



**National
Multiple Sclerosis
Society**

Maine State Legislature – Committee on Health Coverage, Insurance and Financial Services
January 11, 2022
LD 1783

Testimony of Laura Hoch,
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Senator Sanborn, Representative Tepler, and members of the Committee on Health Coverage, Insurance, and Financial Services, thank you for the opportunity to submit testimony on LD 1783, An Act to Require Health Insurance Carriers and Pharmacy Benefits Managers to Appropriately Account for Cost-sharing Amounts Paid on Behalf of Insureds, and how it may impact individuals living with multiple sclerosis (MS).

MS is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms vary from person to person and range from numbness and tingling to walking difficulties, fatigue, dizziness, pain, depression, blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS. Nearly 1 million people in the United States are currently living with MS.

MS is an expensive disease to live with and treat, impacting the healthcare system, health plans and of course, families affected by MS. A person with MS spends three times as much out-of-pocket as the average person in employer plans. Disease modifying therapies (DMTs), which are used to manage the MS disease course, are approximately 75% of the cost of treating MS. Early and ongoing treatment with a DMT is the best way we know to slow the progression of MS, prevent the buildup of disability and protect the brain from damage due to MS. While there are more than twenty DMTs available, only two have a generic alternative, they are not interchangeable, and we do not yet know which medication will work best for each person.

These medications are very expensive - as of 2021, the brand median price of DMTs was \$93,672 and five of them are priced at more than \$100,000 per year. People with MS often face a high deductible and later co-insurance, meaning they are often responsible for thousands of dollars in out-of-pocket costs. This poses a significant challenge in accessing needed medications.

In MS, the rejection of discounts provided, or payments made, by a 3rd party makes it more difficult for people to get the healthcare they need. As many as 40% of people living with MS rely on copay assistance programs to maintain access to their disease-modifying therapy. With the rejection of assistance programs, people with MS are experiencing higher cost burdens as they struggle with unexpected expenses during their deductible period. It is well known that people with chronic and high-cost conditions like MS face significant financial hardship each year until their deductible has been



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met and the full relief of their health insurance kicks in. This hardship is made worse when assistance programs are not counted toward cost-sharing or out-of-pocket costs; preventing assistance from applying to a person's deductible means it takes them longer to reach the end of the deductible period. Because patients are responsible for 100% of their health care costs until the deductible is satisfied, prolonging the deductible period can put other medical needs—such as doctors' visits, rehab therapies, MRIs, or other medications—financially out-of-reach.

The National MS Society has called on all stakeholders in the prescription drug supply chain to come together and find real solutions to escalating price increases, barriers to care, and a system too complex to navigate. It is reasonable to question the role of assistance programs and the potential role they inadvertently play in raising costs or impeding access—but this should not be the first change that happens. Until we find real solutions to the challenges in our healthcare system that prevent people from affordably accessing the care and treatments they need, we cannot take away the support people have come to rely on—like assistance programs. Mechanisms that prevent assistance primarily impact people who are seeking whatever avenue they can find to be able to take their needed medication.

The National MS Society supports solutions that help safeguard access for people who need life-changing medications, without getting them caught in the middle of struggles between other stakeholders. Please support LD 1783.

Should you have any questions or concerns, please feel free to reach out to Laura Hoch at laura.hoch@nmss.org or (860) 913-2550 X52521.