Living on the front lines: A demand for faster ALS treatment access

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Dear Editor,

My name is Elizabeth Greenstein. I have been battling bulbar-onset amyotrophic lateral sclerosis (ALS) since June 2023. I am writing alongside my son, Ethan Greenstein, who is a caregiver of mine and an ALS advocate.

We write to express a deep appreciation for the recent article in *RRNMF Neuromuscular Journal* by Dr. Richard Bedlack and colleagues, titled "A worsening problem in ALS: insurance barriers between drug approvals and patient access." The barriers facing ALS patients in accessing treatments, as outlined in the article, are stark, unjust, and deserve far more of a spotlight than they are currently given.

Part of the reason these barriers receive so little attention is that people with ALS are diagnosed, become very sick, and die within a short period of time. I write to bring this issue to light in a permanent form—while I will not be here forever, I will do everything I can to push for an end to this horrific disease. In the meantime, the least we can do is ensure ALS patients like me have access to the limited treatments that exist.

Since being diagnosed with bulbar-onset ALS, my family and I have been tasked with navigating the complex landscape of healthcare and insurance. The journey has been fraught with obstacles, the most disheartening of which include the insurance barriers that delay access to crucial medications. These delays are detrimental to our health, as the rapid progression of this fatal disease does not allow for the luxury of time.

The article rightly points out the incoherence of labeling FDA-approved therapies as "experimental" and the use of clinical trial criteria to restrict access to medication. These practices are a direct affront to the needs of ALS patients. We require these treatments to maintain function and quality of life for as long as possible. And the time that we are given to begin with is not long—the average person with ALS lives just 2-5 years, with an even poorer prognosis for bulbar-onset ALS.

We urge healthcare policymakers, insurance companies, and the ALS community to come together to dismantle these barriers. Change is urgently needed to ensure no patient is left waiting for the treatments they desperately need.

I am not dying from ALS. I am living with it. Insurance systems should support, not stand in the way of, those of us fighting to preserve our lives and independence for as long as we can.

Thank you once again to Dr. Richard Bedlack and his colleagues for highlighting this pressing issue. It is my hope that their work, combined with voices like mine, will catalyze the necessary changes to make ALS care more accessible and effective for all and, eventually, to find a cure for this devastating disease.

With hope,

Elizabeth Greenstein
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