



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 Citizen Action Network of the National MS Society believes:

- Comprehensive, quality, affordable health care should be available to all.
- Virginia's communities should be Livable Communities.
- Families should have access to quality and affordable respite care.
- ADA Compliance should be fully enforced.

We advocate for affordable cost-sharing for prescription medication.

In response to increasing costs, many health plans and prescription drug plans have instituted a tiered payment system for medications. The tiers are often labeled 'generic,' 'preferred,' and 'non-preferred' and each have a set cost-sharing amount. For example, \$10 for generic, \$30 for preferred and \$60 for non-preferred. Several plans now include a fourth, 'specialty tier' and require enrollees to pay a *percentage* of the cost of the most expensive medications as opposed to a fixed amount. With no generic alternatives available, biologic medications, including MS disease-modifying therapies, are increasingly among the medications relegated to the specialty tier. The tiered cost-sharing structure places a significant financial burden upon people with MS and others with a chronic illness. Subsequently, many people with MS have stopped taking their prescribed medication because they simply cannot afford it.

The National MS Society partnered with Delegate John O'Bannon to introduce House Joint Resolution 579 – legislation that would authorize the Joint Healthcare Commission to study cost-sharing. Understanding the issue is the first step toward resolving it.

We advocate for affordable and accessible housing.

The security of having an affordable place to live is vital for people with MS and other Virginians who live with disabilities. Having stable and appropriate housing decreases stress, increases quality of life, and promotes independence by allowing people to live in their communities as opposed to long-term-care facilities.

- We support an expansion of the Livable Home Tax Credit.
- We support the creation of a state Housing Trust Fund.

We advocate for increased efficiency and coordination of accessible transportation.

There is a critical link between transportation, housing and employment. Virginians with disabilities need access to appropriate transit services to enable full participation in the workforce and in community life, as well as facilitate access to critical medical appointments.

We advocate for a system of coordinated, quality respite care across Virginia and for all ages.

We recognize the importance of respite care programs and their ability to provide rest and relief to families. Respite care makes it easier for families to care for their loved ones in their own homes for as long as possible by decreasing stress and increasing the quality of life for all.

We advocate for disability rights in the workplace.

People with disabilities should have equal access to employment and receive necessary workplace accommodations and adaptations, without undue discrimination.

"Storytelling can change a room. It can change lives. It can change the world."

- Gwenda LedBetter

We choose to tell our stories...what will **YOU** do to **JOIN THE MOVEMENT[®]**?

Teresa Crowson – Newport News, VA

The impact of high prescription co-pays driven by the tiered system spreads well beyond those living with MS. I feel blessed to have the good insurance coverage that we have, but it is difficult for some to understand the true cost of medications for families impacted by chronic illness. In our family of four, we spend \$405 per month on our prescriptions. To put this in perspective, that is our third highest expense, surpassed only by our mortgage and grocery costs. We pay more for our medications than for our cars, our power bill, our oil bill, and other necessities. I advocate for limiting "out-of-pocket costs" for prescription drugs in order to make them more affordable for families like mine.



Grayson Traylor – Richmond, VA

It is important for Virginia to fund and prioritize respite care for all income levels. My dad, Woody, is 62 years old. He was diagnosed with primary progressive multiple sclerosis ten years ago. Since his diagnosis, his health and mobility have slowly declined and he is confined to a wheelchair. As my dad's MS symptoms intensify, he has to rely more and more on my mom for his daily needs. Unfortunately, my mom is also experiencing a decline in her health and well being. It has become difficult for her to handle the strain of lifting her husband in and out of his chair each day. When my mom injured her knee recently, I moved in with them to help for a time, but had to return to Richmond due to demands at work. My mom also works full-time. Like many caregivers, she cannot afford to get sick or take off too much time from work. With the increase in the aging population, and the number of people living with disabilities seeing a sharp rise, respite care programs are crucial for families and would make a difference for my mom. We need to restore



cuts to Medicaid and draw down federal money such as the Lifespan Respite Care grant to help ease the burden on families and caregivers such as my mom.

Gretchen Bogenrief – Alexandria, VA

I want to "age in place" like so many folks now-a-days. My MS was diagnosed after I moved into a condominium in Virginia. Now as my disease progresses, I see the limitations of this 1960s-era building, but don't see many options on the market. Virginia needs more accessible units built using Universal Design standards. We need housing in caring communities that are livable and easy to navigate. Apartments, condominiums and houses must be located near mass transit. It's past time for planning! Just ask any person of a certain age or disability...and there are more of us every day.



Gwen Harris – Roanoke, VA

Paratransit is vital to many people living with disabilities but it can often be inefficient. I live in Roanoke City and like in many other Virginia localities, our paratransit service will only run near a bus line and will not cross the border into the neighboring county or city. I often rely on public transportation because I cannot drive myself and my husband has a busy work schedule. However, the paratransit service is unable to take me to certain doctors' offices, the DMV and the library. Once, a paratransit driver refused to drive me one more block to the library because it was beyond his limits. Dangerously, I had to cross a busy street in my wheelchair. Also, the buses do not run on Sundays and service ends at 8:45pm. What if someone wanted to go to church or needed to work an evening job? This presents a huge problem for me and other people with disabilities who need to access services in the surrounding areas. We need more efficient accessible transportation so that people with disabilities can fully participate in work and



community life, and get to our medical appointments.

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