



Virginia CAN of the National Multiple Sclerosis Society 2008 Legislative Platform

We are MS Activists. The **Virginia Citizen Action Network** (VA CAN) is a collaboration of people who want to do something about MS now. Led by the four Virginia chapters of the National MS Society (Blue Ridge, Central Virginia, Hampton Roads, and National Capital), the VA CAN represents more than 10,000 people living with MS throughout the state. Since MS is a disease that affects the entire family, however, we estimate the representation of the VA CAN to be closer to 30,000 Virginians.

Working with legislators on both sides of the political aisle, the VA CAN raises awareness and advocates for policies and programs that will benefit people with MS. We are strengthened by the work of our MS activists - individuals with MS, their friends and family, professionals, and others - who raise their voices and communicate the needs of people with MS to their elected officials. Through these efforts, the VA CAN promotes policies that allow people with MS to participate fully in their communities, addressing many issues such as affordable health care and health insurance; accessible transportation and housing; caregiver support; disability rights, and more.

We believe that all Virginians have the right to:

- ❖ Affordable healthcare and prescriptions drugs.
- ❖ Safe, affordable, and accessible housing.
- ❖ Services that allow individuals with disabilities to live at home and participate in their communities.

About Multiple Sclerosis

Multiple sclerosis (MS) interrupts the flow of information between the brain and the body and stops people from moving. Every hour in the United States, someone is newly diagnosed with MS, an unpredictable, often disabling disease of the central nervous system. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with more than twice as many women as men being diagnosed with the disease. MS affects more than 400,000 people in the U.S., and 2.5 million worldwide.

About the National MS Society

MS stops people from moving. The National MS Society exists to make sure it doesn't. We do this through our home office and 50-state network of chapters by funding more MS research, providing more services to people with MS, offering more professional education, and furthering more advocacy efforts than any other MS organization in the world. The Society is dedicated to achieving a world free of MS. We are people who want to do something about MS now.

2008 PRIORITY ISSUES

Fully Fund the Virginia Caregivers Grant Program

The Virginia Caregivers Grant Program provides for an annual grant payment up to \$500 for caregivers who provide *unreimbursed* care to a relative or someone for whom they serve as guardian who has a mental or physical impairment. To qualify, the caregiver's Virginia adjusted gross income cannot exceed \$50,000 for an individual or \$75,000 for a couple. The program will need to be funded at an estimated \$2 million level to address the needs of all qualified Virginians. Since it was created in 1999, the program has yet to be funded adequately, receiving only \$200,000 in 2006.

Establish a Housing Trust Fund

The goal of any Housing Trust Fund – including this one -- is to “incentivize” actions that grow the market of affordable homes and rental housing in every area of Virginia. The Fund accomplishes this goal by providing loans and grants for “gap” funding – to first time homebuyers; to nonprofit multi-unit housing; to local governments with local housing development projects; and much more.

Promote Access to Adequate Health Care

The National MS Society believes that all Virginians with MS should have access to adequate, affordable health care coverage, regardless of their income. The VA CAN is committed to collaborating with legislators, organizations, and people with MS across the state to work toward a solution that is both adequate and fiscally responsible.

Specific Actions Needed:

- Educate and engage legislators and constituents about the severe gaps in affordable health care and coverage availability in Virginia.
- Develop a long-term, grassroots plan to secure adequate access to health care for people with MS and other adult onset disabilities.

Expand Prescription Drug Coverage

It is the opinion of the National Multiple Sclerosis Society Medical Advisory Board that early and ongoing treatment with an FDA-approved therapy may reduce future disease activity and improve quality of life for many people with multiple sclerosis. Certain prescription drugs help people with MS manage the disease's symptoms, often enabling them to remain active and employed so they may continue to provide for themselves and their families. Chronic disease prescriptions should thus be tiered to be affordable and economically available to the uninsured, including state employees. Currently, Virginia is one of only 10 states that does *not* offer a state assistance plan to citizens to pay for prescription medications.

Specific Actions Needed:

- Maintain MS drugs on the Medicaid preferred drug list (PDL) that will also be included on the state employee drug list.
- Maintain symptomatic treatment drugs on the Medicaid preferred drug list (PDL), including off-label prescriptions.
- Advocate lowering the tiered status of MS drugs within the state employee health plan.

OTHER CRITICAL ISSUES

Streamline Benefit Eligibility Process

Virginia is one of only 11 remaining states that requires people to complete two separate eligibility processes for disability benefits – one for SSI and one for Medicaid. The administrative costs for this duplicate process could be saved. Virginia should amend the eligibility process so that people who are eligible for SSI automatically become eligible for Medicaid, without requiring a second eligibility process.

Support the Olmstead Initiative

We commend the Governor for continuing to address the recommendations of the Olmstead Task Force. This task force oversees the implementation of the Olmstead Supreme Court decision, which affirms the right of individuals with disabilities to live in their communities. However, to implement the Olmstead Decision fully, a larger investment in community resources and infrastructure will be required. The annual report includes recommendations in several areas:

- Continuing to increase Medicaid reimbursement rates to ensure availability and quality of service providers.
- Developing and fully funding incentives to attract and retain qualified candidates to disability fields of care.
- Increasing Medicaid financial eligibility to 100% of the Federal Poverty Level.
- Improving/expanding Virginia's Home and Community Based Services Programs, which enable people with disabilities to receive consumer-driven care in their homes or in their communities, rather than in institutions.

Another Olmstead-related issue of importance includes utilizing supports, such as the Real Choice Systems Grants, to increase services and supports for people with disabilities.

Increase and Improve Accessible Transportation Options

Virginians with disabilities need access to appropriate transit services that will enable their full participation in the workforce and in community life. This includes supporting improved access and expansion of accessible transportation for individuals seeking health care, employment, and leisure activities beyond the boundaries of the current public transportation system. There is a critical link among transportation, housing and employment - policy and program decisions should be made with full recognition of this linkage.

Specific Actions Needed:

- Monitor the mandated development of a single qualification process for use of paratransit by people with disabilities.
- Urge the Department of Rail and Public Transportation to develop a plan to identify what is required to provide accessible public transportation services in all localities by 2011. The plan should include estimated costs, potential revenue sources, and expected numbers served. The plan shall also include specific references to the needs of people with disabilities and the growing population of older Virginians.

Address Other Housing Issues

People with MS need access to affordable, accessible housing in order to remain with their families in the community.

Specific Actions Needed:

- Enact “*Visitability*” legislation and market-education programs that would make new single-family homes physically accessible.
- Require universal design implementation for all housing developed with public funding.

Promote Employment

People with disabilities have unique needs that should be protected as workforce development restructuring occurs (by employing trained rehabilitation counselors, using accessible sites, etc.).

Specific Actions Needed:

- Enable Virginians with disabilities to work without jeopardizing vital health care benefits by implementing the federal *Ticket to Work and Work Incentives Improvement Act (TWWIIA)*.
- Monitor the implementation of the state plan amendment to allow the Buy-In Program. The Department of Medical Assistance Services (DMAS) is seeking federal approval. The VA CAN encourages continued efforts to gain federal approval of a Medicaid Buy-In program.

Ensure Access to Quality Health Care

The VA CAN urges the Commonwealth to protect the right to have access to quality health care for all Virginians.

Specific Actions Needed:

- Include training on multiple sclerosis and other special populations as a requirement for licensure.
- Support full implementation of programs designed to focus on the attainment of “Healthy People 2020,” which is designed specifically for citizens living with the additional financial burden of managing a chronic disease, including people with multiple sclerosis. Many of the national objectives of Healthy People 2020 have the potential to improve the quality of life for people living with MS. The objectives provide guidance for health policy discussions in Virginia. “Healthy People 2020” is a program of the Office of Disease Prevention and Health Promotion, U. S. Department of Health and Human Services. (The program can be viewed at <http://www.healthypeople.gov/default.htm>).
- Retrofit health care facilities for accessibility.
- Establish links on the Virginia Department of Health website that connects people searching for chronic disease information with the National MS Society website.

Support Long-Term Care Initiatives

Approximately 20-25% of Virginians with MS need long-term care services. Too often, young people living with MS are separated from their children and families and placed in nursing homes with elderly adults when care in their own homes might be just as cost effective and more respectful of their stage in life.

Specific Actions Needed:

- Virginia must assure the quality of licensed Assisted Living Facilities and the safety of residents. This would require the continued monitoring and enforcement of regulations enacted for these facilities. Reform legislation was passed in the 2005 General Assembly. It is now important that the regulations being drafted to implement the reforms are written to ensure: 1) an informed ALF consumer, 2) staff and administrators who are qualified and appropriately trained, and 3) the ALF licensure regulations have appropriate enforcement provisions.
- It is also critical that the Auxiliary Grant rate provides sufficient funding to support the cost of care for low-income Virginians through additional state funding.
- Create incentives for individuals to become trained as nurses, certified nurse assistants (CNAs), and personal care assistants to help address staffing shortages in Virginia.
- Move forward with the implementation of the Medicaid Partnership program in Virginia.
- Actively monitor and provide input in the implementation of the Virginia Acute and Long-Term Care Managed Care Program.

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