

**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**

**ROCHESTER, NEW YORK
NOVEMBER 26, 2007**

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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. This is Michelle Camp, Chapter Volunteer. Working in collaboration with the three other National MS Society Chapters throughout New York State, we are here today to represent the best interests of the 34,000 families in New York that are affected by multiple sclerosis (MS).

As you may already know from our testimony in Buffalo, New York on October 3, 2007, 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, we 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.

At this time, Ms. Camp would like to share her story with you:

“Good Morning. My name is Michelle Camp. I was diagnosed with MS 14 years ago. I am married and have one child. I am fortunate enough to be working part-time, despite my disease. I am also fortunate enough to have access to comprehensive health insurance and prescription drug coverage that allows me to better manage my symptoms and delay the progression of my MS, through my husband's employer. I am here today to share the story of my brother, Dan, who is also living with an MS diagnosis, but is not as fortunate.

Dan is unable to testify today, due to symptoms associated with MS, including increased cognitive impairment, delayed auditory processing abilities, and difficulties with short-term memory and concentration. The progression of such symptoms has been only in the last 10 months. In fact, Dan had owned his own cleaning business for 20 years at the time he was diagnosed with MS in late 2006. He also earned his Realtor's License, and worked, part-time, for a company that was able to provide comprehensive health care insurance and prescription drug coverage that helped Dan afford his primary MS drug, which is retail valued at approximately \$1,600.00 per month. Dan continued to work

through January 2007, until he began to suffer from extreme fatigue and loss of balance that causes him to fall. At that time, Dan was deemed disabled. He applied for Social Security Disability Insurance and was approved two months later in the amount of \$1,415.00 per month. Dan lost access to employer-based health care coverage, as he was no longer working. Now, Dan is caught in the two-year waiting period before he becomes eligible for Medicare. Dan cannot afford to go without his primary MS drug or access to his neurologist. For this reason, a substantial portion of his income must be used to pay for coverage with prescription drugs. Because of such high out-of-pocket health related expenses, Dan lives with our elderly mother. He cannot afford to live on his own; he cannot afford to pay rent and household utilities, to buy groceries, and to pay for car insurance, gas and repairs, on his own. Dan is fiercely independent, and has become increasingly defensive and easily angered by my mother's attempts to offer support. The two of them living together is a potentially volatile situation that I must constantly monitor, in addition to taking care of my own family and trying to manage my own MS. As a family, we struggle to make it through each day without worrying about the health and safety of our mother and brother. If health insurance were more affordable, my brother could live independently.

When my brother gets Medicare coverage in 12 months, I'm afraid his situation will be even worse. He will have exhausted his savings, and he won't be able to afford the donut-hole costs and other cost sharing required by Part D. Nor will he be able to purchase other insurance to supplement the Part D coverage. If he were afforded the same "safety net" as low-income seniors, and could access EPIC, he would be able to access his prescription drugs and would not be forced into poverty and dependence.

I share this story to make you aware that Dan's experience is not an isolated occurrence. I am acutely aware of what this disease can take from you. I am also conscious of the fact that MS has manifested in multiple cases in my family. There is no way to know if my child will have to deal with the same fate as Dan and myself, and it is for my child, my brother, and myself, along with 34,000 New Yorkers living with MS that I urge an expansion of the Elderly Pharmaceutical Insurance Coverage ("EPIC") program to people with disabilities under age 65."

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

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>

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. We recognize that a system where everyone has health care coverage will need to be built step-by-step to make sure it is a sound system. Building upon the EPIC program, a program that has improved the lives of so many seniors in our state, to assist individuals with disabilities who are under the age of 65 would be an important step towards the creation of a system where we all have equitable, affordable and quality health care. Thank you for your time.