWS Georgia athletes participate in swimming, track and field (athletics), soccer, basketball, bocce ball, equestrian sports, bowling, golf and table tennis.

In the summer of 2018, Matthew Wynne attended the Special Olympics USA games in Seattle, WA as an athlete ambassador for Coca-Cola. He had the privilege of interviewing PGA Tour golfer, 3-time major champion and Coca-Cola Brand Ambassador Jordon Spieth. This past January, Matthew was also a part of a gold medal winning basketball team in the Georgia Winter Games.

(con't on page 7)

(con't from page 6)

The experiences and friendships they are building are immeasurable, and they all love the competition. If you are interested in participating in Special Olympics, go to [www.specialolympicsga.org/become-an-athlete/find-a-program](http://www.specialolympicsga.org/become-an-athlete/find-a-program) and click on the contact for your area and look at your surrounding area as well because not all counties offer all sports and you do not need to reside in the county you wish to participate.

Bob Warren



Taylor Warren caught in this great action shot while playing basketball with special olympics.



Connelly Roach during Special Olympics Equestrian Competition



Jordan Spieth and Matthew Wynne, Coca-Cola (Photo Credit: Ted Craig)

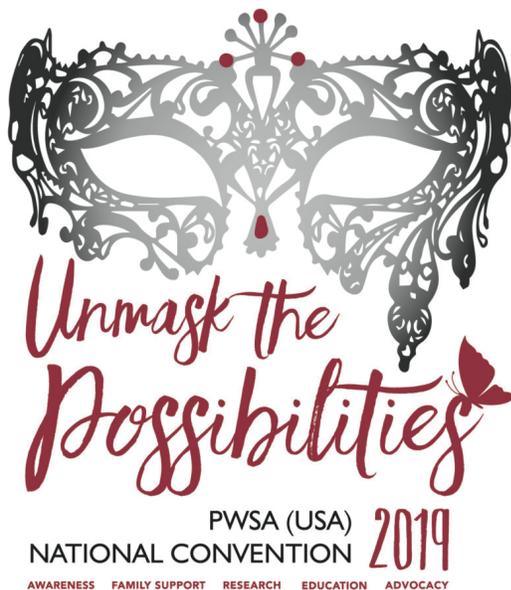


Shawn Cooper and Taylor Warren congratulating each other on their swimming heats at Special Olympics.

Connely Roach and Avery Gavin showing off their medals received in the Special Olympics equestrian while Connely's proud little sister joins in the fun.



Here, Matthew Wynne is posing with his gold medal he earned with his team, the Special K's from North Fulton, in basketball at the Special Olympics winter games this past January.



**With spring just around the corner save \$50 per General Conference registration until March 31st!**

Visit <https://www.pwsausa.org/2019-pwsa-usa-national-convention/> for more information

October 23rd– 26th, 2019  
Caribe Royale, Orlando, Florida

### **Medical & Scientific Conference – October 23rd & 24th**

During this two-day event, Scientists, Researchers, and Medical professionals from different disciplines share ideas and report on progress, helping to meet the ever-present goal to support research that will identify effective treatment, and improve the quality of life for individuals diagnosed with PWS.

### **Professional Providers Conference – October 24th**

Educational, Social Services, and Residential professional providers come together to discuss identified and supported best practice and standard of care approaches, as well as to provide a critical in-person, solution-orientated exchange of ideas for specific concerns that can be addressed by experts in the field.

### **General Conference – October 25th & 26th**

This two-day event attracts parents, grandparents, caregivers, and professionals. The attendees are skillfully guided through a choice of multiple learning tracks covering an array of topics that can be tailored to their individual preferences. It is a time to build relationships with other families, attend counseling sessions and support groups, meet with top specialists and authorities on PWS, and just have fun. Experts in the field provide attendees with up-to-date information and resources for addressing the very complex needs of supporting and caring for an individual diagnosed with PWS.

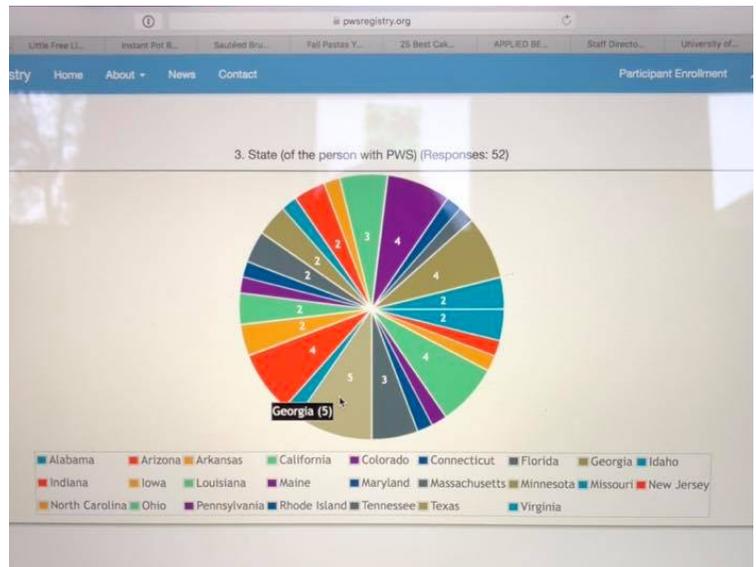
# Georgia Association for Prader-Willi Syndrome, Inc. (PWSA/GA)

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The Georgia Association for Prader-Willi Syndrome, Inc. (PWSA/GA) is the only organization in Georgia dedicated to the support of individuals and families affected by PWS. PWSA/GA is registered in the state of Georgia and with the Internal Revenue Service as a charitable, non-profit, tax-Exempt organization. PWSA/GA is a chapter of the national Association PWSA (USA), located in Sarasota, Florida. *The Georgia View* is published quarterly by PWSA/GA. Opinions expressed in the *Georgia View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA/GA unless so stated.

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Make sure we have current contact information for you and your loved ones' supporter so that you will be updated as set the dates and times of events which have not been finalized at the time of this newsletter. Send corrected contact information to [pwsaga@earthlink.net](mailto:pwsaga@earthlink.net)



Do you know what this is? Check out page 3 and make sure your loved one with PWS is counted!

### Mission Statement

To provide information, education, and family support that will empower people with Prader-Willi Syndrome to lead quality lives as productive citizens.

## Letter from the Editor

As life often does, things are speeding along with our state PWS chapter. We have some new board members, such as myself and others, who will be introduced in the next newsletter. With new blood comes new ideas, and I believe this is shaping up to be very exciting times. Part of this is the taking of an existing event and putting a fresh face on it. Lisa Matesevac has developed an outstanding line-up of speakers for our educational meeting coming up in April. There will be information and strategies discussed, and we think everyone will find something useful to their current situation. For more information, see page 1.

Numerous conferences are scheduled throughout the coming year. It might be time to take that trip to Cuba you have been thinking about or perhaps just to Orlando. Information on both are included in this issue to get you thinking about attending. We hope that some of you will be able to attend, and we would love to hear about your experience if you do go to either.

In the interest of getting our PWS people up and moving, Bob shared some information about Special Olympics Georgia. The activities vary across the state, but it is open to anyone, free to participate and not county specific. Their website is full of more information.

And if you have not already done so, please consider completing the PATH for PWS surveys. Our own Lisa Matesevac leads up this joint project endorsed by PWSA(USA), FPWR and other international organizations. This collection of information will help researchers with clinical trial designs for potential treatments. Five hundred people need to complete the surveys, and we are only halfway there. (I will add that Georgia is tied with a MUCH LARGER state with percentage of people completing the surveys. We really want to be on top, people! And no, I'm not competitive at all)! — Tammy

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