****EMBARGOED UNTIL TUESDAY, AUGUST 21, 2018, AT 3:00 p.m.****

Written Testimony
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Richmond, VA
August 21, 2018

I'd like to thank the committee for this opportunity, my name is Marques Jones and I'm the owner of a small home care business in Richmond, Virginia.

In 2008, I sat on an examination table. With my wife Jesi holding my hand and my grandmother and mother-in-law in the room, at 27 years old, a neurologist walked in and said, “you have Multiple Sclerosis.”

This diagnosis changed my life. There were days that I didn’t know if I’d be able to teach my then, 2-month-old daughter K’Leigh how to shoot a jump shot or walk her down the aisle on her wedding day.

All of this came to a head one night when at 2:00 am, I woke Jesi up and asked her if she wanted a divorce. I said, “You’re 25 years old and didn’t sign up to take care of me for the next 50 years.” She told me to quit acting dumb and rolled over and went back to sleep. From that day on I was determined to do everything I could to be there for her and my daughter.

I was prescribed the MS disease modifying therapy or “D-M-T” Avonex and it worked wonders. Gone were the fatigue, headaches and numbness I was experiencing before. My energy returned, and my neurologist was thrilled to inform me that my disease progression had ground to a halt.

When Avonex was first approved in 1996, it cost a little under $10,000. By 2017, it had increased to about $75,000. The medication itself has not changed—just its price. I have friends whose insurance require them to pay between 20% and 40% co-insurance on their MS DMT—forcing them to pay thousands of dollars per month out-of-pocket. In real terms, I could be paying more than $1,000 each month just for my DMT.

So far, I’ve been fortunate to not encounter significant barriers accessing my MS DMT. But MS is unpredictable and I could experience an exacerbation or progression at any point that could take me out of the workforce. Or, Avonex could stop working for me—and my healthcare provider and I will need to try a different medication. There are more than a dozen medications to treat relapsing MS, but the next medication my doctor thinks is best may not be covered by my insurance. Or, they could want me to fail on other medications first. Can you imagine telling someone they have to get worse—and risk irreversible disease progression—before getting the medication they and their doctor thinks will work best? This happens more often than we think with current step therapy policies.

MS is a chronic condition, so my family and I will have to bear the cost of my DMT for a long time to come. My wife has arthritis—another very expensive condition to manage. So, despite both of us being working, responsible adults—our healthcare costs are tremendous and our long-term health is unknown. These are realities that we live with every day and cause us great anxiety and concern as a family.

Since being diagnosed with MS, I have become an activist with the National MS Society. The Society has comprehensive recommendations and supports a slate of legislation to make medications more affordable and the process for getting them simple and transparent. The drug supply chain is complex and improvements are needed across the system. I urge Congress to consider solutions like those supported by the Society: transparency around drug price increases; transparency for pharmacy benefit managers; instituting electronic prior authorization in Medicare; common sense step therapy; discouraging anti-competitive tactics; and eliminating the PBM gag clause.

You have the power to change the lives of those of us with Multiple Sclerosis who depend on these drugs. I ask for your support today.