



**National
Multiple Sclerosis
Society**
Mid America
Chapter

**House Health and Human Services Committee
HB 2319 - State medical assistance program; expansion of eligibility**

Presented by Marcillene Dover for the National MS Society, Mid America Chapter

March 18, 2015

Mr. Chairman and Members of the Committee:

The National Multiple Sclerosis Society lends its support to Medicaid Expansion so that all qualified Kansans have access to affordable, comprehensive health care. The National MS Society believes that the passage of HB 2319 will have a significant, positive impact on many, including Kansans living with and affected by multiple sclerosis, their caregivers and their family members.

Multiple Sclerosis (MS) is typically diagnosed between the ages of 20 and 50, when most are raising families, advancing careers and maximizing their earnings. Yet studies show that only 40% are in the workforce ten years after their diagnosis, and some lost access to employer-based health coverage. Many others are forced to work part-time to cope with the effects of their disease.

- The average annual cost for someone with MS in the U.S. including both direct and indirect costs (i.e. lost wages) is approximately \$69,000. Of this, approximately \$39,000 consists of health care costs.
- Seventy percent of persons with MS report difficulty paying for health care, even with health insurance and many are forced to delay doctor visits and split their medication doses or skip them altogether.

I am one of the 4,500 Kansans living with MS. It started in early 2013. I was sitting down at work when I noticed my legs felt kind of funny and I couldn't feel them the way I used to. I was uninsured. My mom had enrolled me in CHIP when I was in high school, but since I was over 18, I was no longer eligible. My mom paid for my initial doctor's visit. The doctor said she would really like to do an MRI, but since I had no insurance, she was just going to try treating it as a pinched nerve. She prescribed 6 weeks of physical therapy, with no follow up appointments.

During the summer of last year, walking to and from class became difficult. I stumbled a lot and even fell down on occasion. Maybe my pinched nerve just hadn't healed. That happens right? I tried not to worry and to just carry on. Then, one day at work, I started slurring my speech. It lasted about ten minutes or so, every other sentence. It didn't feel right. Then, out of nowhere, I remembered something I read on a website: slurred speech is a symptom of MS. I thought again, no way, not me. I don't have a disease. I'm 21 years old. I'm in the prime of my life. No way. I told myself that I should go get tested one day, but I wasn't thinking seriously about it. I didn't have insurance; just to get diagnosed would be expensive.

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I decided to visit the clinic doctor on campus at WSU and told him about my symptoms. I found an organization that would pay for a free MRI, should he suggest one. The doctor referred me to a neurologist, just to be safe. It's hard to get in to see a neurologist, so I had a few months to save up the \$300 it was going to cost me.

I went to the neurology appointment with my health checklist and application for an MRI in hand. I was pretty scared going in, but the doctor was really nice. He had me describe my symptoms and then he did a physical examination. He signed off for me to get an MRI and he seemed pretty concerned. I was in tears.

I tried to be excited, hoping to hear anything, good or bad, from my doctor. I went on with my life as usual, going to school and tutoring students. I was at lunch at the high school when I got the call. It was a nurse practitioner. She said the doctor had reviewed my MRI results and that they showed signs consistent with MS. I couldn't help but start bawling. I told myself any news is good news; it's better than not knowing. But that's not true. Now I didn't want to know. I wanted to crawl up in a little ball and give up on life.

But that's not what I did. Instead, I had to figure out how I was going to pay for this new, very expensive part of my life. I found Project Access, an organization that connects uninsured people with donated specialty care. I was accepted into their program and was able to see my doctor and get more MRIs.

Since Project Access is not insurance and patients only have access to donated healthcare, I can only receive care as long as they are able to give it. Recently, Sedgwick County reduced their funding. MS is expensive. Without insurance or an assistance program, my disease modifying therapy drug would cost \$2,000 to \$3,000 every month.

I am lucky for now to receive my medication through a patient assistance program and my neurology care through Project Access.

What about other people who are living with MS and uninsured? Multiple Sclerosis, like many other diseases and cancers, could affect anyone. And not everyone is as lucky as I was; I had all the right connections this time. Many people are not so fortunate. That's why we need to expand Medicaid in Kansas. No one should have to go through receiving a devastating diagnosis and then feel further devastation as they wonder how they will get the care that they need.

I encourage the committee to vote yes to HB 2319. That will allow the debate and conversation surrounding Medicaid expansion in Kansas to begin. My hope is that people living with MS in Kansas would be provided health care access that is afforded to people living with MS in the 28 states that have opted for some form of Medicaid expansion.

Thank you for your consideration,

Marcillene Dover
For the National MS Society,
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