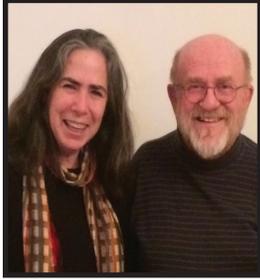




More than 10,000 MARYLANDERS are living with MS.
These Activists are doing something about MS NOW
... WILL YOU?

We tell our stories to make connections. Together we are stronger.



Marina Baudoin – Silver Spring, MD

I was introduced to multiple sclerosis (MS) in 1980 when I met my future father-in-law. Little did I know that 8 years later, the day after my second child was born, my husband would also be officially diagnosed with MS. He has primary progressive MS, as does his brother. Since the onset of the disease, his condition has slowly but surely worsened. Today, he walks with a cane, has very little endurance and spends a great deal of time at home.

We have been living in the same house for 27 years. Sadly, my husband was forced to retire three years ago because he could no longer endure the hour and a half commute into Washington, DC. I was always aware that I would become a full-time caregiver for my husband, but I was unsure of when that would be. My mother-in-law had done this and it was my plan to follow in her footsteps. Twelve years ago, armed with this awareness, I began a small business working from home. Working from home gives me the flexibility to take my husband to doctors' appointments, help him get around, and be there whenever he cannot do something himself. While I work from my basement, I need to feel assurance that he will be safe as he moves around upstairs. As he becomes more and more immobile, he spends more and more time in the house, and our house is not completely accessible.

We are now at the point in his disease where we will need to make structural changes to our house in order for him to remain living as independently as possible and to keep him safe from falling. We have begun researching the costs to make changes that will allow us to stay in our forever home. The costs are astronomical. To make the necessary changes, we will spend upwards of \$50,000. This, in addition to all of the expenses we incur already because of the disease, is very frightening. While the Independent Living Tax Credit won't cover the full expense, it will ease some of the financial burden so that we can make these life-changing renovations to our home.



Linda Schmidt – White Marsh, MD

I am 67 years old. For the past 27 years MS has gradually eroded away my ability to live independently. I can no longer take care of even my most basic needs on my own. Gary, my husband of 47 years, has taken care of me throughout the progression of my disease but now faces his own physical challenges. But with help from a variety of community based services I am able to continue to live with my husband in the community. I receive daily assistance from home health aides to take care of my personal needs. I live in an accessible building to make it easier to get out into the community. I use para-transit to visit friends and family, get to community activities, and to go to medical appointments. Without the community supports I receive I have no doubt that I would now be living in a nursing home.



Karen Jackson – Ft. Washington, MD

I was diagnosed with relapsing-remitting MS (RRMS) when I was 36, in the prime of my life and career as an athletic trainer. I tried all three disease-modifying therapies that were available at the time but unfortunately none were helpful to me. In 2003, I enrolled in a high-risk bone marrow transplant study. I was willing to take the risk to help better understand and treat MS, but I was not accepted. That was probably the toughest day in all of my 18 years of battling the challenges MS presents; not just because I was not accepted into the trial, but because it was the first time I was told I had primary-progressive MS (PPMS). I now know that I had PPMS from the start. Hearing I have a form of MS that is chronically progressive and has no therapies felt like being told to "go home and make the best of it" because they had nothing to offer me.

I continue to look forward to treatments for PPMS. The Maryland Stem Cell Research Fund has allowed Maryland scientists to target a number of diseases including MS. I feel that stem cell research is critical to moving forward in treating and hopefully curing diseases such as MS. Stem cell research offers me hope for which there is no price tag.



We believe that all Marylanders have the right to:

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

Our Priority Issues in 2016 Include:

Independent Living Tax Credit

As more people choose to age in place, and as people with disabilities face challenges functioning independently in their homes, impediments to living safely in our communities must be removed. People with multiple sclerosis (MS), older adults, and others with disabilities need the resources and funding necessary to increase the safety and accessibility of their homes or the opportunity to purchase a home that meets these standards in order to remain independent, active members of their community.

Accessible housing includes any home modifications made to adapt living spaces to meet the needs of people with physical limitations so that they can continue to live independently and safely. People with MS have very unique, personalized needs and home modifications range greatly to meet those diverse needs. Modifications can be as simple as installing a grab bar in the shower and have minimal costs associated; involve assistive technology coming at moderate expense; or can require much costlier structural changes to the home, such as widening doorways or building a ramp or an accessible bathroom. According to the Center for Universal Design, home modifications can range in price from \$100 to \$50,000.

Having stable, affordable and accessible housing not only increases quality of life and promotes independence for people living with disabilities—it allows them to remain actively engaged in the community, benefitting the entire community.

The National MS Society supports HB 371/SB 819 because it creates a tax benefit when an individual takes the necessary steps to make their home safe and accessible.

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 National MS Society 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.

Funding Stem Cell Research

Keep stem cell research funding in Maryland at the Governor's budgeted amount of \$9 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 seven years, the MSCRF has funded a total of 349 research project at a cost of \$120 million. Funding has targeted 35 diseases and conditions, including MS. Scientists are making groundbreaking discoveries. Therapies are beginning to advance from the bench to the bedside as stem cells are used to create disease models and test new drugs.