

National Multiple Sclerosis Society

## Maine Legislature – Committee on Health Coverage, Insurance and Financial Services Public Hearing – March 9, 2021 LD523/LD617

Testimony of Laura Hoch, Senior Manager of Advocacy, National MS Society

Chair Sanborn, Chair Tepler, and members of the Committee on Health Coverage, Insurance, and Financial Services, thank you for the opportunity to submit testimony on LD523 and LD617 and how they might affect people 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 and 2.3 million worldwide are currently living with MS.

A growing body of evidence indicates that early and ongoing treatment with a disease modifying therapy (DMT) is the best way to modify the course of the disease, prevent the accumulation of disability and protect the brain. Ongoing access to these medications is essential for people with MS to be able to live their best lives. Innovation has brought us to this point where we now have over twenty treatment options for those with relapsing forms of MS. However, price increases for the MS DMTs have been on a steep upward trajectory. In 2013, the average price of MS DMTs was around \$60,000; in 2018 the median price of brand DMTs increased to \$80,000 and just two years later in 2020, the brand median price was \$91,835. Five MS DMTs are priced at more than \$100,00 per year. We continue to see significant price increases for most of the medications. Between 2004 and 2015, the average price of MS DMTs increased 300%. Nearly three-quarters of the MS medications average more than one price increase per year. The MS medications' continual escalating prices are noteworthy—but people with MS are not the only patients facing high costs and struggling with barriers to access. Nearly one-third of branded medications increased in price by 20 percent in 2015.

This is all to note how critical it is for MS patients to understand the true out of pocket costs for their DMTs. Every insurance plan is different and there are no uniform costs or coverage. Formularies change constantly and this coupled with confusing coinsurance rates often leave



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patients in the dark about how much their medications will actually cost at the pharmacy counter. That is why the Society supports LD 523 and LD 617. These bills would allow providers real-time access to their patients' specific formulary and cost-sharing information at the time of prescribing so that both the provider and the patient can make an informed decision about the best course of action for the individual living with MS.

Effective treatments only work if patients have access to them and too often they do not because DMTs can be cost-prohibitive. LD 523 and LD 617 would take a step in the direction of ensuring that individuals living with MS can access these treatments and that is why the National MS Society urges passages of these important bills.

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

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The uploaded testimony is for both LD523 and LD617.