



**National
Multiple Sclerosis
Society**
New York
MS Coalition
Action Network

New York MS Coalition Action Network 2009 Legislative Agenda

The National Multiple Sclerosis Society-New York MS Coalition Action Network (“NY MS CAN”) represents New York’s four National Multiple Sclerosis Society chapters and the approximately 34,000 families in New York affected by multiple sclerosis (“MS”). According to data analyzed by the National MS Society, New York State is one of nine states with the highest incidence of multiple sclerosis in the nation.

Multiple sclerosis interrupts the flow of information from the brain to the body and stops people from moving. Every hour in the United States, someone is newly diagnosed with MS, an unpredictable, often disabling disease of the central nervous system. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted. Most people with MS are diagnosed between the ages of 20 and 50, with more than twice as many women as men diagnosed with the disease.

The New York State chapters of the National Multiple Sclerosis Society fund research into the cause and treatment of MS and affiliate with 20 MS Care Centers around the State that specialize in providing health care to individuals with MS. The chapters also provide a range of services for individuals with MS and their families, including information and referrals, support groups, education, health and wellness programs, adult day care services and access to durable medical equipment.

Support Eligibility Expansion for Family Health Plus & the Streamlining of the Medicaid Application Process

Support Eligibility Expansion for Family Health Plus: The NY MS CAN supports the Governor’s proposal to expand eligibility for the Family Health Plus (FHPlus) program to adults with gross income up to 200 percent of the federal poverty level. FHPlus provides comprehensive health care coverage essential to the well-being of individuals with chronic illnesses, such as MS. Without health insurance, people with MS are unable to access specialized medical providers, 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.

There are 2.1 million uninsured New Yorkers between the ages of 19 and 64 constituting 18 percent of the population in that age group. Nearly half of New York's adult uninsured population are living below 200 percent of the federal poverty level (FPL) and 70 percent of adults ages 19 to 29 live below 200% of the FPL¹. The uninsured must pay out-of-pocket for all of their health care costs, often forcing them to forego preventive and medically-necessary care and ultimately relying on expensive emergency room treatment when a health crisis strikes. For example, 47 percent of New York residents have reported not receiving or postponing necessary medical care or prescriptions due to a lack of insurance or money².

By raising the income limits of FHPlus to 200 percent of the FPL, the State would provide over 400,000 low-income New Yorkers with access to primary care and treatment of chronic diseases. This would reduce emergency room visits, hospital stays, and nursing home admissions that often trigger a spend-down to Medicaid eligibility and increased costs to the State.

Streamlining of the Medicaid Application Process: The NY MS CAN supports the Governor's proposed eligibility simplification and streamlining measures associated with the Medicaid application process, including:

- Elimination of the Medicaid and Family Health Plus resource test
- Elimination of mandatory face-to-face interviews
- Elimination of the fingerprinting requirement
- Aligning and Expanding Medicaid eligibility

Medicaid provides comprehensive health care and prescription drug coverage for many low-income New Yorkers with MS. Alleviating unnecessary administrative barriers to accessing this program will allow many individuals living with chronic illnesses, including MS, the opportunity to secure the specialized, complex and high quality care and services they need.

Oppose Changes to Medicaid Long Term Care Services

The NY MS CAN opposes two Executive Budget proposals relating to the approval of personal care services and how they are provided for those Medicaid beneficiaries in managed care.

Implementation of Regional Long-Term Care Assessment Centers: The Governor proposed creating regional long-term ("LTC") care assessment centers to evaluate individuals' needs and to authorize LTC services. Currently, the need for these services is assessed by local social services districts. Decreasing the number of offices with the authority to process the applications and renewals for these vital services will result in a

1 J. L. Kriss, S. R. Collins, B. Mahato, E. Gould, and C. Schoen, Rite of Passage? Why Young Adults Become Uninsured and How New Policies Can Help, 2008 Update, The Commonwealth Fund, May 2008

² Health Care for All New York-www.hcfany.org

severe “back log.” Ultimately, this will cause a dramatic increase in the time it takes for people to receive essential services associated with activities of daily living such as housekeeping, meal preparation, bathing, toileting, and grooming. For example, in 2004, when the Department of Health closed the New York City Office of Prior Authorization for Durable Medical Equipment (“DME”), the result was a remarkable increase in the time it took for individuals throughout New York State to receive the mobility equipment they desperately needed. We feel that decreasing the number of offices and qualified staff currently processing the requests for LTC services would create the same kind of disruption and inefficiency. For this reason, we strongly oppose the implementation of regional LTC assessment centers.

Carve-In Personal Care to Managed Care Benefit: The Governor proposes to include personal care services as part of the standard Medicaid managed care benefit package. Currently, personal care is provided to all Medicaid beneficiaries under the Medicaid fee-for-service program, eliminating unnecessary administrative processes.

Following the implementation of Medicaid managed care, Medicaid beneficiaries who were enrolled in these plans began to experience significant barriers to accessing services not previously encountered while covered under Medicaid fee-for-service. This includes difficulties accessing health care providers, case management services, and medical transportation as well as experiencing increased wait times to see physicians. Given this history, we feel that adding personal care services to standard Medicaid managed care benefit packages would have a negative impact on New Yorkers with MS who require assistance to complete activities of daily living in order to maintain their independence and to remain living safely in their communities.

Preserve Full EPIC Wraparound Coverage for Medicare Part D Drugs & Support EPIC Expansion

Preserve Medicare Part D Wraparound: The NY MS CAN opposes the Governor’s proposal to eliminate EPIC “wraparound” coverage for drugs not covered by the particular Part D plan in which an EPIC participant is enrolled.

Individuals with MS age 65 and over must have access to all of the medications available that are used to treat MS, and any associated co-morbid conditions to help maintain wellness, good health and quality of life.

Individuals enrolled in a Medicare Part D plan who are eligible for the EPIC program can only change their plans during a brief, specified enrollment period one time per year. Eliminating the Medicare Part D EPIC wraparound coverage for those individuals enrolled in EPIC and Medicare Part D programs living with MS, will ultimately prevent the timely and efficient treatment of MS symptoms and other conditions. Examples of situations where a patient could experience a gap in prescription drug coverage include: (1) if a patient’s Part D plan changes its drug formulary mid-year, or (2) if a patient is given a new prescription for a drug that is not covered by their particular Part D plan.

With no options to switch their Medicare Part D plans, seniors with MS living on fixed incomes cannot afford to privately pay for medications and will be forced to forego recommended pharmacological treatments. For those individuals living with MS who are enrolled in both EPIC and Medicare Part D, EPIC wraparound coverage for ALL prescriptions- including those that are not covered by an individual’s specific Part D Plan, is essential to manage not only the progression and symptoms of the disease, but to help address co-morbid conditions as well.

Support for EPIC Expansion: For many years, the NY MS CAN has advocated for a full expansion of EPIC to provide individuals with disabilities equal access to the program as well as to those disabled individuals who are in the two year waiting period for Medicare. In light of the current fiscal climate in NYS, we realize that a full expansion of the EPIC program to people with disabilities is not feasible this year. However, the NY MS CAN will continue to support this expansion and encourages the State legislature to remember the importance of this expansion when the State’s fiscal situation is healthier.

Proposes Prohibiting Specialty Tiers in Commercial Drug Plans
(S.191 – Sampson)

For people with MS, access to prescription drugs can dramatically improve the quality and duration of their lives. The National Multiple Sclerosis Society published a Disease Management Consensus Statement to help ensure that all appropriate candidates for FDA approved MS medications have access to them as early in the disease process as possible. Unfortunately, due to the fact that the medications used to treat MS cost more than \$2,000 per month each, many people go without these crucial treatments.

Currently, the commercial health plans offered in New York cover the medications used to treat MS and assign them a reasonable co-payment which ranges from approximately \$10 to \$60. However, commercial insurance plans in several states across the country have assigned the consumer the responsibility of paying for these cost-prohibitive medications. The plans have created “specialty tiers” within their prescription formularies and have placed the more expensive medications in this new tier. The tier is then assigned a “co-insurance,” or a percentage of the cost of the medications as opposed to the standard “co-pay” or set dollar amount. Most specialty tiers have a co-insurance of approximately 25 percent which would dramatically increase the monthly out-of-pocket costs for people living with MS:

MS Disease Modifying Therapies	Monthly Cost	25% Co-Insurance	33% Co-Insurance
Avonex	\$2,270	\$567	\$749
Betaseron	\$2,198	\$549	\$725
Copaxone	\$2,110	\$527	\$696
Rebif	\$2,347	\$586	\$775

Though commercial plans in New York have not yet been allowed to implement specialty

tiers within in their drug formularies, there is no state law that prohibits this practice. In 2008, bills were introduced by Senators Sampson and Hannon as well as Assemblymembers Gottfried and Titus to address this issue. We are working with these members and other interested legislators to introduce legislation in the 2009 session that will prohibit commercial insurance plans from creating specialty tiers within their drug formularies, encouraging commercial health insurers to retain their current two or three tier formulary structure and keep crucial medications affordable.

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