

Susie was referred to the Early Intervention Program in Fulton County at 4 months of age for mild torticollis. We started services in January, which focused on feeding issues. At the time, Susie required at least 45min to complete a 6-ounce bottle of milk, which was significantly affecting her play time as well as the activities of our family. Speech feeding therapy began at once per week and continued on that frequency through October 2019.

We requested that BCW complete a PT and OT evaluation for Susie, but they were unable to do so because of staffing issues, so we had evaluations completed at Childrens Healthcare of Atlanta in April. BCW was able to have OT services in place once per week beginning in July, but was not able to provide PT due to staffing shortages. We utilized CHOA for PT until BCW communicated they were hiring a new PT, but due to BCW miscommunications and delays, PT did not begin until October at a rate of once per week.

When Susie received a genetic disorder diagnosis on October 3, we learned how vital it was to increase her therapy frequency to 4 speech, 3 OT, and 3 PT visits per week as soon as possible. We requested an increase with BCW, which began the process. While waiting for that to finalize, we utilized CHOA for additional PT appointments. We received approval through BCW and have just recently been able to schedule therapy through them twice per week for OT, PT, and Speech. We are supplementing with privately funded therapy for additional speech therapy, music therapy, and are on a waiting list for aqua therapy. Our current therapy schedule includes weekly sessions of 3 speech, 2 OT, 2 PT, and one Music. Any weeks not meeting this frequency are due to sickness, therapist scheduling conflicts, holidays, or financial restrictions. Our private insurance covers unlimited speech therapy, but only covers up to 60 combined OT and PT visits per plan year, which will only cover four months of OT and PT visits at our current frequency. While we have been approved through BCW for two OT and PT visits per week, the expert recommendation from Dr. Jones, the world expert on Susie's disorder, is recommending significant therapeutic intervention beyond this level. With the support of the Katie Beckett Waiver, we will be able to not only continue our current frequency but add other therapies as will best help Susie's long-term development (i.e. increased existing therapies, aquatherapy, hippotherapy).

Susie has shown good progress with the increase in therapy so far and has responded very well to these services. She was not walking independently before the increase in frequency, and in the past couple of weeks since the increase has begun doing so. This is an example of how well she responds to the therapists' interventions. She is pleasant, engaged, and hard working. The entire therapy team is confident that this increased level of frequency will maximize her chance for success.