Strength in Service: A Young Mother's Battle with ALS

By Alexander Diegel

In October of 2022, 38-year-old Melissa Diaz-Viera was a new mom to a happy eight-month-old baby and had recently recovered from a bout of COVID-19. At around that time she started experiencing mild impairments, such as pincer grasp weakness that made it difficult to use a pair of nail clippers, button her baby's clothes and use chopsticks. She also noticed some twitching in her thighs. By January of 2023, her symptoms had not subsided and it was time for a trip to her primary care physician. They began testing for autoimmune diseases, rheumatoid arthritis and vitamin deficiencies.

An electromyography (EMG) was also ordered to ensure nothing was off with how her brain was communicating with her muscles, but this was believed to just be precautionary. It proved to be anything but, however, and by February 2023, Melissa was diagnosed with amyotrophic lateral sclerosis (ALS).

"Obviously, it was a very big shock. The diagnosis was just three weeks after my daughter's first birthday; it was overwhelming," Melissa explained. As a Licensed Clinical Social Worker, she dug into her experience and was determined to fight back against a disease without an answer. "I was diagnosed with something that didn't have a solution. With my social work background, I had been presented with plenty of 'impossible situations,' and had to figure out how to work within them. So, I brought that social work mentality with me in my journey."

The young mother quickly got connected with different people and organizations. "It's important to think about how we can put our resources together and collaborate to figure this disease out. I've been really lucky to be involved with groups like Her ALS Story, a group of young women that raises awareness about the diversity in ALS patients and provides a community for us to connect, learn, and find support."

Melissa is also part of the Les Turner Foundation's Support Services Committee, serves as a Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS) Research Ambassador, and is the Research Operations Coordinator for Project ALS, a nonprofit that funds preclinical research for ALS.

"I'm really grateful for my opportunities and all the ways that I've been able to connect not just with other people living with ALS, but also researchers and people in the industry," she explained. "By connecting with others living with ALS, you see how different this disease can look for every person, not only physically, but also in terms of resources available and where they are in their life. So, when I'm doing advocacy work, I really try and keep all of those stories in mind and make sure that we're not forgetting anybody when we're thinking about how to better support patients. When I speak to researchers, I try and make sure that they also understand that, as well as the systems that we are working within as patients."

Of course, in her relationship with Thom Hart, who serves as Director of Outreach for C-Path's Critical Path for Rare Neurodegenerative Diseases (CP-RND), she was connected to a community built on collaboration.

CP-RND was founded in September 2022 to lead collaborations that advance treatments to improve the lives of those affected by rare neurodegenerative diseases, including ALS.

CP-RND brings together experts in ALS treatments and research, as well as biopharmaceutical companies, regulators, communities of people living with ALS and advocacy organizations to accelerate and advance our understanding of disease pathology, treatment options, diagnostics and drug development.

“At C-Path, our role is to be the neutral convener,” Thom explained. “So, we go out and work with community, which in CP-RND’s case, means people living with ALS, their care team, and families. But it’s also academic researchers, and regulatory bodies. C-Path spends time and resources working on patient focused drug development, to amplify the voice of those like Melissa living with diseases.”

Through collaboration, sharing of data and resources, and the work of CP-RND, Melissa sees a world for people living with ALS where better, more effective medicines can be tested faster, and individuals affected can feel more confident to participate in clinical trials.

“With the current technological advances, I think we will get a lot faster at screening new drug candidates. So, by the time they get to clinical trials we will feel a lot more confident about them,” she explained.

“Collaboration is everything, whether you’re a person with ALS trying to get through this, or you’re a scientist trying to figure it out. I think the more people that we can bring together, the better, and the work that C-Path is doing is working towards that.”

Melissa Diaz-Viera joined the Les Turner Foundation’s Support Services Committee in 2024. As a Licensed Clinical Social Worker, she brings extensive experience in advocacy and community support. Diagnosed with ALS in 2023, Melissa is actively involved in various ALS groups and serves as both a NEALS Research Ambassador and Research Operations Coordinator for Project ALS. Outside of her ALS work, she enjoys spending time with family, singing, and raising her 3-year-old.