



**National  
Multiple Sclerosis  
Society**

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**Testimony in support of Proposed S.B. No. 1, "An Act Increasing Access To Affordable, Quality Health Care", Public Health Committee - January 31, 2007**

Senator Handley, Representative Sayers and members of the Public Health Committee,

Thank you for the opportunity to submit testimony. **The National Multiple Sclerosis Society supports Proposed Senate Bill 1, "An Act Increasing Access to Affordable, Quality Health Care."** The Greater Connecticut and Western Connecticut Chapters of the National Multiple Sclerosis Society provide services, education and support to over 6,000 people with MS in Connecticut and the families, friends and professionals who care for them. Our clients with multiple sclerosis are often uninsured or underinsured.

Multiple sclerosis is thought to be autoimmune disease of the brain and spinal cord. The disease can cause blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, blindness and more. These problems may be permanent or may come and go. MS is diagnosed at the prime of life usually between the ages of 20 - 50.

Over 65% of people with MS have to leave employment because of symptoms and disability. These individuals often have no disability coverage and they are not able to obtain unemployment because they cannot work. On average, it takes over two years for individuals to obtain Social Security Disability Insurance. During this time, most are not eligible for State Administered General Assistance or Medicaid. The individuals with MS and their families lose their health insurance coverage because they cannot afford expensive COBRA payments. As a result, the person with MS may go without treatment, increasing their risk for a relapse and hospitalization. Untreated, complications can develop and lead to the individual having substantial physical, emotional and cognitive disabilities. Ultimately, this will have a significant economic and social impact on society.

If a person gets Social Security Disability Insurance, which can provide some monthly income, it will take two years before the individual is eligible for Medicare. Therefore, the average individual with MS who has to leave employment will have no health insurance for four years.

Another obstacle to accessing affordable quality healthcare is the huge shortage of specialists who will take Medicaid and Medicare. We work with people with MS who cannot get care, even when they have public insurance like Medicaid or Medicare.

Since the implementation of Medicare Part D we are seeing an increase in the problems that people with MS face in obtaining not only medications but also in receiving health care services. Now it is more difficult for individuals who have Medicare and Medicaid to reach their "spend-down" amount. Dually eligible individuals are **getting no health care** because they cannot afford the cost.

Changes brought by Medicare Part D are very financially challenging for our members, especially those who need the biological therapies used in MS. When the Medicare Part D coverage enters the "donut hole" the individual becomes responsible for the full cost of the medication. These can cost



over \$1500 per month. Even when a person has Part D coverage, they can be faced with copays that are hundreds of dollars a month.

Individuals with insurance can have gaps in their coverage during different life events. BC, a woman in her 40's with MS is married and receives Social Security Disability. Her husband works two jobs and struggles to help keep a roof over their heads and takes care of her as she can barely walk and needs help with personal care. They have insurance now, but when he was laid off, they lost coverage. Medical bills were so high, it was necessary to declare bankruptcy. Even with insurance, they face huge bills and many of her specialized medical equipment needs are not being met. She was trapped in her home until a stair-lift was donated to carry her down the stairs of her home.

The January 29, 2007 journal, *Multiple Sclerosis*, includes the largest study ever undertaken to explore insurance concerns in people with MS. From May – November 2005, 983 Americans living with MS were interviewed. Among the findings, "27.4% indicated that, since being diagnosed with MS, health insurance concerns had significantly affected employment decisions. In addition, 16.4% reported considerable difficulty paying for health care, 27.4% put off or postponed seeking needed health care because of costs, and 22.3% delayed filling prescriptions, skipped medication doses, or split pills because of costs. Overall, 26.6% reported considerable worries about affording even basic necessities, such as food, utilities, and housing. Finally, over a third reported worrying "a lot" about losing or not having health insurance, about the cost of health insurance, and about whether their health coverage might change." <http://msi.sagepub.com/cgi/content/abstract/1352458506071356v1>

This study emphasizes that simply having insurance does not necessarily ensure that a person will be able to afford care and medications that are so important for treating MS. It also confirms the importance of the 'safety net' and our ongoing efforts to improve health insurance coverage for people with MS. <http://www.nationalmssociety.org/Research-2007Jan30-2.asp>

The National Multiple Sclerosis Society urges the Public Health Committee and the Legislature to pass comprehensive reform that meets the Institute of Medicine principles, supporting health care that is:

- **Universal**- covers everyone
- **Continuous**- portable with jobs and between employed and unemployed status
- **Affordable**- especially to low-income individuals and families
- **Sustainable**- affordable for society
- **High quality**- enhances health and well-being by promoting access to effective, efficient, safe, timely, patient-centered and equitable care

Modifying HUSKY is not the answer. Reform needs to cover all individuals, including single people and families without children. People with chronic health conditions need comprehensive coverage that includes rehabilitation, home care, mental health services and coverage of assistive technology. Comprehensive coverage needs include services that enhance health and well-being by promoting access to high quality care that is effective, efficient, safe, timely, patient-centered and equitable.

Thank you for support and your work to change the broken health care system in CT.

Submitted by,

  
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