



The Georgia View

A NEW BEGINNING

Every year, January brings the hope for something new. A new beginning. As we as a chapter look forward to a new year, we are also facing a new beginning but not one we had anticipated. In August, Governor Brian Kemp ordered all state agencies to review their budgets and to make a 4% to 6% cut in a mid fiscal year adjustment to make up for the lower state income tax rate and to keep the pay increase promised to educators all while keeping the state within its budget for the year.

Early on, it appeared that public health, mental health and disabilities would be spared any cuts. As lawmakers combed the budget to make the necessary cuts to keep the state on budget, a little-known contract under Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) attracted some attention. It was PWSAGA's contract. With this contract, DBHDD would call our chapter to help any people with PWS who they encountered who needed assistance. We had been rewarded such an honor through the connections of Dr. Greg Talley some 16 years ago. Through the years, the contract went through several changes and budget increases and grew into being a major part of our organization. In the most simplified terms, the contract was a way for the state to pay the chapter to provide services and support to people with PWS and their families. This was to give the state somewhere to send families and their people with PWS to for most current information and advice.

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PENCIL US IN

In order to stay current with our latest developments and to learn about our coming events sooner, join us on Facebook under Georgia Association for Prader-Willi Syndrome.

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Letter from the Editor

We hope that each of you are doing well and enjoying the rain. Just kidding. I know we all are looking forward to some sunshine and warmer temps. But before we get there, let's not forget to email or call our state senators and representatives. In this newsletter, we have shared ways to contact your representatives and shared talking points that you are welcome to use when formulating your argument.

As of right now, we are no longer in a contract with DBHDD due to midterm budget cuts mandated by the Governor. If the House finalizes the budget as it currently stands, it will go on to the Senate where we can appeal again. After the Senate finishes with their cuts and changes, a committee will be in charge of making the budgets agree. And although that sounds like a lot of steps, the House will be sending their version of the budget to the Senate on or before March 12. I contacted my Senator, and he responded within the hour that he would see what he could do although it isn't in the Senate yet. My House Representative also responded early the next morning that he was looking into it. And I went ahead and appealed to the Chair of the Appropriates Committee as well. Yes, the time to act it now.

As things move along, our members will be able to keep abreast of the happenings by joining us on Facebook at Georgia Association for Prader-Willi Syndrome. We highly encourage everyone to join us there. In addition to details as they relate to this matter, we also share other information as it relates to our people with PWS. And please make note of our new mailing address (9585 Rod Road, Johns Creek GA 30022), new email address (info@pwsaga.com) and phone number (404-955-0296).

Thanks,
Tammy Galloway, secretary & newsletter editor

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A New Beginning

Educating others about the syndrome was one aspect of the service as was talking to families who were in crisis situations. Community outreach, being the PWS expert to schools, members of the medical community, and providing support to families was the main objective of the contract. It required a certain number of events in each category in order to meet the terms of the agreement. There was a lot of bookkeeping and counting that took place to track everything. And it dictated many of the things we had to do and when we had to do them. But there were categories that allowed us some fun outings as well. It is this contract which allowed us to sponsor events such as the Braves game last spring, the annual family retreat at Stone Mountain Park each fall, the annual Educational Workshop in the spring and a salary for an executive director to oversee it all. Each of these programs were paid for by the state of Georgia via the contract with the cost ranging from a couple thousand up.

We are not the only ones being negatively effected by these cuts. The area of mental health which also falls under Judy Fitzgerald, commissioner of DBHDD, is also seeing cuts in an area which is predicted to result in an increase in the suicide rate. Fitzgerald has been in budget meetings and told legislators that these are “painful cuts.” Other health agencies experiencing cuts include the Department of Human Services, which is where caseworkers who process applications for Medicaid and other benefits are housed. The department would eliminate just over 100 open positions for eligibility caseworkers. The largest cuts were grants to county public health departments which will have a large, negative impact in rural areas.

How can you help? Perhaps you used the chapter for support in an IEP, or enjoyed meeting other PWS families at the Braves game, or benefited from some respite at the family retreat at Stone Mountain. Email or call State Rep. Katie Dempsey, R-Rome, the chairwoman of the House Appropriations subcommittee who oversees the DBHDD budget. She needs to know that this cut effects real people. Explain to her what PWSAGA means to you and your person with PWS. Make it personal by giving her examples of how you have benefited. Rep. Dempsey’s address is 245 State Capitol, Atlanta, GA 30334, and her phone number is 404.463.2248.

These debates are going on right now, and we strongly encourage everyone to contact State Rep. Dempsey to express your concerns for having our contract cut. And don’t just stop with Dempsey. Here is a link to the list of all the state representatives who are on the appropriations committee. They are in charge of the state’s budget and these cuts. <http://www.house.ga.gov/Committees/en-US/Committee.aspx?Committee=88&Session=27> See if your representative is on this committee and let them hear from you. Also use the following link to identify and connect with your state representative and express your concern to them as well: <http://www.house.ga.gov/representatives/en-US/Member.aspx?Member=92&Session=27> Legislators are trying to make changes to these cuts. Perhaps we can effect these cuts in some matter for the next fiscal year.

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PATH for PWS

Just a reminder that PATH for PWS continues to move forward. Everyone should be aware that participants will receive reminder emails to update five surveys every six months. Please be on the lookout for these surveys. Here's where to find the ones that are to be completed every six months:

- Thrombotic and Serious Medical Events _____
- Hyperphagia and Food Behavior _____
- Food Safe Zone _____
- PWS Profile _____



Results (11)	Updatable (40)	Graph Results (50)	Surveys to Retake (5)
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- Research Trials _____



Although the time it takes to complete the surveys may vary depending on the participant's medical history, we expect these follow-up surveys to take approximately 30 minutes overall to complete. Once you complete this list of surveys, you will receive a \$50 [Amazon.com](https://www.amazon.com) e-gift card. Thank you for your participation in making a difference in our loved ones' lives!

Talking Points to Request Reinstatement of State Contract

1. Prader-Willi syndrome (PWS) is a life-threatening disorder by which individuals with this syndrome experience hyperphagia, a debilitating hunger that drives them to eat without limits and can result in death by stomach rupture.
2. Cancellation of the contract compromises the safety and health of people with Prader-Willi syndrome in the state of Georgia. All previous supports have been eliminated.
3. One of these supports was to group homes to provide strategies to keep those with PWS as safe as possible.
 - a. DBHDD is not equipped to manage the needs to those with PWS in crisis
 - b. DBHDD continues to have an expectation that our chapter will provide critical supports without the necessary funding to employ a person to do so.
 - c. PWS is a profoundly unique and serious medical condition that few truly grasp the intricacies of the diagnosis and even fewer are equipped to manage.
 - d. We are no longer able to meet the needs of our community and the end result is that those in crisis remain in crisis, at risk for death.
4. Other impactful services provided included support for IEP meetings and school interventions.
 - a. PWS behaviors coupled with the school's lack of understanding about food safety make it imperative that proper guidance and training is provided.
 - b. An Executive Director funded by the contract would provide support to educate the school system about PWS behavior management surrounding food and ways to manage aggressive behaviors.
5. The Executive Director also provided necessary education to families so they can meet the needs of their children in their homes on a daily basis.
 - a. Organization of a state conference
 - b. Share research driven data and management strategies to keep our loved ones safe, healthy and ensure they meet their fullest potential.
 - c. Education to our families in a large group format where they were able to meet one-on-one with PWS experts for individualized expert advice.
 - d. The elimination of the contract results in no formalized education for our families.
6. Of concern is support for newly diagnosed families and lack of support to at-risk families
 - a. Education is the key to ensure these children stay safe and healthy.
 - b. We need an Executive Director who can provide the guidance to the families new to the world of PWS and those at risk so they begin the journey armed with the education needed for successful outcomes.
7. We depend on the chapter supports for our survival as PWS parents.
8. Georgia Association for Prader-Willi Syndrome supports over 480 people with PWS and their families.
9. Georgia Association for Prader Willi Syndrome was able to address all of the above risks and deliver a variety of services in the period 06/2004 to 10/2020 during which the contract was provided.
10. Crisis support, school trainings, conferences with PWS experts, new diagnosis and at-risk support are critical.



Meet the New Board

This issue of the newsletter, we would like to introduce Marcello Schutzer. We are thrilled to have him join the board. Some of you got a chance to meet Marcello at the Fall Family Retreat and at the national convention in Orlando. We thought you would enjoy getting to know him more about him.

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

I am the father of a 16-year old teenager, Giulia, that has Prader-Willi Syndrome. I raised her in Brazil, and while there I have always been in touch with the PWSA to be better prepared to manage the challenges associated with the syndrome. Now that I live and work in Atlanta, I have the unique opportunity to share my experience and knowledge to help other families.

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 Sao Paulo-Brazil, where I got a college degree in Business. Before moving to Atlanta in 2016 for a job in Corporate Finance, I have lived in London (where I earned a Master degree in Business Administration), Ann Arbor, MI (as an exchange student) and Milan, Italy (as a business consultant). I am married to Andrea for 19 years, and besides Giulia, I have an 11-year old daughter, Nina.

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

Watching a movie on Netflix, reading the last thriller from Josh Grisham, or going out for a 5-mile run (my favorite song while running is "Don't Stop Believing", from Journey).

What particular strengths do you bring to the board position?

I have the drive and skills with which I am helping my daughter thrive under very challenging circumstances. Now I want to leverage not only my experience as a parent, but also my business acumen, leadership and team work abilities to make a positive impact in the lives of other families that deal with PWS.

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

I want to expand the reach and impact of PWSAGA to a broader range of families.

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

Our kids opened an entire new world for us; without them, we wouldn't have had the opportunity to meet the people we have met along this journey. Let's join our forces, share our learnings, advocate for our rights, and contribute to build a more inclusive world. And don't stop believing!

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A New Beginning

So, as we begin the new year, the chapter is faced with our new reality without a contract with the state. This mean means we have less funding to carry out our mission of serving the people in Georgia with PWS and their families. As a board, we are committed to continuing to service but will have to turn more of our attention toward fundraising in order to meet our mission, and we foresee having to scale down some activities due to the lack of funding unless we can get our contract re-instated.

Here are links to articles referred to in this article:

<https://www.ajc.com/news/state--regional-govt--politics/governor-orders-georgia-agencies-develop-plans-cut-budgets/dwZTj31DL1bMW6c4Gnvt00/>

https://www.ajc.com/news/state--regional-govt--politics/proposed-cuts-state-mental-health-budget-called-life-robbing/ruF0CuzvC6fkZHaVtefoCJ/?fbclid=IwAR1sl3Rfwz2acO4ARvYWdt0Rb0JpSdE6J3Sw9m69S_C9yvftoCQVbwNXKjc

Craig Matesevac (age 17) and
Evan (age 13)

Sibling Stories

From an outside perspective, it may seem like my life is more stressful than the average person. As the brother to someone with PWS, my role is more hands on than that of most other siblings. More than just looking out for my brother, I find myself involved personally in his life whether that is helping him with his struggles or his greatest accomplishments. Guiding him, watching over him, entertaining him, these tasks are ingrained in my daily life and that separates my experience as a brother from those that don't live with PWS, yet often I don't even notice.

I would describe the role I was given as second nature, always present but hardly bothersome. Living in a PWS family is my definition of normal. My life isn't altered; I have little to contrast it. I can hardly even remember a time before Evan's birth so any prior expectation of "normal" family life has adapted to a new definition of normal. Like any change in family structure you adapt to the circumstance and learn how to make it best work for you and your family.

One way Evan and I often spend time together is playing games. Through trial and error I have found what he best responds to and what can easily set him off for the rest of the day. I am able to use the knowledge of what works to make him calm beyond just playing a game. One of the most difficult situations for Evan is getting help on his homework. I may have the knowledge of the material for which he needs help but I often lack an approach that he responds well to and doesn't give up on. After all, Evan's baseline reaction to homework is one of a negative connotation, not understanding, so the approach to helping has to be delicate yet instructive. This is still something I am working on and is of increasing importance, especially as Evan progresses in school and more is demanded of him. I want to be able to help him but I have to try at a pace that works for him and doesn't just frustrate him.

In the future I hope to have more valuable time spent together simply enjoying each other's company and relaxing, especially before I leave for college. I hope to be able to help him whenever he is struggling since even knowing there is support can be reassuring. Mostly, I want for him to be happy.



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.

Georgia Association for Prader-Willi
 Syndrome, Inc. (PWSA/GA)
 9585 Rod Road
 Johns Creek GA 30022
 Phone: 404-955-0296
 Email: info@pwsaga.com
 Facebook: Georgia Association for
 Prader-Willi Syndrome

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

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.

Acceptance and Commitment Training

The Acceptance and Commitment Training (ACT) Study will examine the effectiveness of ACT training for fathers of adolescents ages 13-18 with PWS with the goal of improving life satisfaction, reducing stress and improving family functioning. This remote study will use Zoom video conferencing to provide 4 sessions of ACT training.

The study is seeking fathers who have an adolescent with PWS age 13-18 to participate in a 4-session, on-line, small group training exercise to reduce father's perception of stress, improve parenting satisfaction and increase family involvement. Participants must reside at home with their adolescent and the adolescent's mother, have a personal computer with a camera, microphone and internet access, and agree to privacy and confidentiality of shared information. They must be able to read and speak English. Sessions will be scheduled to accommodate 8 fathers per group. After an initial 90 minute session, three additional 60 minute training sessions will occur at a frequency of every other week. Additional "on-your-own" time will be needed to practice newly acquired skills. Both fathers and mothers will be required to participate in a brief screening interview by phone and then complete several on line questionnaires at the outset, during the study, and at the conclusion of the study. These questionnaires will assess stress, family function and behaviors unique to the adolescent with PWS.

This study is funded by the Foundation for Prader-Willi Research and is being conducted by Dr. Janice Forster and Dr. Stuart Libman with help from Dr. Marjorie Royle and Dr. Lauren Roth. Please see <https://www.fpwr.org/clinical-trials/act> for more information.

Georgia Association for Prader- Willi Syndrome, Inc.

9585 Rod Road
Johns Creek GA
30022

Email:

info@pwsaga.com

Facebook: Georgia
Association for
Prader-Willi
Syndrome