

National Multiple Sclerosis Society

February 8, 2022

Oregon State Legislature House Committee on Health Care Salem, Oregon

RE: MS Society Support HB 4035 to improve health care access and lower costs

Chair Prusak, Vice Chair Hayden, committee members,

Thank you for the ability to comment on House Bill 4035 which would direct the Oregon Health Authority to study and provide and implement recommendations to improve access to or lower the cost of health care in Oregon. The National Multiple Sclerosis Society (Society) offers the following comments on the costs borne by your constituents living with multiple sclerosis.

Multiple sclerosis (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 with the highest concentrations found here in the Pacific Northwest.

The Society's vision is a world free of MS and our mission is that we will cure MS while empowering people affected by MS to live their best lives. Our responses and advocacy around expanding access to comprehensive, affordable health care is based largely on the Society's <a href="Access to High Quality Healthcare Principles">Access to High Quality Healthcare Principles</a> (Principles). We believe that these Principles are realized when people with MS:

- Are at the center of their healthcare decision making,
- Have access to and receive high quality MS care regardless of their race, ethnicity, cultural background, socioeconomic status, sex, gender, sexual orientation, level of disability, age, geographic location, language and care setting that is culturally relevant, accounts for treatment and care preferences and differences in identity.
- Have access to a comprehensive network of providers and healthcare services focused on producing the best outcomes at affordable costs,
- Have access to comprehensive health insurance plans with affordable premiums, deductibles and other out-of-pocket costs
- Are able to see healthcare providers who have greater awareness, resources and tools to enable the timely diagnosis, treatment and symptom management of MS, and

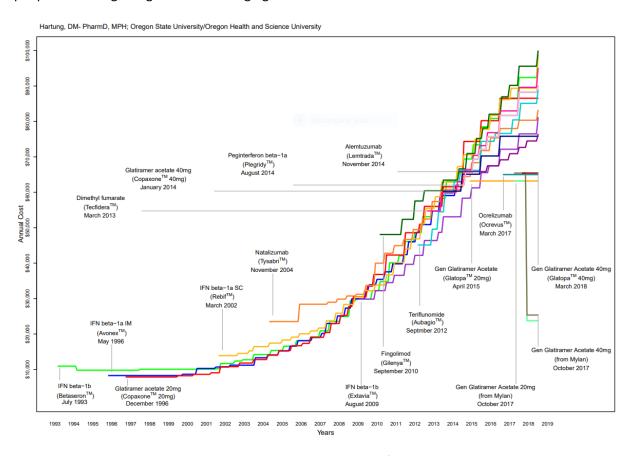


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 Have access to high-quality long-term supports and services in settings that best meet their needs and prevent financial hardship for the individual and their family.

A full overview of our principles is available on the <u>Society's website</u>, and it is through this lens that we will evaluate any policy proposal put forth to assess its impact on healthcare needs for people affected by MS. We appreciate your commitment to providing high value, low-cost health care options to all Oregonians and continue to look forward to working together on this endeavor.

Central to accessing high quality health care is being able to afford needed medications. Drug pricing and access are complicated issues. The Society is awaiting the Oregon Prescription Drug Affordability Board getting started with their work. While there is no single solution, but we think affordability boards take an important step in managing the prices of medications both for individuals and health systems. The continually escalating prices of MS disease-modifying therapies (DMT) are creating barriers to people with MS getting these life-changing medications.



This OHSU produced graphic shows the price increases year-on-year from 1993-2019, rising each time a new therapy is introduced, the opposite of what market competition ought to do.



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The price of MS treatments has dramatically risen since the first DMT was approved in 1993. In 2013, the average price of MS DMTs was around \$60,000 per year; in 2018 the median price of brand DMTs increased to \$80,000; and just three years later in 2021, the brand median is \$93,672.

Unfortunately, it is normal for MS DMTs to experience one or more price increases every year, beyond prescription drug inflation. **Five MS DMTs are now priced at more than \$100,000 per year**; almost all these treatments must be taken each year, for years, as MS is a chronic condition.

In a <u>2019 survey</u> conducted by the National MS Society, 40% of respondents reported that they have altered the use of their DMTs due to cost—by skipping or delaying treatment, taking less than prescribed, or even stopping their treatment altogether. For Oregonians living with MS, DMT costs are front and center and we again look forward to the forthcoming recommendations made by the Prescription Drug Affordability Board. Insightful and full of excellent data are the Drug Price Transparent Program reports which will aid in any efforts to study and lower health care costs for all Oregonians.

Thank you for your continued attention to the issues of high-cost health care and high-cost prescription medications. We hope this study will provide the legislature with actionable items beyond what is already encompassed by the 4005 Transparency report and other state issued documents.

Regards,

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