

**Drug Pricing Testimony (Prescription Drug Affordability Board)**  
**Bob Miller**

Good afternoon.

My name is Bob Miller. I live in Prior Lake with my wife, Mary. I live with multiple sclerosis and am an MS Activist with the National MS Society.

Multiple sclerosis is a chronic disease of the nervous system that interrupts the flow of information between the brain and the body. Symptoms of MS vary from person to person—ranging from mild impairment of motor function to severe paralysis. There is currently no cure for MS and since the disease is not fatal, a person can live with the disease their entire life. Nearly one million people live with MS in the United States.

I am here today because I am one of the nearly 40% of people living with MS who have altered the use of their MS medication due to cost.

I was diagnosed with MS in 2004, on my 25<sup>th</sup> wedding anniversary. I probably had MS for many years before that, but that was the year that I was hit hard by the effects of the disease. I had tingling in my cheek, and then dizziness; I started to have difficulty with one of my legs; and then the speech problems started. At one point, it got so bad that I was slurring my speech every 15 minutes. I was in the height of my career, and these symptoms were simply debilitating.

I was able to get a diagnosis relatively quickly, and within a few months I was put on a disease-modifying therapy called Betaseron. MS disease-modifying therapies have been shown to modify the course of MS and prevent the accumulation of disability. For me, the drug worked. I was on the medication for 12 years and never had a relapse.

It was only when I enrolled in a Medicare Advantage plan that I realized that the cost of my medication had become prohibitively expensive. Betaseron—which came to market in 1993!—was around \$13,000 a year at the time I started taking it, but its cost has risen exponentially since then, to the point where its price in 2020 was over \$103,000 annually. And as you can imagine, over the same period of time, the out-of-pocket costs for people with MS have skyrocketed. When I was on my employer's coverage, I was able to get copay assistance from the manufacturer of my drug, and it was affordable. But under Medicare, I am now ineligible for manufacturer assistance—and the drug is so expensive that my out-of-pocket costs are high enough to drive me to stop taking my medication altogether. I'm on a fixed income, and these costs are high enough to jeopardize my retirement security.

I've been off my medication for around four years now. My doctor told me I was rolling the dice on my health when I stopped taking it—you just simply do not know if your disease will progress without the meds. I've been lucky and have not had a relapse. But I don't know what my future holds. And I strongly feel that no one should have to make that kind of decision.

I checked with my insurer last week, just to see what my out-of-pocket costs would be, for this medication that costs over \$100,000 a year. I was told I'd pay around \$2500 the first month, \$2300 the second, \$2200 the next, and so on, and that over a year's time it would cost me \$10,000.

I'm not the only person with MS in this situation. There are over 20 medication options for people with MS now, but in spite of all the competition, prices continue to rise. The median price for these medications last year was over \$91,000. And people with MS are prescribed to take these meds every year, for the rest of their lives.

Medications like the MS drugs are life-changing—but medications can only change lives if people can access them.

I am a volunteer leader for the National Multiple Sclerosis Society, which is supporting House File 801, to create a Prescription Drug Affordability Board. This Board would have the opportunity to analyze the impact of high-cost drugs on the state, and on patients, and have the option of regulating prices in the state of Minnesota in certain circumstances. This legislation could have a meaningful impact on the lives of Minnesotans living with MS. As you may know, Minnesota has a high incidence of this disease.

Right at this moment, there could be another father, mother, sister, colleague, or close friend that is sitting in a doctor's office receiving their life-changing diagnosis. Living with MS is unpredictable and challenging. I still have moments when I wonder if my disease is progressing and what this means for my future and the future of my family. I urge your support for HF 801, the Prescription Drug Affordability Board, and I thank you for your time.