



## The Georgia View

# Sorry, I haven't written.

Sitting down to write this newsletter reminds me of an old greeting card I sent to my Australian penpal as a teen. There was a mouse on the front who stated matter-a-factly that he was sorry but he had not written because everything was the same ol' same ol'. I don't know about you, but there is a lot of the same ol' same ol' right now. The weeks have stretched on into months for many of us staying close to home. I do not know if anyone has worked up the stages of quarantine yet but I trust you are like me. We did not really realize how long the "long haul" was going to be, did we? I remember the week before quarantine trying to buy up supplies to keep us out of the stores for as long as possible. I bought the largest bottle of shampoo and conditioner I could find. I was convinced that it would last me through the uneasy and unsettled life that COVID-19 was about to bring. Fast forward to last week when I emptied them. So much for thinking this was going to outlast COVID-19. Now the days move on as the new normal has become routine. We have cleaned out our pantries, organized our spices and emptied our linen closets. This feeling of uncertainty and the lack of routine has our people with PWS upset and anxious as well. They feel the same concerns and fear we feel and they desire to return to life before. But they may not be able to process it nor verbalize their concerns.

We, the board, have continued to meet virtually on a regular schedule to discuss the business of the chapter. While we wait for a time when we can gather together either at a picnic, family outing or educational seminar, we continue to be here for you. We have been able to support families vitally with their individual needs and always welcome your emails and calls. We are keeping a close watch on the situation and have made tentative plans for a get together sometime in the future. Until then, we all hope you and your family stay safe and healthy. Feel free to reach out to us if there is something you think we could help you with.

One thing that is new is PWSAUSA's updated color scheme which we will follow. So there, I wrote you to tell you that!

By Tammy Galloway

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## Letter from the President

I hope you and your families are well and finding your way to a new normal. School, work, recreation, and social gatherings all look drastically different than they did one year ago. Even though we haven't been able to have any chapter events since March, we are still at work. We have regular board meetings (on Zoom) and continue to discuss ways to support Georgia families and dream about future plans. One exciting event that is taking place was created by a Georgia mom, The Running for Research fundraiser, which took place January 9, 2020. You can read the details in "Georgia Heroes Continue to Fundraise" in the newsletter. Be sure to check out her Facebook page and get involved. Donations will be accepted through the end of this month. Everyone can impact the future of PWS through this event whether by running, donating, or sharing the information with others. Thank you, Kelly and the other Georgia families, for all you are doing to support research. We are grateful! Thank you, parents and caregivers, for what you do every single day to support our loved ones who have PWS. There is much talk about heroes in the current global challenges – you are heroes, too.

Neal Spradlin  
President, PWSAGA

## Georgia Heroes Continue to Fundraise

While the world turned upside-down for the last ten months, reacting to the pandemic and focusing on flattening the curve, several Georgia families continued their annual fundraising efforts via virtual settings. The Matesevac family of Lawrenceville held their 4th annual Atlanta One Small Step kickball tournament fundraiser remotely last November. Although everyone who has ever attended this event will tell you how much fun we have competing in the tournament, it was not possible to practice proper socially distancing while during a spirited game of kickball. This year participating families created their usual kickball fundraising pages for their loved ones via the One Small Step website. Families were encouraged to all play kickball with their own quarantine bubble team while posting pictures via Facebook. Lisa and Mike have raised \$61,904 in Atlanta over the four years in honor of their son, Evan, for research. This is their smaller, annual fundraiser with their larger one being held in their home town of Silver Creek, NY during July each year. While virtual as well this year, this 5th annual fundraiser has brought in \$71,602 over the eleven years with 100% of the donations going to research.

In another event, the Guillou family, along with the Abshires, the McCabes and the Owens-Harris families of Georgia were among 50 teams who raised \$119,793 in the Running for Research Prader-Willi Syndrome Virtual 5K. Our Georgia families were responsible for \$39,064 of the funds raised. For Kelly and her husband, Stephen, and daughter, Clementine, this was their third year participating raising \$19,000 and \$29,000 respectively the previous year. They ran in the virtual race this pasted Saturday near their home in Fayetteville. The RFR giving platform will be open through January 31, 2021. Please follow this link to make a donation: <https://donate.giving.ufhealth.org/.../running.../c274151>



The efforts of these families and those who donated in either of these fundraising efforts show your dedication to helping our loved ones with PWS through research. These fantastic families have been fundraising for PWS for many years now, and we will look forward to supporting their efforts again next year. We would like to thank them for the dedication and service, and we would like to encourage others to find their own unique ways to fundraise and bring awareness. Please see page for more photos of our fundraising heroes!

left: Kelly, Stephen and Clementine Guillou (PWS)

# PATH for PWS

## D-dimer Sub Study

At the start of the PATH for PWS study, participants who live in the United States had the option to consent to participate in the D-dimer sub study. D-dimer is a protein that is found in the blood, and is present when a blood clot is forming or has recently formed. The aim of the sub study was to determine if persons with Prader-Willi syndrome have higher levels of D-dimer in their blood and to identify whether the D-dimer test could be used to understand their risk for forming blood clots.

The D-dimer sub study ended on September 30, 2019. We want to express our gratitude to the 215 participants who had blood drawn for this study. Completing a blood draw on a person with PWS is not always easy, for various reasons, and we are thankful for your contributions to PWS research. We are just beginning to analyze the data and have found that overall 15% of the participants had elevated D-dimer levels. We plan to publish the complete findings in a medical journal in the near future, and we will share them directly with you.

As a reminder, it is important to seek medical attention immediately if your loved one exhibits any signs or symptoms of a blood clot. Below is some additional information on what to look for.

## How often are Serious Medical Events happening to our loved ones?

The picture is becoming clearer thanks to the continued commitment of participants who update surveys. We have learned that approximately 20% of individuals with PWS have experienced a **Serious Medical Event** since the beginning of the PATH study. These events have included surgeries, visits to the emergency room, blood clots, mental health crises, and binge eating episodes, among other things. The age distribution of those experiencing serious medical events recorded to date is shown below. If you aren't sure if an event qualifies as a 'Serious Medical Event' contact the PATH study coordinator at [info@PATHforPWS.com](mailto:info@PATHforPWS.com) or call (760)420-5878. See page 5 for a graph of what the surveys show us so far.

## Don't Forget to Update Your Surveys

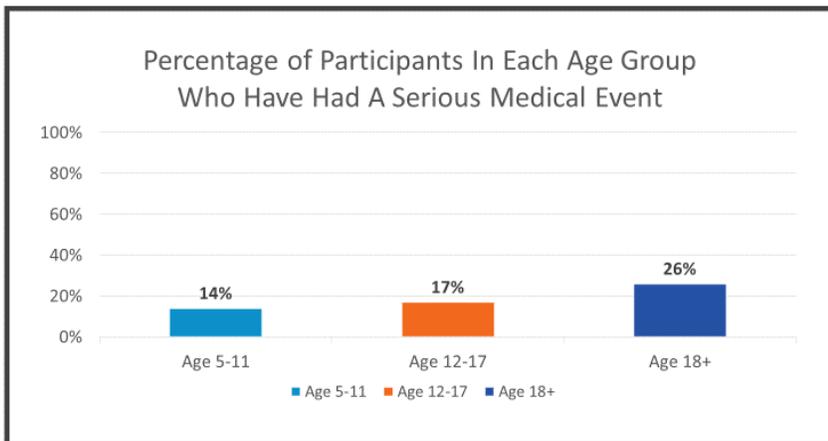
The Global PWS Registry Needs YOU to Update Your Surveys! By updating your current surveys and/or completing new surveys, you ensure that the most current information is available to support PWS research and improve care. And by updating your surveys TODAY and be entered to win 1 of 10 \$50 Amazon eGift cards! Updates must be completed by January 31, 2021 to be eligible. Read our blog for more details, including the list of eligible surveys. <https://fpwr.us/38oJ2WI> Go to <http://www.PWSRegistry.org> to update your surveys now!

## Nominations for Volunteer of the Year

PWSAUSA is accepting nominations for volunteer of the year. This is a great way to recognize volunteers and chapters for their contributions in several different categories. Nominations must be submitted by February 28, 2021. See <https://www.pwsausa.org/volunteer-nomination/> for complete details.

## What the Global Registry Shows Us Regarding Serious Medical Events in People with PWS

The following information is an example of the kinds of data collected and housed in the database which help researchers, parents and doctors when trying to understand what might be going on with their loved one with PWS. The collection of this type of information is a tremendous resource for all of us. Please consider participating if you have not already done so.



Approximately 4% of the participants have experienced **MULTIPLE** Serious Medical Events since the inception of the study. The average age of a participant who has had multiple events is 23. It is clear that participants in the 18+ age group comprise the majority of participants for which a **Serious Medical Events** is documented. The 18+ age category represents 40% of the total number of participants enrolled in the PATH study yet, 56% of the total number of medical events have occurred in this age group. Of those in the 18+ age group, 26% have reported having a medical event. In the 12-17 age group 17% have reported having a medical event and in the 5-11 age group 14% have reported having a medical event.

## Meet the New Board

This issue of the newsletter, I would like to introduce myself, Tammy Galloway. I joined the board mid year of 2017 and took over as secretary and newsletter editor at that time.

### What are your PWS credentials? (Relationship and role with someone with PWS)?

I am the mother of a 22 year-old, Kyle, who has Prader-Willi Syndrome. He was born at Piedmont Hospital, and we have always lived in the north-metro area.

### Tell us something about you. Where did you go to school? Degrees? What kind of work do you do?

I grew up in central Georgia and came to Atlanta for college. I have a BA and MA in history from Georgia State. I worked as the manuscripts archivist at the Atlanta History Center and assistant university archivist at Emory University. I quit that job when Kyle was born to take care for him. I have published three books of historical, non-fiction. Most recently, I have worked as a freelance writer for CountyLine magazine in Johns Creek and am writing the histories of private institutions. Currently, I am writing the history of Holy Innocents' Episcopal Church after finishing the history of Holy Innocents' Episcopal School last year. And I work as an Event Coordinator at the Atlanta History Center on a as-needed bases.

### If you find yourself with a free afternoon, what might we find you doing?

I enjoy my plants and there is always something to be done in the garden. I also love a good home improvement project. I am currently refinishing our bar stools in a worn, distressed style. I bought myself a stain/lead glass semester long class for Christmas. And I enjoy textile crafts like knitting, sewing or silk painting although my kids are convinced that laundry and cooking would rank high on my list of hobbies.

### What particular strengths do you bring to the board position?

My strengths are writing and organizing information. Taking the minutes at the board meetings, creating the agenda to reflect the old business, and organizing the newsletter are the most obvious ways I support the chapter. The other thing I bring to the board is 22 years experience in PWS with Atlanta area doctors, therapist and educators. I am at a point of transitioning from public school to having an adult with PWS which is a completely new experience for me.

### Do you have any particular things you would like to achieve while on the board?

I would like to bring the chapter to the different regions of Georgia so that everyone feels they are a part of organization and can create close relationships with other, great PWS parents we have around the state.

### Is there anything you would like to tell the chapter members about yourself or what they might expect?

This chapter is as much about you finding the support you need to get through the rough times as it is anything else. Don't pass up connecting with others who are on the same journey. Just to have someone to lend on or talk to is priceless.

## Georgia Heroes Continue to Fundraise



Left: Amy Owens Harris & Thomas Harris (PWS)



Right: Craig & Evan Matesevac



Above: McCabe and Abshire families. Jessica McCabe (kneeling) is holding Julius McCabe (PWS). Jennifer Abshire (right) is holding Claire Abshire (PWS).

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

Board of and Officers  
 President, Neal Spradlin  
 Vice President, Lisa Matesevac  
 Secretary/Newsletter, Tammy Galloway  
 Treasurer, Bob Warren  
 Board Members,  
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 Marina Jones  
 Marcello Schutzer  
 Tom Underwood

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 many of the dates and times of events have not been finalized at the time of this newsletter. Send corrected contact information to [info@pwsaga.com](mailto:info@pwsaga.com)

### Mindfulness Study

The Mindfulness-Based Intervention for Temper Outbursts intends to evaluate the feasibility and acceptability of a mindfulness-based intervention for managing temper outbursts in PWS. The study will also evaluate the interventions impact on anxiety. This study will be conducted remotely via phone, email and video-conference and is, therefore, open to families both within and outside of Australia.

Eligible participants with PWS, their primary caregiver (parent or resident carer) and a teacher or support worker will be invited to participate in an 18-week trial. Two weeks before the start of the trial primary caregivers will be trained to use and teach the mindfulness-based intervention. The 18-weeks will be divided into three six-week periods termed baseline, intervention and follow-up. Throughout the 18-weeks, primary caregivers and a teacher support worker will be asked to monitor the person's behaviors. During the intervention period, primary caregivers will teach the mindfulness-based intervention to the person with PWS.

A webinar sharing details on this study was recorded May, 2019. You can watch the webinar below or [read a transcription of the webinar on our blog](#). Visit <https://www.fpwr.org/clinical-trials/study-mindfulness> for more information.

### Mission Statement

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

## Some of the Studies Recruiting Now

### CBDV as Treatment for PWS Study

This phase 2, randomized, double blind 12-week treatment trial of Cannabidiol (CBDV) will assess the affect of CBDV on behavior in people with PWS. The study is recruiting 26 patients ages 5 to 30 years with PWS and will take place at the Montefiore Medical Center in Bronx, NY. This study is opening soon. See <https://www.fpwr.org/clinical-trials/cbdv> for more information.

### Pitolisant for Excessive Daytime Sleepiness in Prader-Willi

This study will measure the effectiveness of the drug, Pitolisant, on excessive daytime sleepiness in PWS in an 11 week double blind, placebo controlled study, followed by optional open label extension. Participants can range from ages 6-65. In the southeast it will be conducted at Vanderbilt University and the University of Florida. They are currently enrolling participants. See <https://www.fpwr.org/clinical-trials/pitolisant> for more information.

### Evaluating the Play-Based Remote Enrichment to Enhance Development (PRETEND) Program

This 8-week telehealth (remote) intervention program focuses on building play skills, emotional understanding and regulation, and social skills. The study involves two in-person visits, one at the beginning and one at the end, that would be conducted in the family's local area and then the 8-week intervention, which is all done via remote videoconferencing. Participants must be between the ages of 3 and 12. For more information, visit. <https://www.fpwr.org/clinical-trials/study-pretend>.

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