



More than 10,000 Marylanders are living with MS. These Activists are doing something about MS NOWWill YOU?

Carrie B. Scott - Glen Arm, MD

This is my story...

My name is Carrie Scott. I am one of the many faces of MS, or Multiple Sclerosis. I am one of over 400,000 Americans, 10,000 of whom are Marylanders.

When describing MS, I like to compare it to a stereo with wires. The stereo represents my central nervous system, which includes my spinal cord, optic nerve and brain. The wires represent my nerve fibers and the plastic coating on the wires represents myelin. Myelin is an insulator or protective coating which helps to keep the nerve fibers safe. In Multiple Sclerosis, the myelin becomes scarred and breaks down. This causes symptoms such as leg numbness, vision problems, sensations of burning, cognitive issues as well as many other symptoms. These symptoms vary from person to person and day to day. Eventually, the wires can break and your leg that was once numb can become paralyzed, or you can lose your vision. Again, there are many symptoms which over time can become permanent.

My symptoms have become part of my everyday life; new changes are the things I notice. I have accepted the symptoms that have become permanent. My most disabling and permanent loss is a huge decline in the way my brain works, memory being a big one. Again, MS varies from one person to another and can change in a day, hours or even minutes. There is no cure. There is no known cause. My family is greatly affected by MS.

There are eight disease modifying therapies to slow the progression, all but one are injections. I have tried them all, and have failed with all but one. The side effects were unbearable. I was and continue to be in a clinical trial for the first oral treatment. I must start and stop this treatment when I reach liver levels that represent drug-induced hepatitis. I am out of options.

But, we are not out of options. There is a whole world of research to be done with the help of stem cells. In order to do more research we need continued support of the Maryland Stem Cell Research Fund. This year the governor has proposed \$10.4 million for the fund. I ask you to please secure this necessary funding. As I said, I am out of options. Please help me and the 10,000 Marylanders with MS live a productive and healthy life.



Shayla Cook - La Plata, MD

This is my story...

My name is Shayla Cook and I am 36 years old. I have progressive MS. Two years ago, I entered a nursing home when limitations in my vision and mobility made it impossible for me to live independently. I was much younger than the other residents and the nursing home environment was not a good fit for me.

With the help of numerous community-based services, I am happy to be living in my own apartment once again. I live in a subsidized, accessible building. I receive daily assistance from home health aides. I use para-transit, and have prepared meals delivered to my home. These services allow me to continue living in the community with as much independence and dignity as possible. I wish the same options were available for all young adults living with progressive MS and other disabilities.



MS stops people from moving. The National Multiple Sclerosis Society exists to make sure it doesn't.

We believe that all Marylanders have the right to

- ◆ Quality and comprehensive medical care and health insurance.
- ◆ Well-researched and up-to-date treatments and therapies for chronic conditions.
- ◆ Supports so individuals are able to live at home and participate in their communities.

Our Priority Issues in 2012 Include:

Funding Stem Cell Research

Keep stem cell research funding in Maryland at the Governor's budgeted amount of \$10.4 million. The National MS Society supports stem cell research funding in accordance with federal, state and local laws to find new ways to slow, prevent, and repair the effects of MS. Maryland is a national leader in biomedical research. The Maryland Stem Cell Research Fund (MSCRF) was established in 2006. During its first five years, the MSCRF has funded a total of 218 research project at a cost of \$78.8 million. Funding has targeted 35 diseases and conditions. MS is one of those diseases. According to the Maryland Stem Cell Research Fund, the MSCRF has produced an estimated \$75 million in labor income and over \$125 million in business sales and estimates that it has created an estimated 1,000 high-level jobs that attract and retain clinicians and researchers to the State. The 2009 World Stem Cell Summit, held in Baltimore, was the largest stem cell meeting in the United States that year, attracting 1200 participants from 40 states and 27 countries.

Improving Home and Community Based Services

Community-based long-term care services are critical to people with MS, especially as they experience disease progression. The Maryland Citizen's Action Network (MDCAN) supports efforts to enhance the independence and long-term care options for people with MS such as personal home care, household help, chore services, meal preparation, and accessible transportation. There is a critical link between transportation, housing, and employment; policy and program decisions should be made with full recognition of this linkage.

Health Care Reform

The National MS Society commends the Maryland General Assembly on its prompt implementation of the Affordable Care Act and the coordination of the Health benefits exchange. The National MS Society encourages a multi-faceted essential benefits package to include prescription drug coverage with reasonable out of pocket limits, rehabilitative services and devices, chronic disease management and mental health services.

Defending Fiscal Priorities Important to People with Multiple Sclerosis

Due to the worsening state fiscal climate it will be difficult to maintain or increase spending on many of the MDCAN's priorities within the state budget. Thus, the MDCAN will advocate to secure state funding of the programs that benefit people with MS, such as Medicaid expansion, funding for stem cell research, and community-based services. The Maryland Citizen's Action Network (MDCAN) believes that protecting services for the most vulnerable Marylanders should be foremost.

MS Kills Connection > < Connection Kills MS

www.nationalMSSociety.org 1-800-344-4867