What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- Symptoms range from numbness and tingling to blindness and paralysis.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.
- Early successful control of disease activity appears to play a key role in preventing accumulation of disability, prolonging the ability of people with MS to remain active and protecting quality of life.

Access to Coverage and Care

- The Congressional Budget Office estimates that under the AHCA as introduced, 24 million people would lose health insurance coverage by 2026.
- Phasing out Medicaid expansion and changing Medicaid’s financing structure to a per capita cap would reduce federal funding to states by $370 billion over 10 years, likely forcing states to make service and/or population cuts. (Center on Budget & Policy Priorities, 2017)
- Past experience with non-traditional approaches to health insurance including high risk pools (which could be created under the AHCA’s Patient and State Stability Fund) and health savings accounts (HSAs) clearly demonstrate their inability to adequately serve the needs of people with chronic, complex and high-cost health conditions like MS.
  - High risk pools often had waiting lists, premiums that were 150-200% of standard rates for healthy individuals, high deductibles, limited benefits and lack of access to needed specialists.
  - HSAs are best suited for healthy individuals with high incomes and are often not helpful to people with MS who have complex needs and high cost conditions.

Affordability of Coverage and Care

- A 2007 national study on medical bankruptcy found that of common diagnoses, nonstroke neurologic illnesses such as MS were associated with the highest out-of-pocket expenditures. (Himmelstein et al, 2009)
- To avoid financial devastation, or tough choices between care and critical needs like housing and food, people with chronic conditions such as MS need protections such as premium assistance, annual out-of-pocket caps, elimination of lifetime caps, and out-of-pocket costs spread throughout a plan year.

Request: Oppose the American Health Care Act.
• Instead, the AHCA would provide flat tax credits up to $4,000 per year based on age, significantly less than the actual cost of health insurance premiums and out-of-pocket costs.
  ○ Tax credits should be inversely related to income—to assist individuals with the least means afford coverage.
  ○ Flat tax credits adjusted for age ignore the fact that there are many younger individuals with complex, high cost healthcare needs.
• Repealing the cost-sharing subsidies in silver level Marketplace plans will add to the financial burdens of those most in need, and increase the likelihood of non-adherence to treatment.
• The AHCA’s 30% premium penalty to the cost of coverage for those unable to maintain continuous coverage for 63 days or more would interrupt treatment, putting people with MS at risk of relapse and irreversible disability.
• The progression of MS over time is typically accompanied by worsening disability, and the costs of MS have been shown to increase with greater disability. As a result, allowing health insurers to charge older individuals as much as five times as much as younger enrollees will be especially challenging for older persons with MS.

An effective health insurance system must promote the following criteria to meets the needs of people with MS are: Access, Affordability, Comprehensiveness, Transparency and Quality and Value. For more information on the Society’s position, see nationalmssociety.org/qualityhealthinsurance.

Carol Hardaway, Maryland

I first realized something was wrong when I reached into my 8-month-old son’s crib and my right arm couldn’t lift him. Four years later, I was diagnosed with MS in 1990. Almost 30 years after that diagnosis, I made my debut on the CNN Debate Night where I asked Senator Ted Cruz (R-TX), “I like my coverage, can I keep it?”

I had called Texas home since 1994 but in 2014, was forced to relocate to Maryland so that I could gain coverage under Medicaid and begin treatment on a disease-modifying therapy for my rapidly progressing MS. Throughout the years, I went through relapsing-remitting periods of complete blindness, numbness, tingling, debilitating fatigue and short-term memory loss—but in Texas, I fell into the “Medicaid gap.” While other states were expanding Medicaid, Texas has not and only covers specific groups like the completely disabled, pregnant women, and low-income families. I did not fit into any of those categories. For this very reason, the Affordable Care Act expanded Medicaid for people like me who live below 100% of the federal poverty level and make less than $12,000 a year.

Once I made the move to Maryland, I was able to get enrolled with Medicaid within two weeks. I was able to see a neurologist for care and start on an MS disease-modifying therapy, for which I pay $3 a month. Without Medicaid, this treatment would be $6,000 a month out-of-pocket. As a substitute teacher making $260 every two weeks, that is unattainable. Since gaining coverage through Medicaid expansion, I have been able to manage my disease progression and symptoms and am living my best life.
When I was diagnosed with MS 10 years ago, I was working full-time and had healthcare benefits. But life, like MS, is unpredictable. Down the line, my employment status changed, and I lost my employer-sponsored coverage. My husband and I reached out to brokers and learned that I could not get private health insurance due to my pre-existing condition. Another option was to change jobs and accept group coverage at $2,300 per month for my family of five. It was more than we could afford but for people like me, healthcare coverage isn’t an option—it’s a necessity. And so we went on and paid for health insurance but could have been saving more for our family.

The Affordable Care Act was life-changing for me. I could no longer be denied coverage or charged more for my pre-existing condition. I also had new options for health insurance coverage through the Kansas marketplace—that were comprehensive for my complex needs and affordable for our family’s budget. The first year, we selected a “gold” plan for $1,376 per month for our family. It had a higher premium—but this spread my healthcare costs evenly throughout the year. The next year, we chose a “bronze” plan that was only $925 per month!

As Congress discusses the American Health Care Act and considers changes to our healthcare system, I’ve heard things like “the cost of insurance should match the risk of the individual.” As someone with a chronic, complex disease, that is scary. I fear being put back in the place where I can’t afford coverage, my coverage isn’t comprehensive enough for my needs and/or I have gaps in coverage—which could cause MS exacerbations.

MS has no known cause and no known cure. While my disease is unpredictable, I need my healthcare to be reliable. I finally have comprehensive, affordable healthcare options. Please do not take us backwards.