



We mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by multiple sclerosis.

**National
Multiple Sclerosis
Society**

The Virginia Chapters of the National MS Society

2013 Legislative Priorities

Increase Affordable Access to Prescription Medication

Several health and prescription drug plans have instituted a tiered payment system for medication. The most expensive medications are often relegated to the highest “specialty” tier which requires enrollees to pay a *percentage* of the cost of the medication as opposed to a fixed co-pay. With no generic alternatives available, MS disease-modifying therapies are typically assigned to this specialty tier. This places a significant and unjust financial burden on people with MS. Many have had to forego treatment because they simply cannot afford it.

Senate Bill 945 / House Bill 2030

The Co-insurance Fairness Bill will help Virginians who have high medication costs to budget and prepare for their monthly medical expenses. It provides an option for individuals to spread their annual out-of-pocket limit over an entire year through a monthly installment plan.

Senate Bill 947

The 60-Day Notification Bill will protect and prepare patients by requiring health plans to notify them in advance when their medication will be moved to a higher cost-sharing tier.

Expand the State Medicaid Program

Medicaid is a critical lifeline for people living with MS. The program provides access to important medical services such as durable medical equipment and is the primary public source of funding for long-term services and supports for people with disabilities of all ages. Personal care services, respite care and other home-and-community-based services allow individuals with MS to live and work in their communities and avoid costlier and premature admission to institutional facilities. Despite federal health care reform, thousands of Virginians will continue to fall into a no-coverage gap. We urge legislators to expand Medicaid so that 400,000 uninsured Virginians will have access to care.

Increase Access to Care in Rural Areas

People living with MS in rural areas tend to be diagnosed later than those living in urban areas; are more likely to report that MS interferes with their quality of life and are less likely to be taking one of the MS disease-modifying therapies (Buchanan, et al, 2006). We support efforts to increase access to specialized MS care in rural areas.

Support Livable Communities

Having stable, affordable and accessible housing; access to appropriate transit services; and opportunities to remain actively engaged in the workforce and in the community helps to increase quality of life and promote independence for people living with disabilities. We support **House Bill 2005** which codifies the Virginia Housing Trust Fund.

Fund Critical Resources

As legislators work to amend and balance the state budget, we ask that they prioritize services for Virginia’s most vulnerable citizens.

We are MS Activists and we choose to tell our stories.

What will **YOU** do to JOIN THE MOVEMENT[®]?



Sarah Keitt - Woodbridge, VA

In April of 2000, I was diagnosed with MS. When I was diagnosed, the ten-year prognosis for a person with MS was not encouraging, but the outlook now is much brighter due to the new treatments that are available. I credit these treatments for keeping me healthy and without the need for disability benefits. However, the medications are expensive and at times, I have delayed refilling my prescriptions so not to cripple my family's finances. I am currently taking an oral multiple sclerosis disease-modifying therapy that costs \$48,000 annually. My insurance charges me a monthly copay of \$450 after I meet my \$2,500 deductible. January is a painful month for our budget. This week I spent \$3,100 at the pharmacy for the medications I take for my MS and the medications my daughter takes to manage her ADHD. If my family

had an option to spread our medical costs out over a plan year, we would be able to better manage our budget, handle unexpected expenses and not begin each year in a financial hole.

Pam and Ray Heron - Charlottesville, VA

My wife Pam has secondary progressive multiple sclerosis. I was forced out of a job when Pam's MS diagnosis significantly raised the company's health insurance premiums. Fortunately, we were able to qualify for Medicaid; but since 1999, I've been working at the same job with the same pay because I'm afraid if I make more money we will no longer qualify for the program and Pam needs a lot of care. The only body parts that Pam can control are the fingers on her right hand. If it was not for the Certified Nursing Assistants (CNAs) that are provided by Medicaid, I would not be able to adequately take care of her or work at all. In fact, she would probably be in a nursing facility. Medicaid eases the burden, provides respite hours and covers critical necessities such as diapers for my wife. These services provided through Medicaid are so vital for us.



Robert Lyons - Mechanicsville, VA

Last year, I developed a serious case of vertigo caused by my MS. I needed to sleep with my head propped up, so my wife and I bought a special hospital bed. At first, our insurance company said they would cover the bed but in the end we paid \$7,000 out-of-pocket. In addition, we pay \$400 every three months for my MS disease-modifying therapy and thousands more for the 15-18 other medications I require. My wife and I break up the payments to make it easier for our budget. It would be a relief to be able to plan ahead and arrange a monthly installment plan with our insurance company to help cover our out-of-pocket costs.

Teresa Schmidt - Richmond, VA

I have MS and after losing my job and health insurance I was unable to afford my medication. Without medication, my MS progressed and over the last few months I have gone from being fully mobile and independent to being completely bedridden. The house that I own is not accessible, which makes it difficult to take care of my every day needs. My bedroom is on the second floor and my bathroom is on the first. I need a safe way to get down the stairs or a bathroom on the second floor that allows me to be safe and clean. I'm a single mother of four children and it's hard for the kids to watch me go through this. I was denied disability benefits and I've applied again. Meanwhile, I am trying to keep up with my mortgage to avoid losing my home and also renovate it to be more accessible so I can take care of myself and my family. Housing that is both affordable and accessible would significantly increase my quality of life.



Katrina and Brian Wise - Williamsburg, VA

I was diagnosed with MS in 2001 and in 2002 I had to leave my job in the medical field because I lost my vision. Sadly, I also lost my health insurance. My husband Brian was able to add me to his employer provided coverage, but his payments skyrocketed from \$60 a month to \$350. Not only were we newlyweds learning how to live with my blindness, but we began to struggle financially. We were unable to keep up with our utility bills and pay for food. We defaulted on our student loans and the companies began to garnish our wages. They didn't understand that we were facing huge health changes with financial implications. Before my MS diagnosis, we were saving money to buy a house. Now, we have ruled out the chance of ever owning a home; it seems like we just can't get back on our feet. A state Housing Trust Fund that facilitates the development of affordable housing and assists Virginians with down payment and closing costs would help us reach our goal of home ownership.