

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

**TESTIMONY BEFORE THE NEW YORK STATE DIVISION OF THE BUDGET  
"ACHIEVING BALANCE THROUGH PRIORITIZATION" HEARING IN PREPARATION FOR  
THE 2008-09 BUDGET**

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**Presented by:**

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Good afternoon. 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 Joseph Miller, a 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).

First, we 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.

For this reason, today we are here to urge the inclusion of an expansion of the Elderly Pharmaceutical Insurance Coverage ("EPIC") program to people with disabilities under age 65 in the SFY 2008-09 Executive Budget.

As you know, EPIC was created to assist low-income senior citizens who lack adequate prescription drug coverage. It was established in response to heartbreaking stories of senior citizens choosing between food and medications or splitting pills and missing doses in order to make ends meet.

Low-income New Yorkers with disabilities under the age of 65 often find themselves making the same impossible choices that low-income seniors once faced. But, unlike today's seniors, they have no safety net. If they worked long enough to receive Social Security Disability Income ("SSDI"), they are usually ineligible for Medicaid and Family Health Plus. While they will be eligible for Medicare, they will not be able to receive benefits until two years after their eligibility date for SSDI. So, those with disabilities are forced to choose between their health and food, shelter, or clothes for their children. All too often, medication is sacrificed in favor of paying the rent or buying a winter coat for a growing child. But, who will take care of the children if a parent is hospitalized as a result of failing to take necessary drugs?

Once eligible for Medicare, the Medicare Part D benefit does not solve this problem. The Part D benefit requires significant cost sharing that is unaffordable for many low-income families. For example, a family of three with income just over 150 percent of the federal poverty level (\$25,755 annually in 2007) will have to pay monthly Part D premiums, a deductible, coinsurance, expenses in the “donut hole,” and co-payments. This will likely amount to as much as \$4,000 annually and may be even higher for individuals with intensive prescription drug needs.

We’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.

While Part D will not solve the prescription drug problems of people with disabilities, it will substantially reduce the cost of an EPIC expansion for this population. Part D will cover most of the cost of an EPIC expansion for those with disabilities under the age of 65, and EPIC would cover only the individuals caught in the two-year waiting period for Medicare, consumer cost-sharing in excess of EPIC fees and deductibles and the cost of uncovered drugs.

As our state strives to provide health care coverage for its citizens, we must remember those individuals with severe disabilities who are struggling to maintain their health and support their families. We strongly urge support and consideration of this proposal for inclusion within the next Executive Budget as one of the first steps the state takes towards providing universal health care coverage.

We appreciate your commitment to expand access to health coverage. This is one of the most important issues facing people living with multiple sclerosis. Thank you for your time.