



## The Georgia View

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### FAMILY RETREAT AT STONE MOUNTAIN

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The Georgia Association for Prader-Willi Syndrome (PWSAGA) is pleased to offer families in our state an opportunity to gather for a relaxing getaway of fun and support. This event is made possible by the *Georgia Department of Health and Developmental Disabilities (DBHDD)*. This year's retreat will be held at Stone Mountain Inn, inside Stone Mountain Park, Stone Mountain GA. Families will arrive at the Inn on Saturday, September 28, 2019. Registration begins at 10:00 am. This retreat is sponsored by PWSAGA and is FREE to families registered as members of The Georgia Assoc. for PWS. All meals for this event are included along with lodging for Saturday night. Local families are welcome to register for "Event Day" participation only (no lodging).

*(continued on page 3)*

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# PENCIL US IN

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## UPCOMING EVENTS

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**September 28-29**

**Fall Family Retreat @ Stone Mountain**

**October 25-26**

**National PWS Convention in Orlando, FL**

### IN THIS ISSUE

Grants for National Convention	2
Fall Family Retreat	1&3
PATH Update	4
Calendar of Events	5
Meet the Board	6-7
Sibling Stories	7

## Grants for National PWS Convention

The board is inviting all residents of Georgia to complete an application for a scholarship that will cover their registration fees of the PWSA (USA) National Convention scheduled for October 23-26 in Orlando, Florida. Eligible for the scholarships are: persons with PWS, their siblings, and their parents or legal guardians. If the application is granted, the chapter will pay the fees directly to PWSA (USA). Those who have already registered, can submit an application as well, and, if granted, their registration fees will be refunded.

There is funding available for at least 50 attendees, and the only criteria for the application is the awardees' be related to a person with PWS. Registration for youth has closed. Currently can accept registrations for adults only. No financial need or information is required. The board is encouraging all attending the convention to complete this application.

Attendees will pay their other expenses including their transportation costs and hotel accommodations, as well as the cost of the gala dinner if they wish to attend it. When completing the application, proof of a hotel reservation confirmation needs to be provided. Some conditions apply.

Please email our executive director at [pwsaga@earthlink.net](mailto:pwsaga@earthlink.net) for further info to receive a copy of the application. The deadline to submit applications is September 15, 2019. Details of the conference and hotel accommodation bookings are at [www.pwsausa.org](http://www.pwsausa.org)

Thanks to the state of Georgia and DBHDD for providing funding which makes this and many of our programs possible.

(continued from page 1)

## Family Retreat at Stone Mountain

About Stone Mountain Inn: Located inside of Georgia's Stone Mountain Park, the historic Stone Mountain Inn provides magnificent views of Stone Mountain. The Inn is a carefully preserved replica of a nineteenth-century plantation. Check out all the activities you can enjoy at the park at [www.stonemountainpark.com](http://www.stonemountainpark.com)

A special day of relaxation is being planned for this year's theme of "Parental Self Care". Hailee Hunt Hawkins will join us, once again, to share her vast knowledge and suggestions on our theme.

There will be activities for Mom's and Dad's to enjoy. For our "kids" there will be an activity room with supervision and activities provided by the Rotaract Club (Claire Gordon managing). Meals for this group will be served in the Activity Room.

There are many places to enjoy around the hotel grounds including the rocking chair front porch and a swimming pool.

Included with your stay:

- **Free entrance to park (NOTIFY GATE AGENT YOU ARE ATTENDING PWS EVENT)**
- Lodging: one hotel room per family. Limit 6 people per room.
- Lunch on Saturday
- Dinner on Saturday
- Entertainment on Saturday
- Breakfast on Sunday

For the evening meal on Saturday night, parents and caregivers will enjoy a special (not appropriate for anyone with PWS) meal along with a cash bar (bring cash). No one under age 21 is included in this special meal. Our "kids" and siblings will be served a PWS friendly meal with celebratory activities provided by the Rotaract Club. On Sunday morning, September 29, a breakfast buffet, in the Restaurant, is included for those who stay overnight. Another benefit is **mileage reimbursement** for families. Reimbursement forms will be available at the event!

**NOTE: By completing registration for this event, you are agreeing to become a registered member of PWSAGA.**

**PLEASE REGISTER ONLY IF YOU ARE SURE YOU CAN COME! NO SHOWS ARE AN EXPENSE WE TRY TO AVOID. ONLY 1 TICKET IS NEEDED PER FAMILY. ADDITIONAL QUESTIONS ABOUT YOUR GROUP WILL BE REQUIRED TO FINISH REGISTRATION.**

### FAQs

#### **What are my entrance/parking options for getting to and from the event?**

Your entrance to the park has been paid for by PWSAGA. Notify gate agent that you are with our group and your entrance will be free. There is ample free parking at the Inn and throughout the park.

#### **How can I contact the organizer with any questions?**

Please contact Debbie Lange, Executive Director, with any questions you may have. She can be reached at 770-886-2334 or [pwsaga@earthlink.net](mailto:pwsaga@earthlink.net)

# PATH for PWS

PATH for PWS continues to move forward. They will have presentations at both the FPWR and PWSA conferences, updating the progress. In the meantime, everyone should be aware that participants will receive reminder emails to update five surveys every six months. Those are:

1. Hyperphagia and Food Behavior
2. Food Safe Zone
3. PWS Profile
4. Research Trials
5. Thrombotic and Serious Medical Events

Thank you for your participation in making a difference in our loved ones' lives!

## My Double Life as a Swede/Englishman with Prader-Willi Syndrome

(Reprinted from <https://ipwso.blogspot.com>)

(Anders' mother, Jean Phillips Martinsson, was IPWSO's first President from 1991 to 1998 and the founder of IPWSO - ed.)

My name is Paul Anders Martinsson and I live in Sweden. I'm now 48 yrs. old and have always loved my double life!

My father was Swedish and my mother is English. I wasn't diagnosed with PWS until I was 14 years old. It was then I decided that I wanted to learn English and follow in my mother's footsteps by going to boarding school in the UK. On arrival I spoke no English but, after 2 yrs there, I was completely fluent – contrary to advice given to us by the Swedish specialists, who insisted that my parents should only speak the one language to me – not both.

I shall never forget those 2 years, especially when I joined the ATC Air Training Squadron and was awarded a Flying Certificate!

The only thing I missed during those 2 yrs in the UK were my judo classes. I started learning when I was 8 yrs. old. Today I still have Solveig, the same teacher, masses of gold, silver and bronze medals and a brown belt.

Since I was 22 yrs. old, I've been living in a group-home with six others who have PWS. We all love it and have our own 45 sq.m. apartments, with balconies and our own garden plots. We go to work every day, and have been living together for 26 yrs.

Beside these 6 friends, I have many others, without PWS, whom I've known since I was born. I still have regular contact with them. We go to the cinema, concerts, musicals, and work on computers, smartphones and tablets together. They always come to my annual birthday party, where I invite them all for fruit salad, light ice-cream and alcohol-free cider. I also have a wonderful Ethiopian girl-friend!

## **2019 PWSAGA Meetings and Events Calendar**

**(rev 9/10/19)**

Here's a copy of our chapter's calendar. As we look forward to the cooler fall temps, there are several Prader-Willi related events to explore around the southeast. Please plan to join us in September at Stone Mountain for our Fall Family Retreat. See pages 1 & 3 for details!

**September 28-29**

**Fall Family Retreat @ Stone Mountain**

**October 3-5**

**Foundation for Prader-Willi Research Convention,  
New Orleans, LA**

**October 25-26**

**National PWS Convention, Orlando, FL**

**November 2**

**One Small Step Kickball Tournament, Atlanta**

**November 13-17**

**International PWS Conference in Havana, Cuba**

**November**

**PWSAGA Newsletter distributed**

**February**

**PWSAGA Newsletter distributed**

There will be several Prader-Willi Syndrome conferences this fall including on the national and international levels. We encourage you to participate in these as you find you can. If you will be traveling to a conference, let us know and we will help you connect with other Georgia families making the same trip. For further information or questions you might have regarding specific conferences, please contact the individual organization or visit their website.

## Meet the New Board

This issue of the newsletter, we would like to introduce our new Vice President, Lisa Matesevac. We are thrilled to have her join the board. Many of you have known her for years but might enjoy learning something new about Lisa in our recent interview.

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

I have a 13 year old son, Evan, who has Prader-Willi Syndrome. I currently serve as the Vice President of the PWSA-Georgia Chapter. I am also married for 24 years to Michael and have 2 other boys, ages 17 and 20.

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

I was born and raised in Buffalo, NY until moving to Atlanta, GA in 1997 to serve as Director of Audiology in a large pediatric ENT practice where I worked for 21 years. While in Buffalo, I attended Buffalo State College for my undergraduate degree in Communication Sciences and Disorders and University of Buffalo for my Master's degree in Audiology. In 2006, I went back to school but little did I know that later that year my son would be born with a rare syndrome. Needless to say, the first year was hectic and at times, overwhelming. My studies proved to be a helpful distraction from the worries about my son's future. In 2008, I graduated with my Doctorate in Audiology.

Growing up with a younger brother with severe hearing loss inspired me to become a Pediatric Audiologist. I dedicated over two decades to the pursuit of helping families understand communication options, hearing technology and navigation of school support services. In October 2018, I changed careers and began my new role as the PATH for PWS Coordinator. This is a longitudinal natural history study documenting serious medical events in PWS with the goal being to inform development and clinical trial design for potential new treatments in PWS. It is a four year study during which time caregivers will be asked to update information every 6 months. This study is important because it will help track changes in PWS over time. It will also help with understanding the medical complications individuals with PWS experience, and what factors decrease or increase risk.

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

As a family we like to explore the outdoors, going on hikes in local parks. I also enjoy reading, particularly mysteries and science fiction.

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

I enjoy participating in outreach and organization of activities. As a medical care provider, I understand the importance of providing guidance and education to families so they may make informed decisions about the care of their children. Of equal importance, I advocate for parents to expend energy on self care while caring for a child with special needs. This is critical to the health and well being of a family. I enjoy organizing activities for the chapter. This year I participated in the organization of the Educational Seminar featuring speakers such as Dr. Jessica Duis and Hailee Hunt-Hawkins from Vanderbilt University. I am also actively assisting with organizing the Annual Family Retreat at Stone Mountain.

*(continued from page 6)*

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

I have several goals, some of which are long term for the chapter. I would like to increase membership by implementing a statewide campaign targeting medical professionals and hospitals who can provide membership information to the patients they encounter. I would like to advocate at the state level to have Prader-Willi Syndrome recognized as a qualifying disability, clearing the path for access to state assistance programs. Engagement events around the state are an important future goal to better reach the communities outside of Atlanta.

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

I am committed to serving the PWSAGA chapter with dedication to service and a focus on outreach and growth. I encourage the sharing of ideas so we can best serve the needs of the chapter members. I am honored to serve alongside my distinguished board members committed to serving the families of Georgia.

## Sibling Stories

In this segment, siblings of those with PWS are encouraged to share their stories, feelings or concerns about life as a PWS sibling. This issue Madeline Jones tells us about Jonathan:

“It’s no secret that being a PWS sibling is challenging. My brother, Jonathan, is 10, and it certainly hasn’t been a walk in the park. Over the years, PWS has tested my patience, my temper, and my understanding of how my brother thinks. However, as I matured I have learned that Jonathan is teaching me more about life than anything I could learn at school or online. Having a sibling with PWS is not always easy, or fun, or exciting. One thing I do know is that my brother looks up to me and learns from everything I do. I also know that I wouldn’t have it any other way.”



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

**Upcoming Holidays**

As many look forward to the upcoming holiday season, we connected to someone with PWS must prepare for a season of being on guard at traditional holiday gatherings. Featured in the next newsletter, let's share our strategies for facing buffets full of food, dieting in the face of a table of desserts and disrupting schedules. And let's share what we have tried and didn't work. Send your suggestions to the editor.

**Crisis Support**

If the person with PWS is experiencing a crisis, know that you can reach out to our executive director who is experienced in dealing with school issues and medical situations. Contact info is to the left of this box.

*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

There is a hint of fall in the early morning hours. That means the Fall Family Retreat is just around the corner! This is one of our most popular annual events, and we would love to see everyone there. Come for the day or for the weekend! It will expand on our previous years' successes with the addition of programs and new elective activities to enjoy as well as some old favorites like the laser show, free time to explore the park or visit with friends and, of course, the pool. Lodging, park entrance, meals and mileage are all covered. See the details on pages one and three. Registration closes soon.

Another new thing we are doing this year is offering grants to Georgia families wishing to attend the national PWS convention in Orlando in November. The grants will cover the registration fees of the convention. For information regarding the grants and how to claim one, please see page two.

In this issue, we continue our Meet the Board segment and get to know our new vice president, Lisa Matesevac, a little better. See page six for the full story. We are so thrilled to have her join the board!

From IPWSO's blogspot, we meet Paul Andres Martinsson, son of Jean Phillips Martinsson, who founded International PWS Organisation and served as president from 1991-1998. We learn about him and his experiences as a man with PWS on page four.

And we thank Madeline Jones for sharing with us her experiences of being the older sibling of a person with Prader-Willi Syndrome in Sibling Stories on page seven.

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