



**National
Multiple Sclerosis
Society**

What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- MS interrupts the flow of information within the brain, and between the brain and body.
- 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.

Background on Lack of MS Data

- The last national study of incidence and prevalence of MS was conducted in 1975. Today, no accurate estimates are available.
- In 2000, the Pew Environmental Health Commission recommended that neurological diseases, such as MS and Parkinson's, be tracked by a national data system.
- The Commission stated that this data could identify populations at high-risk and related environmental factors.
- A national harmonized data collection system does not exist in the United States — only several small and uncoordinated MS registries and databases exist currently.

Need for Robust MS Data to Advance Research

Request: Co-sponsor and pass the Advancing Research for Neurological Diseases Act (H.R. 292 / S.849).

Legislative Background

- H.R. 292 was included in the 21st Century Cures Act (H.R. 6), which the House passed on July 10, 2015 by a vote of 344-77.
- The Senate HELP Committee unanimously passed S. 849 on February 9, 2016.
- This bill would create a centralized data collection system at the Centers for Disease Control and Prevention (CDC) that will track and collect data on the epidemiology of neurological diseases, including MS.
- The proposed data collection system will rely on existing databases to create permanent and separate national systems for each neurological condition.
- Information collected will provide a foundation for evaluating and understanding many factors, such as:
 - Geographic clusters of MS
 - Variability in racial and ethnic risk
 - Changes in the gender ratio
 - Outcomes measures, and
 - Healthcare practices and utilization.
- The bill requires privacy standards at least as stringent as HIPAA.

Lead Sponsors and Cosponsorship

- Representatives
 - Burgess (R-TX-26)
 - Van Hollen (D-MD-8)
 - As of early March: 115 cosponsors
- Senators
 - Isakson (R-GA)
 - Murphy (D-CT)
 - As of early March: 22 cosponsors



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Rebecca K.



I missed what would have been my first father-daughter dance, because my father—who was living with secondary progressive MS—could not take me. Twirling in my new dress like a princess, at 7 years old I could not comprehend why. To this day tears fill my eyes as I picture the dance invitation and think about my own daughter. But today, I am keenly aware of the struggles of MS—as I too was diagnosed with MS just one month after my daughter’s birth.

My father’s neurologist predicted a 1% higher chance of me developing MS given my father’s diagnosis. I can’t help but wonder if my daughter will hear “you have MS” someday; my current neurologist says that her chance is 1 in 40. Without real, current data—the number and type of people like me / families like ours around the country affected by MS—MS researchers have difficulty identifying and pursuing potential leads of environmental or viral triggers that may influence incidence of MS.

There are no words to describe the lengths that a mother will go to protect her child, and by supporting the Advancing Research for Neurological Diseases Act, I am protecting mine. I want my children to grow up in a world where the phrase “you have MS” is a thing of the past. I want my children to never be afraid of MS or of visiting a neurologist. I want my children to become strong advocates for their mom, for their grandpa, and for everyone affected by MS.

Seth Morgan, MD



I first encountered the term “multiple sclerosis” in medical school—a subject for me to cover on my way to becoming a neurologist. Fast forward 21 years into my career, when I myself became an “MS patient.” Within a couple of years of my diagnosis, my schedule of working 50-60 hours a week, fatigue and other symptoms caught up and led me to the difficult decision to retire.

MS was no longer something that happened to others—my patients—but it happened to me. My diagnosis of MS means that my children are pre-disposed to developing MS too. I can’t just sit back and hope that researchers figure it out. I drive for a cure for MS—I don’t want my loved ones ever to hear the words, “you have MS.”

So, I’m an MS activist. I advocate for policies and programs that will improve the lives of people affected by MS while we work to end this disease forever—namely the Advancing Research for Neurological Diseases Act which would create a nationwide system for tracking the incidence and prevalence of neurological diseases including MS, which could one day lead to a cure—a world free of MS.