

Good morning. My name is Danielle.

Shortly after my daughter was born, she was diagnosed with sickle cell anemia. Before that moment, I didn't know anything about sickle cell. I had to learn a lot very quickly.

By the time she was one, my daughter had been hospitalized several times with fevers and infections, a scary thing for any parent to go through. I missed a lot of work because of her illness, and I ended up losing my job. While I looked for a new job, I applied for Supplemental Security Income benefits, or SSI, for my daughter. I wanted to make sure that her life was as normal and as stable as possible, despite her diagnosis.

My initial application for SSI was denied, but I was encouraged to re-apply by someone at Children's Hospital. The application was denied a second time because of a missing signature. In the meantime, I found a job as a caseworker at the Head Start program my daughter attended, which allowed me to look after her *and* help other families like mine. Through that work, I learned about Greater Boston Legal Services, and I contacted them for help getting SSI for my daughter. That's how I met Tara, my legal aid attorney.

Little did I know that she would be our support for seven long years.

We went before an administrative law judge with our appeal. Despite the dangers my daughter faced, the medical expert at the hearing said sickle cell wasn't always severe, that that my daughter's hospitalizations up to that point had been precautionary. I was angry, and I was scared. I knew that for kids with sickle cell, and for my daughter, almost any infection could be life-threatening. Unfortunately, my appeal was denied again.

With Tara's help, we fought through many denials and appeals; Tara was part of a team of people working to keep my daughter healthy. The Social Security Administration always took the maximum time to respond after each denial and appeal, so the process dragged on for years. During that time, my daughter faced many health crises and hospitalizations and in one case, her spleen nearly ruptured. It was hard for me to see her suffer, because she already missed out on so much of a normal childhood because of sickle cell.

Her medical crises can be triggered by cold temperatures or dehydration, so in the winter, she has to spend recess in the nurse's office, missing out on social time with her peers. One summer, she ended up in the hospital in extreme pain after dipping her legs in a cold lake at a friend's birthday party—the temperature change was too much for her body to handle. I have to be on guard all the time, and as a mom, I had to become an expert on my daughter's condition.

I didn't have anything but a high school diploma when this process started, but I had to learn the skills to fight for my daughter. I wanted to help others navigate the same complicated system, so I went back to school and became a social worker. It took years, and it was hard to juggle work, school, and family, but because of what I had been through with my daughter, I knew it was worth it, so I could be a resource for moms and families in need.

Finally, after almost eight years, and with significant legal help from Tara, my daughter's SSI benefits got approved, retroactive to the date we originally applied. She's nine now, and she's doing really well. We were able to use part of the retroactive payment to get a car so I could drive my daughter to school and take her to her doctor's appointments, and she now has ongoing benefits to cover other costs related to her illness. I feel so much safer knowing she has support for her medical needs, and I can focus on more important things, like my kids and my work.

I know that we wouldn't be where we are now without legal aid. Whenever I felt out of my element and scared, Tara told me, "I'll take care of the lawyer piece, you take care of your daughter." It helped me so much to leave it in her hands. It gave me a sense of security, a feeling that I had a voice.

If you don't have somebody that's going to fight along with you all that time, you want to give up. GBLS—and Tara—never gave up on us, and that gave us hope.

I am here today to say thank you, and to ask you to support civil legal aid, so that other families like mine can get the help they need.