July 24, 2021

Dear Representative Eshoo,

I first want to say that I hope I am addressing you properly. I sat back thinking, "Is it Madame Chairperson, Chairwoman, Congresswoman or Representative?" I honestly do not know and I never want to come across as rude, so I hope that I selected the proper title. As for me, my title is typically "Mommy", even from my husband! We have been together for 26 years and we have a 9-year-old daughter. Somewhere along the way, I went from being called "Honey" to being called "Mommy". I guess that is the way it goes, and I am ok with that.

My daughter, Chloee, often calls me her best friend. That warms my heart, to no end. I realize the teenage years might turn "Mommy" into "Mom". I will also probably lose the title of "Best Friend" and become "The Wicked Witch of the West"… and if that be the case, my heart would be filled with joy and delight. You might ask why any mom would want to become the wicked witch of the west, and the answer for me is quite easy: **It would mean that I am still living**. As a person living with and dying from ALS, statistically speaking, I will not make it to Chloee's 13th birthday. My family is the reason I cannot stop advocating for my life and for the lives of those who can no longer advocate for themselves.

In November of last year, you wrote a personal letter to me regarding my advocacy for ALS awareness and the Act for ALS Bills, after reading an article about me in The Mercury News. The article was published in the same Sunday edition that announced President Biden's victory. *I felt that it was an added bonus for ALS awareness, because I think a lot of people read that edition. My Mom bought every copy she could find!* I was excited that you took time to write to me, simply from the kindness of your heart. When faced with a monster like ALS, it is wonderful to know that you are being heard. *I still have the letter….and my Mom has about 10 copies*!

I was part of a Zoom meeting on July 12th, with Aisling McDonough and I Am ALS. We discussed living with ALS and the desperate need for access to promising drugs/therapies that could improve the quality of our lives. (Expanded Access) Therapies and drugs that could make ALS a treatable disease. We were pleased with the meeting, and I hope Aisling was as well. I was incredibly happy with the level of compassion that she showed. She was also very considerate with her time, which means so much when you are talking about your life or your eminent death with another person. Once again, I felt like I was not alone, and I felt heard…at least I hoped that we were heard.

I now *know* that we were heard. When I read that you will be holding a hearing in your subcommittee to examine the FDA's decision regarding patient access (and that it had a real date, July 29th), I cried, and I thanked God for hearing our prayers. Up until that moment I felt like a speck of dust on the flower in Horton Hears a Who. *I hope you know the story. Side-note, I always thought he carried the specks of dust on a Dandelion, but it was actually a Sensitive Briar flower.* Words on paper simply cannot express the gratitude and relief that we in the ALS community felt to read such great news.

I realize that the hearing is just one step in a massive process. To my knowledge, you have 5 minutes to speak on the topic. With that in mind, I would like to share a real-life example that there *are* therapies

that *do* work for people with ALS. You may recall my advocacy for a treatment called NurOwn. A man named Eric Stevens was part of the NurOwn Phase 3 trial. Since nobody knows if he received placebo or the actual treatment, I will not talk about his results during the trial. As you know, a selected group of patients from the phase three clinical trial were granted expanded access to NurOwn. Eric is one of these patients. Prior to expanded access, Eric could not hold his baby without assistance. He could not grip a spoon to feed his baby. He was too weak to push her stroller. Since being treated with NurOwn via expanded access, his speech has significantly improved, he can hold a spoon to feed Peyton, he is strong enough to push her stroller and the best part of all: Eric can hold Peyton in his arms, a treasured experience that ALS had taken from him.

Those were things he could not do prior to receiving NurOwn…and we know without a doubt that he is 100% being treated with NurOwn and he has experienced improvement. With ALS, we do not improve.

The frustration that is felt amongst the ALS community is unbearable at times. Knowing there is possible help and yet we cannot access it is as painful as knowing our lives will be cut short in the cruelest of ways. We know that all drugs and treatments may not work for all of us, but we *do* know that they will work for some of us. One year ago, I was walking with a limp; today, I am writing this letter to you from my wheelchair. In one fast year, ALS took my legs. NurOwn existed one year ago. If I had access to NurOwn one year ago, it is quite possible I would still be walking. It is also possible that I would be sitting in this wheelchair right now, but at least I would have had the opportunity to try and save my legs.

With ALS, a piece of you dies every single day. We are simply asking for a fighting chance to live the lives we were meant to live. I can state without hesitation that there is not a person battling ALS who would turn down the opportunity to be treated with a drug that gave a young father the ability to hold his baby daughter in his arms, for the first time.

Thank you for your continuous support and advocacy for people with ALS. You have given us a glimmer of hope in a hopeless situation. I look forward to the hearing on July 29th.

Kind regards,

Jamie Rose Caglia-Berry

Jamie Rose Caglia Berry

Mommy