



**National
Multiple Sclerosis
Society**
New York City
Chapter

**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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Good morning. My name is PJ Weiner. I am the Manager of Advocacy Programs and Services at the New York City 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.

I am presenting testimony this morning with a member of our chapter, Susan Lall. Susan will tell you her story and I will then follow up with a few brief concluding statements.

Ms. Susan Lall: Good Morning. My name is Susan Lall and I am testifying today on behalf of the New York City Chapter of the National Multiple Sclerosis Society. After suffering with headaches and other symptoms for years and after numerous tests, I was finally diagnosed with MS in March, 2005 at the age of 48. After working for over 30 years, where during most of which I held two jobs, my symptoms of extreme fatigue, vision problems, dizziness, impaired mobility, chronic aching pain, bladder dysfunction, numbness and weakness made it impossible to continue to working.

I worked two jobs in order to pay for my mortgage and maintenance payments of \$1250 per month in addition to my food and utilities costing around \$400 per month. I was awarded Social Security Disability in the amount of \$1,877 per month, which could barely cover my monthly expenses. However, because I wouldn't be eligible for Medicare for two more years, I had to also pay for COBRA premiums ranging from \$667 to \$777 over the next two years. My total costs for living expenses and health care totaled between \$2300 and \$2500 each month while receiving an income of \$1877 per month.

I exhausted my savings in a year. After maxing out my credit cards, I started borrowing from my family and friends because my expenses were well over my SSDI income. It was essential for me to stay on the insurance provided through COBRA because it was comprehensive. It allowed me to purchase my walker

and other durable medical equipment, to get my prescriptions at reasonable prices, and to visit my doctors with reasonable co-pays.

Because paying for my COBRA had created such a financial hardship, I looked forward to the day when I would begin receiving Medicare. Medicare, so I thought, was the light at the end of the tunnel. Little did I know that Medicare was going to be just as much of a financial burden as paying for my COBRA.

I finally became eligible for Medicare on October 1st of this year. The medication I take to treat my MS costs \$1600 per month. Because it is so expensive, under Medicare part D, I owe \$630 for my medication in the first month of my Medicare coverage. On top of this, Medicare will not pay for one of my treatments, IVIg, an intravenous infusion, which costs \$4000 per month. After three weeks without my medications, last week I suffered an MS exacerbation, which is a sudden worsening of MS symptoms caused by an area of inflammation in the central nervous system. My doctor prescribed the usual treatment for an MS exacerbation, a course of intravenous steroids, but I could not afford the co-insurance for that treatment. I'm currently taking the pill form of the steroids and they are doing nothing to combat my symptoms.

After working all my life, the system has failed me. I am fighting to change a system that does not work. I would like to see people like me, on SSDI, who fell through the cracks, be treated more equitably. That is all I'm asking for. I am not asking for hand-outs ... just access to the medical care that I need.

Ms. PJ Weiner: I wish that I could say that Susan's story is an anomaly. Unfortunately, this is a very common situation for people living with MS. Susan did everything she could to find affordable health care options. She researched the Healthy NY program while in the 2 year waiting period for Medicare, but Healthy NY is not an option for anyone living with a chronic illness or disability as it doesn't cover durable medical equipment, mental health services, and has a \$3000 cap on prescription medications (which would only cover Susan for 2 months). Susan wasn't eligible for FHPlus while she was waiting for Medicare because her disability income was too high. She isn't eligible today both because of her income and because FHPlus is not available to people on Medicare. However, if she were eligible, FHPlus would not cover durable medical equipment, creating another barrier for people with disabilities. Susan isn't eligible for the EPIC program because she is under the age of 65, despite the fact that this program would have reduced the cost of her prescription medications by more than 80%. Susan was fortunate that this MS exacerbation did not require hospitalization, but a flare up of symptoms in multiple sclerosis does require hospitalization in many cases, often a cost borne by the Medicaid system.

Susan's testimony today has demonstrated our three primary goals for a universal health care system. 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.

Thank you for your time.