National
Multiple Sclerosis
Society

National Multiple Sclerosis Society Testimony in support of HF 801 (Morrison): Prescription Drug Affordability Board

On behalf of the National Multiple Sclerosis Society (Society), we are pleased to share our support for HF 801, legislation establishing a Prescription Drug Affordability Board. We are supportive of the goals of this legislation and believe it is a good step towards addressing the impact of high prescription drug costs for Minnesotans.

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.

A growing body of evidence indicates that early and ongoing treatment with a Food and Drug Administration (FDA) approved disease-modifying therapy (DMT) is the best way to manage the MS disease course, prevent accumulation of disability and protect the brain from damage due to MS. Fortunately, there are now over 20 FDA-approved DMTs for different forms of MS. The full range of MS DMTs represent various mechanisms of action and routes of administration with varying efficacy, side effects and safety profiles. No single agent is 'best' for all people living with MS[i]. As MS presents differently in each individual, every person's response to a DMT will be unique. In fact, it is critically important that payers, payment models, delivery systems, and the health care stakeholders at large recognize that despite similarities in their indications and usage, these medications are not therapeutically interchangeable. It is not uncommon for people to work their way through several of the medications as they find the one that stabilizes their disease, or as different medications stop working for them.

The availability of MS DMTs has transformed the treatment of MS over the last 25 years. Unfortunately for people affected by MS, the price of MS treatments has dramatically risen since the first DMT was approved in 1993. The first medication, so anxiously awaited for, was approximately $11,500 when it came on the market. That same medication today has a list price of more than $98,000. It's not the only one. In the MS DMT market, price increases occurring one or more times per year for almost all DMTs have become the norm. Between 2004 and 2015, the average price of MS disease modifying treatments increased 300%. Those trends have continued. In 2013, the annual median price was less than $60,000. In 2019, the median price for brand MS DMTs was $88,853 (see attached charts). While some of these increases are associated with new treatment options entering the market, the MS space is a prime example of escalating prices for products already on the market—some for a considerable amount of time. For almost all of these medications, they must be taken continuously. For a person with MS diagnosed at age 25, they could experience over 50 years of DMT costs.

In a recent survey of people with MS conducted by our organization, 40% of people with MS shared that they have altered or stopped taking their medications due to high cost. The reality is, the high cost of MS treatments creates significant barriers to treatment, increase stress, and result 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. People with a chronic illness like MS need to know that they'll be able to get the life-changing medication they need, when they need it.

We believe that HF 801 has the potential to help address price increases for existing MS medications. Prescription drug affordability boards can provide important oversight needed to reform the system to work better. This board would be an independent, nonpartisan body advised by community stakeholders, tasked with reviewing prescription drug prices. The board would have authority to review specific high-cost prescriptions and would conduct a full analysis related to their impact on the health care system in Minnesota and on individual patients' access. The board would also have the authority to potentially set an upper payment limit for what payers in the state would pay for that medication. This process is intended to be transparent and deliberative, giving all stakeholders opportunities to contribute and participate. We believe a board such as this one could help ensure greater accountability for significant drug price increases in the State of Minnesota.

People with MS cannot wait, and the system must change to strike a better balance between access to innovative therapies and affordability. We thank you for your attention to these important and complicated issues. The National MS Society is committed to working with you to find solutions for people with MS. Please direct questions or feedback to Steffany Stern at Steffany.stern@nmss.org or 612-718-8924. Thank you.

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[i] MS Coalition. The Use of Disease Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence. http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT_Consensus_MS_Coalition_color. Accessed December 26, 2018.