

December 2, 2025

Oregon Department of Consumer and Business Services Division of Financial Regulation Drug Price Transparency Program Salem, Oregon

## RE: 2025 Prescription Drug Price Transparency public hearing, submitted written testimony

Thank you for the opportunity to offer comments to the Prescription Drug Pricing Transparency hearing for 2025. The National Multiple Sclerosis Society (Society) would like to highlight recent news in MS disease-modifying therapies (DMTs) and discuss overall affordability.

Multiple sclerosis (MS) is an unpredictable disease of the central nervous system. Currently, there is no cure. Symptoms vary from person to person and may include disabling fatigue, mobility challenges, cognitive changes, and vision issues. An estimated one million people live with MS in the United States. Early diagnosis and treatment are critical to minimize disability. Significant progress is being made to achieve a world free of MS.

No single agent is 'best' for all people living with MS, and, as MS presents differently in each person, every person's response to a DMT will vary. Early and ongoing treatment with a DMT is the only way to modify the course of the disease, slow the accumulation of disability and protect the brain from damage due to MS. People with MS and their treating clinicians require access to the full range of treatment options that represent different mechanisms of action and routes of administration with varying efficacy, side effects, and safety profiles.

It is common for people with MS to move through several different DMTs throughout their life with MS, as they "breakthrough" on medication - have disease activity or need to try a different DMT. Delays or disruptions in treatment can risk permanent, irreversible disease progression, worse health outcomes, and increased healthcare costs over time. Managing MS can be a difficult process that requires several "trial and error" changes to the medication before finding the one most effective at controlling disease progression with the fewest negative side effects for each individual.

## Access to the full range of options is essential for optimal MS management.

Early and ongoing treatment with a DMT is the best way to modify the course of the disease, slow the accumulation of disability and protect the brain from damage due to MS. People with MS and their treating clinicians require access to the full range of treatment options for several reasons:

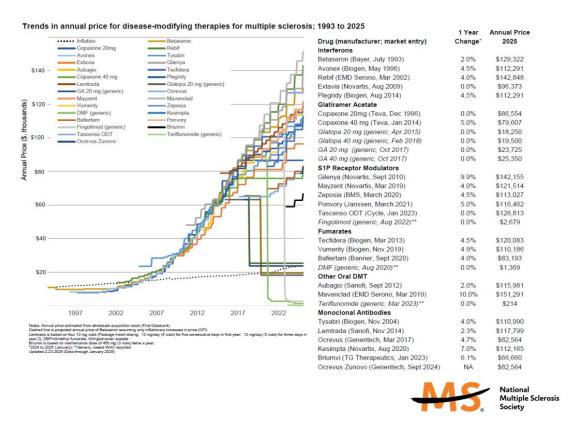
- Individual differences related to tolerability and adherence may necessitate access to different medications within the same class.
- Individuals' access to treatment should not be limited by their frequency of relapses, level of disability, or personal characteristics such as age, sex, or ethnicity.
- Different mechanisms of action allow for treatment change in the event of a sub-optimal response.

- Potential contraindications limit options for some individuals.
- Risk tolerance varies among people with MS and their treating clinicians.
- Route of delivery and side effects may affect adherence and quality of life.
- Absence of relapses while on treatment is a characteristic of treatment effectiveness and should not be considered a justification for discontinuing treatment.
- Treatment should not be withheld to allow for determination of coverage by payers as this puts the patient at risk for recurrent disease activity.

## Costs of living with MS

People with MS have a variety of healthcare needs including, but not limited to, addressing neurological symptoms, emotional and psychological issues, rehabilitation therapies to improve and maintain function and independence, and long-term care. These needs vary dramatically from person to person and can change year-to-year as the disease progresses.

MS is a highly expensive disease, with the average total cost of living with MS calculated at \$88,487 per year¹. MS may impact one's ability to work and can generate steep out-of-pocket costs related to medical care, rehabilitation, home & auto modifications, and more. For individuals with MS, medical costs are an average of \$65,612 more than for individuals who do not live with this disease. Disease-modifying treatments (DMTs) are the single largest component of these medical costs. As of July 2025, the median annual brand price of MS DMTs was more than \$113,000. Seven out of nine of the DMTs that have been on the market for at least 12 years are priced at over \$100,000 annually and continue to see regular price increases.



<sup>11</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9109149/



national MS society.org

## Generics and Biosimilars in MS

Generic medications have a role in driving down high medication prices and making medications more affordable. However, as we see within the MS DMT class, the existence of generics alone does not guarantee affordability for people who rely on these medications. Today, there are multiple generics for several brand name DMTs. While the generic prices have dropped considerably with multiple generics per brand and other market considerations, people with MS are struggling with the affordability of the generics. The generic fingolimod, for instance, ranged in price from \$2,679 to \$27,022. It is unclear how these generics are being covered in formularies. For example, even as a generic, the medication may still be on a specialty tier or a nonpreferred tier. This means that even though the generic may be the lowest priced option, a person with MS may still have a high copay or even coinsurance, where they are responsible for a percentage of the cost of the medication. While we are not yet aware of data looking at generic tiering in private health insurance, data on the distribution of generic drugs on Part D formulary tiers was recently published by Avalere Health. That data shows a shift of generics away from generic tiers, which traditionally have lower cost-sharing for patients, towards preferred brand, non-preferred, and specialty tiers which have higher cost-sharing requirements. This could place the medication out of reach for them.

Additionally, there is a lack of clarity regarding a situation like dimethyl fumarate in MS- multiple generic options exist, there is a wide range in price across the generics, and only some of the generic companies offer financial assistance. If an Oregonian takes one of the higher priced generics, will patient assistance still be available? The decision on which generic is available to individuals is likely determined by the insurer, the pharmacy benefit manager (PBM), or the pharmacy used. In this example, the individual may be required to use a specific specialty pharmacy and not have the option to look for lower-cost options.

In a recent survey of people with MS conducted by our organization, 40% of people with MS shared that they alter or stop taking their medications due to high cost. They may have stopped treatment for a period, they may skip or delay filling a prescription, maybe they skip or delay a treatment, or they do not take the medication as prescribed to try and make it last longer. The reality is that the high cost of MS treatments creates significant barriers to treatment, increases stress, and results in greater burdens for those who already live with a chronic, life-altering condition. The Society's survey also showed that more than half of those surveyed are concerned about being able to afford their DMT over the next few years. Many people with MS tell us that without copay assistance, they would not be able to afford their medications to slow the progression of their disease.

The Society advocates and supports policies which increase access to personalized, affordable and high-quality healthcare for those affected by MS. Generic and biosimilar medications approved by the FDA are safe and effective. The growth of the generics and biosimilar medication market for MS DMTs can increase access to affordable medicines, improve adherence and help contain healthcare costs.

Thank you for your work on behalf of all Oregonians. The Society is here to serve as a resource and advocate for medications and services critical for people living with and affected by MS. Please visit our MS Research News and Progress webpage and contact Seth Greiner, Assistant Director of Government Affairs, <a href="Seth.Greiner@NMSS.org">Seth.Greiner@NMSS.org</a>, with any questions or clarifications.

Sincerely,
Seth Greiner
Assistant Director, Government Affairs

