Consumer Membership Spotlight – Wheeler Alcalá

By the NDTA Membership Committee

Did you know that our clients can become members of NDTA? NDTA offers a one year free membership to consumers of NDT with ongoing membership at very reasonable rates. Wheeler Alcalá has been a consumer member for a few months now. I talked with Wheeler and learned more about her family, son, and experience with therapists educated in Neuro-Developmental Treatment (NDT). Below you will read about a few of the experiences she wanted to share with her fellow NDTA members and their clients.

About Our Family
My name is Wheeler (Alcalá), and Gabriel, my two-year-old son, was born prematurely at 29 weeks’ gestation, then diagnosed with periventricular leukomalacia before leaving the neonatal intensive care unit (NICU). He has since been diagnosed with cerebral palsy. From birth, he has had increased tone and lots of extension. My husband and I also have an 8-year-old daughter. We currently live in San Antonio, Texas.

Our First Experience with an NDT Therapist
When Gabriel was only a few months old, we found a great group of therapists at Le Bonheur Outpatient Rehabilitation in Memphis, TN. Our primary physical therapist (PT), Audrey Vaughan, was NDT trained, and she worked very closely with many C/NDT (NDT Certified) PTs. They were all very knowledgeable about the appropriate NDT therapies for Gabriel and were very optimistic about his future capabilities. In fact, there was an NDT course scheduled in the fall of 2016 that several of the newer PTs were scheduled to attend. Gabriel was asked to participate in the course, giving student therapists hands-on experience with a child with increased tone. We loved our therapists, and with their help, watched Gabriel learn to roll over, commando crawl, and walk in a gait trainer before the age of two. Unfortunately, we had to move away last summer from Memphis to our new home in San Antonio, Texas, for my husband’s work. This meant that we could not participate in the NDT course in Memphis and had to leave our beloved therapists behind.
What I Like to Hear from Other Parents in Therapy

When talking with other families, I like to hear positive feedback about how well their child is doing in therapy. That provides me with hope that real therapeutic benefits are happening for the time commitment required. It also helps me to see where my child might be going with continued work. For example, Gabriel started PT early due to his diagnosis given in the NICU. The therapist set goals, and I was asked to pick and choose goals. I understand that Gabriel has some disabilities and will not function as a child developing typically would function. However, I was told that he would never roll, so I gave up on that. But I felt that we should not stop working on some of these things. When we started therapy with our NDT-trained therapist, we found renewed hope in Gabriel’s abilities because she was willing to keep working on our goals and helped us with other things. The therapist asked me what was important to me and included them in what she did in therapy. She shared with me how his brain is still developing and change can occur. She explained that rolling is a good skill. It was a major milestone for us when Gabriel rolled on his own at 15 months of age.

In Texas, I met another parent with a child three years older than Gabriel who helped me find other activities that we could try that I didn’t think he could do, including trikes and horses. Hope... Wow! There are more ways to give him movements that will benefit him.

How I Felt About the Services

My hope was renewed and I was empowered. I had more buy-in to therapy so I could learn what they were doing, practice in therapy with my child, try it at home. Practical help in my day-to-day activities. My life is going to be about realizing what difficulties I am having at home and sharing them with my therapist. She might say things such as, “Here are some things we can do to practice commando crawling, walking in gait training, and side stepping so you don’t have to carry him all the time.” I might say, “Here is what I am struggling with; help me to figure out how to address this. What are some things we can do to make it better, such as bathing?” I am starting to work on standing with support with side stepping with him so that he can help me stand up and hold on the edge of the tub instead of using a bath chair.

What Functional Changes Did I See Because of Therapy?

I am a stay-at-home mom. The grocery store was a common challenge for me. I needed both hands to hold Gabriel in a cart due to his lack of trunk control. I would maneuver the cart to get close to the shelves to quickly grab an item. When I shared my struggle with my therapist, she sewed a Boppy pillow into a standard fabric grocery cart cover. It supported Gabriel in the cart
and helped him to sit up so that I was not so nervous about going to the store.

In the past few months, he has such improved balance that he can now put his hands on the bar and hold on with the seatbelt, using his muscles to keep himself vertical so I don’t have to bring the Boppy anymore. I discovered this one day mostly by mistake. That day I didn’t have to take time to put the Boppy in the cart so I tried him without it, and he could do it! Simple everyday things like this highlight for me how often others may take for granted that their child can sit there. I was so excited for what he could now do; the little things can make such a big difference.

I really attribute Gabriel’s progress with his mobility to his therapist who worked more upright on walking with support (in a gait trainer) so that Gabriel would know that his feet were for moving. About two weeks later he wanted to commando crawl but could not yet roll over from his back. The movement upright set off a lightbulb in his head that maybe he could roll to his stomach to commando crawl. He to rol...led to his stomach and started crawling.

We are not sitting unsupported yet; that is one of my goals for him. The therapists are wonderful in helping what he needs to do to grow. My personal goal is for him to sit unsupported. He needs the protective reflex to put his hand down. He has a lot of tone and we are looking at the right ways to help with that. Once he can be more relaxed, then input to his hands can help him know they can help him to balance, just like he learned about his legs for movement.

What Advice Would I Have for Other Parents?
I contacted several NDT therapists on the website and asked for help... that was my lifeline... getting connected to a therapist and getting treatment for Gabriel. Reading online blogs and articles makes me nervous. I don’t spend a lot of time doing that because it can be disheartening. There are a few trusted people from whom I seek help and insight, including Gabriel’s therapist. I want to be informed but not swayed one way or another. Without the medical background that the therapist has, I might be swayed. It has helped me to have contact with someone who was informed about the current research. That’s the way I work. Gabriel will be the best version of himself, and (with the help of our therapists) we will work tirelessly to get him to the most functional and capable person that he can be.
What I Would Like to Add

I was surprised when I got to Texas that there were not a lot of facilities advertising NDT therapists. Several non-NDT therapists at different locations evaluated Gabriel, but I couldn’t set up regular appointments because I was never completely impressed with how they handled him. I really felt that I needed a C/NDT therapist.

I went online and the closest I could find was in Austin, 70 miles away. I thought to myself, “I’ll go there.” I called Austin and started going there last year. She’s great, but near retirement, and I was panicked when I had to start finding another therapist. I decided to try the NDTA website to look for a therapist nearby in San Antonio (I’m not sure why I didn’t do this when I first arrived). There were more in my area than I thought. I contacted a couple of therapists on the website and found one to meet with us. I was hopeful that this would be the person that could help us pick up where we left off. I was beginning to feel hopeless about finding quality help for Gabriel close to our home. We started seeing Todd Schwartz with Christus Santa Rosa Westover Hills Outpatient Rehabilitation (we found him on the NDTA website) and he is fabulous! He is wonderful with Gabriel – very patient and kind. He plays and sings with Gabriel the entire therapy session, making it go so quickly. We have two sessions a week – one to work on trunk control, the other to work on walking. I can already see some small progress being made with both Gabriel’s trunk control and walking capability!

My only concern going forward is this new insurance company; we are close to the end of our allotted 30 annual therapy sessions and very concerned that they won’t approve additional visits for the rest of the year. I’m ready to fight them for more, but what a pain! I know we aren’t the only family going through this; it is so frustrating to need help, and the insurance company becomes the barrier. Anyway, I digress. I’m really pleased that we’ve found such an amazing therapist here in San Antonio due to your website. It was such a blessing to have the NDTA website as a resource and to be able to support NDTA as a consumer member.

Do you have a client who would be an asset to our membership? By sharing Wheeler’s story with them and connecting them with NDTA today you will allow them to share in your support and passion for our vision and mission.
Wheeler Alcalá is a stay-at-home mom with two beautiful kids, Gabriel, 2, and Marcela, 8. She lives in San Antonio, Texas, with her husband, Alberto, the kids, and her wonderful dad. Her education and experience was in marketing and business operations before becoming a full-time mom. She enjoys cooking, traveling, and spending time with friends and family. She considers herself capable, forward-thinking, perseverant, and optimistic. Having a child with special needs has set her back on her heels and has taught her so much. It has also made her deeply grateful for all those in the medical field (including physical, occupational, and speech therapists) who are capable of making her son’s life a little easier. She can be contacted via email at wsm1031@gmail.com.