April 8, 2025

Chairman Brian Lampton

House Insurance Committee
1 Capitol Square
Columbus, OH 43215
Room 122

The Honorable Chair Lampton, Vice Chair Craig, Ranking Member Tims, and Members of the Insurance Committee:

RE: SUPPORT, HB 24 – Provide Medigap policy for certain Medicare-eligible individuals

I was 27 when my body started failing me, 28 when I first walked into an ALS clinic, and 29 when four neurologists separately confirmed that my brain would slowly, and in no particular order, stop speaking to my arms, legs, vocal cords, tongue, jaws—robbing me of my ability to move, speak, chew, and swallow. It would eventually stop commanding my lungs to expand, suffocating me to death. I would feel and remain aware of it all.

ALS is not a diagnosis you would want at any age let alone 29 and working a then-coveted job at VICE Media in New York City.

Six months after my diagnosis, I transferred to the LA office and shacked up in a studio a block from the beach. I spent two years—the last of my independence—chasing the promise of experimental treatments and clinical trials while producing a documentary about the grave state of ALS. I swiped my credit card for daily green juices, weekly massage and acupuncture appointments, supplements but only the third-party tested for quality, anything in the hopes of halting the spreading paresis.

But ALS prevailed, and at 32, I moved back in with my parents.

While the average lifespan of an ALS patient is two to five years, my decline has always been relatively slow. I'm one of the 10 percent who lives with the disease for a decade or more.

I've been lucky in other ways, like having my parents to help take care of me and my old employer insurance until the beginning of 2024.

That was when I learned that I couldn't enroll in traditional Medicare, because I was under 65 and ineligible for a Medi-gap plan in Ohio. My only option was, and still is, Medicare Advantage, although many have dubbed it a more accurate term—Medicare Disadvantage.

These privatized plans masquerading as Medicare are notorious for delays and denials, tactics to increase profits at the cost of patient care. When I first enrolled, my plan lived up to its reputation.

My medication refills and feeding tube formula—my main source of food—were delayed a whole month due to prior authorizations. The absurd amount of time to review the paperwork aside, the insurance company legally evaded paying for my medication and food even though I had coverage. In what other industry is that acceptable?

My plan pigeonholed me into only seeing my regular providers, and when an opportunity arose at Ohio State University to try an experimental medicine that could improve my speech, it was out of network. In other words, not covered. I seethed with envy as other patients' speech improved from the new treatment and wondered why I was stripped of the same opportunity.

At the end of my first year on Medicare Disadvantage, my insurance company informed me that it would no longer cover one of my medications and another would be moved to a new tier, skyrocketing my copay to $800 a month. I was forced to switch insurance companies, which is never pleasant but with Medicare Disadvantage, it's torture.

Upon changing plans, my doctor had to waste more of her time on new prior authorizations, time that could be better spent on more important aspects of patient care. I had to wait, yet again, while the insurance company approved my medication.

Then came the denial for my feeding formula, the one I've been using for the past four years. The insurance representative suggested that I switch to a different formula, one with calories from added sugar opposed to my whole blended foods formula. That much consistent overconsumption of sugar could trigger diabetes, but these companies are tending to their bottom line not my health.

I plan on appealing, but this will siphon even more of my very limited time and energy. ALS makes it so that my muscles ache like I've been training for a triathlon except it's from lying in bed or reclining in a wheelchair, and on top of my baseline pain, I'm expected to fight these jabronies for decent nutrition.

I fear what else is to come. I need a new wheelchair, since I can no longer drive mine with either hand. My occupational therapist helped place an order for a new power chair I can operate with my legs. I'm awaiting any news about payment or denials. I'm at their mercy.

I truly don't understand why I'm being punished for becoming disabled at a young age. ALS already robbed me of so much, why must I be robbed of choosing my healthcare, too?

Angelina Fanous

15410 Whitney Rd
Strongsville, OH 44136