

2nd GAND Gathering and Scientific Conference

I just returned from the 2nd GAND Gathering and Scientific Conference in Orlando where I had the wonderful opportunity of presenting to a group of families of children with GAND about AAC. GAND which stands for GATAD2B-associated neurodevelopmental disorder is a rare genetic syndrome with 93 identified worldwide, 43 in the United States and 29 families represented at the conference. Most of the people identified with GAND present with intellectual disability, low muscle tone, difficulty with speech production related to a motor speech impairment called apraxia, strabismus, as well as specific physical characteristics. Due to difficulty with speech production, many children with GAND can benefit from access to an AAC system to provide them with a way to communicate and develop their expressive language skills while they are also working on their speech production skills.

I was invited to present at the conference because I am fortunate enough to work with a little girl with GAND named Olivia. Olivia's mom, Mindy Youngs is one of the board members of the non profit Helping Hands for GAND. Mindy Youngs along with the two other board members, Jennifer Martin and Colleen Parker, have done a phenomenal job raising awareness about GAND, providing families with information and resources and connecting families of those affected by GAND as well as planning and executing a well run, informative and fun conference.

Meeting the families of children with GAND from all over the country and world provided an opportunity to learn about the challenges and struggles these families face on a daily basis. I also learned about their needs in terms of speech, language and communication support. In speaking with a number of the families I look forward to being able to connect them with professionals in their areas who can help with each of their child's speech, language, communication and AAC needs. I feel incredibly honored to have had the opportunity to meet the families, hear their stories and share information with them that will hopefully help them along their journey. Thank you Mindy, Jennifer, Colleen and Helping Hands for GAND for the opportunity and Olivia for teaching me about GAND! www.gatad2b.org

