



New to our chapter this year from the Department of Behavioral Health and Developmental Disability (DBHDD) was a grant designated to support Georgia families attending a conference to learn more about Prader-Willi syndrome. We are very thankful for this new addition to the services offered by our chapter! Because of this grant, 12 Georgia families attended the Prader-

Willi Syndrome Association National Convention October 24-26, 2019 in Orlando Florida. This convention provided an opportunity for education, fellowship and new friendships.

“Sharing Experiences, making connections, learning from cutting edge research, developing a sense of belonging, building hope...the Convention provided so many great moments that helped build the strength we need in our journey.” – Marcello

Earlier in the week, Lisa Matesevac and Bob Warren attended the Chapter Leaders meeting which allowed for interaction with the leadership of the National PWSA(USA) organization as well as other leaders in state chapters around the United States. Each leader brought a unique perspective addressing such topics as advocacy, family support and education. We learned that PWSA (USA) is developing several tools designed to help chapter leaders support members, such as a Chapter Success Manual and an Advocacy and Public Policy Toolkit. PWSA(USA) is also developing a list of residential facilities nationwide that accept people with PWS.



The Family conference began with a welcome reception on Thursday evening where everyone could enjoy time with a cast of characters like Superman and Supergirl, as well as participate in face painting, balloon art and cape decorating. On Friday morning, the educational seminars began. A diverse range of topics was covered by several very distinguished speakers. Dr. van Bosse and Janice Agarwal, P.T. presented to a full house on the topic of musculoskeletal issues such as hypotonia, flat footedness and scoliosis. Much attention was given to the topic of siblings and family dynamics. Lisa Thornton, attorney and president of PWSA Utah, provided a comprehensive overview of legal planning and guardianship. Other topics included preparing for an IEP, Nutrition, GI issues, and research updates to name a few. It was an eventful few days and families came away feeling energized and full of information ready to return home and implement new strategies.



Lisa Thornton, attorney and president of PWSA Utah, provided a comprehensive overview of legal planning and guardianship. Other topics included preparing for an IEP, Nutrition, GI issues, and research updates to name a few. It was an eventful few days and families came away feeling energized and full of information ready to return home and implement new strategies.

"I am just blown away by the conference last weekend. What an amazing opportunity! So much learned and shared. The level of commitment and drive of this community truly inspires me. I wouldn't trade my son and I being at this event for anything! Thank you to the GA Chapter and National for all you do!" - Jamie

Where were the kids during all this you may be wondering? PWSA(USA) offered the YIP (youth/infant program) and the YAP (youth/adult program) for our loved ones packed with so many fun things to do! Volunteers from the Church of Latter-Day Saints provided supervision. While the children and adults with PWS were entertained, parents could relax knowing their kids were well cared for and they could focus on learning and making connections with other families. Rounding out the end of the conference was a truly wonderful show put on by the kids and adults with PWS choreographed to the song 'This is Me'. Our loved ones with PWS, siblings and volunteers danced and celebrated the end of another successful convention.

"The 2019 PWSA Convention in Orlando was the first PWS convention I have attended. I definitely plan on attending the next one in 2021! I am so glad I was able to become closer with other PWS parents and kids. I was crying happy tears within the first 15 minutes of the opening presentation. We consider ourselves well-read when it comes to PWS, but I learned SO much from each presentation. I walked away with a wealth of new information that can help Eva (our 2 year-old with PWS) live her best life." - Sarah

“I am always thankful for the opportunity to go to the conference. I look forward to seeing old friends and meeting new friends. Rebecca feels such a strong bond to “her friends” that she only connects with every two years. She made a new friend this year from Ohio. She looks forward to seeing doctors and professionals she has met over the years and is happy they always remember her.”

“The information and meetings are so informative. It can be a little challenging to keep up with all the fast changes and information that affects our family with an older adult with PWS, but so important to hear about health issues that affect all ages of PWS, changes in federal regulations of resident living that can affect the health and safety of our children and long term financial planning (because for us that is becoming more short term planning). There is always something for everyone to learn and grow from. And all this while having a wonderful and supportive environment. Thank you to everyone who worked so hard to make this event great and to our GA chapter for all the work to help everyone who wanted to go have a good experience. Thank you to DBHDD for your support to our family.” – Sandra and Rebecca



Join us next time!

PWSA(USA) National Convention

June 24-26, 2021

Orlando, Florida

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