

**NATIONAL MULTIPLE SCLEROSIS SOCIETY
NEW YORK MS COALITION ACTION NETWORK**

**TESTIMONY BEFORE THE NEW YORK STATE DEPARTMENTS OF HEALTH AND
INSURANCE
"PARTNERSHIP FOR COVERAGE" HEARING ON INCREASING HEALTH INSURANCE
COVERAGE IN NEW YORK**

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Presented by:

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Good morning. My name is Courtney Totter. I am the Manager of Advocacy Programs and Services at the Upstate New York Chapter of the National Multiple Sclerosis Society. Working in collaboration with the three other National MS Society Chapters throughout New York State, I am here today to represent the best interests of the 34,000 families in New York that are affected by multiple sclerosis (MS).

First, I would like to provide some background on multiple sclerosis. MS is an unpredictable, life-long, neurological disease usually diagnosed in early adulthood (between 20 and 50 years of age) when people are beginning families, establishing careers and making their life dreams come true. Symptoms often associated with MS include difficulties with vision, numbness or tingling, muscle weakness, loss of balance/coordination, gait disturbances, excessive fatigue, bladder/bowel disturbances, memory loss and paralysis. About ten percent of individuals with MS will require personal assistance and/or home health care in order to live independently. While there is no cure for MS, appropriate treatment can reduce the frequency, severity, and duration of flare ups and slow the progression of the disease.

Access to comprehensive health insurance is essential to the well-being of people with chronic illnesses like multiple sclerosis. Through health insurance, people with multiple sclerosis are able to access specialized medical providers and other services, prescription drugs, and durable medical equipment that are necessary to slow the progression of the disease and enable them to lead long and productive lives. Without health insurance, the costs of these services and supplies are prohibitive for most people.

We applaud the Governor's and Legislature's work toward expanding public health insurance for children and streamlining the renewal process for Medicaid and Family Health Plus. These initiatives are important and necessary first steps in the process of ensuring that all New Yorkers are able to secure health insurance.

Today, I would like to focus on issues affecting health insurance access for adults under age 65 with chronic conditions or disabilities. Health insurance options for this segment of New Yorkers are more limited than for most other groups. Many of my clients are people in their 30s or 40s who once worked full-time and paid taxes. Through no fault of their own, they became disabled and unable to continue working. Employer-sponsored health coverage is not available to them except through a spouse, if, indeed they are married, and their spouse has access to family coverage. The Medicaid Buy-In is not an option because they are not working. Healthy NY will not cover their prescription drug costs. If they are disabled enough to qualify for Social Security Disability payments, they must wait two years before they can receive Medicare coverage. And, Family Health Plus is typically unavailable because their Social Security checks exceed the Family Health Plus income limits. Even after qualifying for Medicare, Part D "donut-hole" costs and other cost sharing places critically important prescription drugs out of their reach.

In New York, more generous subsidized coverage is available for children, people with HIV, people with certain kinds of cancer and the elderly. But for young adults with MS, the health care safety net is full of holes.

We have three overriding concerns related to the design of any initiative to expand health insurance coverage in New York. First, New York's efforts to achieve universal coverage should take into account the needs of people who cannot work due to chronic conditions and disabilities, as well as the needs of employees and employers. Second, our coverage initiatives should address the needs of those who are under-insured, as well as those who are uninsured. Third, universal coverage should make available health insurance that is both affordable and comprehensive.

To address the needs of those who are unemployed, New York's universal coverage initiatives should not focus exclusively on employer-sponsored options. We should examine ways of allowing individuals to buy-in to Medicaid and Family Health Plus on a sliding fee basis. We should not exclude unemployed and self-employed individuals from the new Family Health Plus Buy-In.

The needs of the under-insured are best exemplified among our clients by people with disabilities on Medicare who cannot afford the Part D cost sharing necessary to obtain their prescription drugs. Senior citizens in New York State do not face this problem because the State offers them a generous prescription drug program through EPIC. But low-income people with disabilities under the age of 65 continue to be excluded from that program. They are excluded even though, like seniors, they live on fixed incomes and face prohibitively high prescription drug costs. To make coverage available on a more equitable basis, the National MS Society supports an expansion of EPIC to include people with disabilities.

I'd like to share with you the story of one of our members. Leslie is a 52-year-old woman from Binghamton, New York, who is diagnosed with multiple sclerosis (MS). She lives alone and earns about \$560.00 per month in wages and receives \$890.00 per month in Social Security Disability Insurance. Leslie is a Medicare beneficiary with Part D coverage. However, under her Part D plan, Leslie must pay for 25 percent of the retail value of her primary MS medication - approximately \$400.00 per month, until she hits the "donut-hole," when she must pay the full cost. She cannot afford to pay for both her drugs and basic necessities. Without her drugs, she is likely to suffer an exacerbation of her symptoms that could require inpatient or long-term care.

Our third concern relates to proposals to mandate the purchase of health insurance coverage. Any health insurance mandate must be accompanied by a serious effort to make that coverage truly affordable and comprehensive, as exemplified by the pitfalls in the individual health insurance mandate in the state of Massachusetts.

Massachusetts provides subsidized coverage for individuals who earn less than approximately \$30,000 per year. Where does this leave the residents of Massachusetts who still cannot afford coverage, but have income slightly over the \$30,000 limit? As of

June, according to news reports, there were between 160,000 and 200,000 people who were uninsured and did not qualify for the subsidy.¹

Other states that are looking to provide universal health insurance are proposing bare bones and high deductible health plans that are not appropriate for people living with chronic illnesses and people living on low incomes. Plans that do not offer comprehensive coverage including prescription drug coverage, mental health services, physical therapy and other such benefits are not options people with chronic illnesses can realistically consider.

We appreciate your commitment to expand access to health coverage. This is one of the most important issues facing people living with multiple sclerosis. It is crucial that if a system is created, it is equitable, affordable and provides quality health care to everyone. Thank you for your time.

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¹ Pam Belluck, "Massachusetts Universal Care Plan Faces Hurdles," New York Times 1 July 2007
<http://www.nytimes.com/2007/07/01/health/policy/01insure.html?_r=1&oref=slogin>