



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**

2012 Legislative Platform

### Health Care

It is essential that people with MS have access to care that is affordable, comprehensive and accessible.

#### **Patient Protection and Affordable Care Act**

We are monitoring the process of implementation at the state level and advocating for the development and modification of policies to meet the needs of people with MS.

#### **Affordable access to prescription medication**

We continue to work with the staff of the Joint Commission on Health Care as they complete a study on cost-sharing in Virginia. Several health plans 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.

#### **Rural Health**

We engage in advocacy to increase access to specialized MS care in rural areas.

### 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.

### Care for Our Caregivers

Respite care makes it easier for families to care for their loved ones in their own homes, as opposed to long-term-care facilities, for as long as possible by decreasing stress and increasing the quality of life for all. We are working with the Virginia Caregiver Coalition to implement the federal Lifespan Respite Care Grant in the Commonwealth.

### Funding for Critical Resources

Health Care Cuts Cost Virginia. As legislators work to balance the budget, we ask that they prioritize services for vulnerable communities, including Medicaid.

# We are MS Activists and we choose to tell our stories. What will YOU do to JOIN THE MOVEMENT®?

## Dawn Hodge – Wytheville, VA



I live in Southwest Virginia with my husband and two children. My husband is the main bread winner and has held the same job for 19 years. I have MS and although I receive monthly disability benefits and some benefits from Medicare, my primary insurance is from my husband's employer. Due to the rising cost of insurance and the outrageous cost of my MS medication, my family has had to make life changing and dangerous decisions when it comes to our health. At times, I have stopped taking treatments and cut my pills in half to make the prescriptions last longer. Living in a rural area, access to care has also been difficult for me. To receive a monthly infusion of my MS medication, I had to drive 2 hours away from home and the price of gas made it difficult. I am currently not taking any modifying therapy for my MS because

it is too expensive; I'm praying that I do not have any flare ups.

## Marlon Carvajal – Alexandria, VA

Due to the progression of my MS, I had to stop working. I sold my home and began searching for an affordable and accessible place to live. It was nearly impossible to find appropriate housing that was near the Metro Access transit system, which I rely on. As a result, I moved in with my mom who has kidney disease and needs dialysis 3 days a week. We take care of each other. My brothers had to make modifications to her home in order for it to be more accessible for my scooter. They installed grab bars so I could be self-sufficient and avoid falling. So far, the arrangement is working but I wonder what options I would have had if living with my mother was not a possibility. Virginia needs more communities that are livable - where housing is accessible and affordable and accessible public transportation is widely available.



## Susan Teabout – Virginia Beach, VA



In December 2002, at the age of 38, I was diagnosed with MS. At the time of my diagnosis, I was President of Delta Connection Academy, a subsidiary of Delta Air Lines. I managed 5 pilot training locations and contracts for airline pilot training with airlines throughout the world. My MS progressed quickly and by September of 2005, I had to leave Delta Air Lines due to my disabling condition. Life is made of defining moments and leaving my dream career due to disability was clearly one of those "moments." Having run a division of a large company, I understand first-hand the tremendous pressure to cut spending in a tough budget year. However, cutting health care and safety net programs for those who need them is a step in the wrong direction. In 2011, my annual medical costs exceeded \$40,000. I spent over \$8,000 out of pocket and drove over 1200 miles to doctor appointments. I began to take my MS drug only 2 times a week versus the 3 recommended because I simply could not afford it. I never imagined in a million years as a world-class athlete, a

pilot and ranked in the top 30 fastest women motorcycle racers, that I would become disabled due to a disease for which treatment was financially unaffordable.

## Donna Steigleder – King William, VA

I have often thought about how nice it would be to have respite care. There are times I would just love to get away for more than a few minutes to do something for myself. My husband Lynn has MS. He is 6 feet tall, weighs about 200 pounds and can do very limited things for himself. I care for him 24 hours a day. Finding someone to help me care for him is not easy. We need a skilled companion who can stay with Lynn during the day maybe two days a week so I could run into work for a few hours. Or someone who can stay with him for several hours on a weekend so I could have some "me time." I haven't had any downtime in two years! For respite care to work for us it would have to be affordable and the caregiver would have to be friendly, patient, knowledgeable regarding catheter care and be able to assist with activities of daily living. As a caregiver, you must always think ahead and plan for the "what ifs?" It can be stressful. I've devoted time to providing encouragement and support to other caregivers through a blog called MS Caregiver Sharing. Sharing the challenges of caregiving has helped to reduce the isolation.

