



National
Multiple Sclerosis
Society

February 26, 2020

House Health Care & Wellness Committee
Representative Eileen Cody, Chair
Representative Nicole Macri, Vice Chair
Representative Joe Schmick, Ranking Member
Representative Michelle Caldier, Asst. Ranking Member
Representatives Chambers, Chopp, Davis, DeBolt, Harris, Maycumber, Riccelli, Robinson, Jurado-Stonier, Thai, and Tharinger

RE: SB 6088 Establishing a Prescription Drug Affordability Board – SUPPORT

Committee members,

On behalf of the National Multiple Sclerosis Society (Society), we are pleased to share our support for Senate Bill 6088 which would establish a prescription drug affordability board here in Washington State. We are supportive of the goals of this legislation and believe it is a good first step towards addressing the impact of high prescription drug costs for residents in our region and the country overall. We urge the House Health Care Committee to pass this legislation out of committee and enact meaningful reform that will help those living with multiple sclerosis (MS), and their families, here in Washington.

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 nearly 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 MSⁱ. 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 MS experience with high prescription drug and out-of-pocket costs

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

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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 is \$88,853 (see attached Charts from OHSU, Oregon). 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 alter or stop taking their medications due to high cost. They may have stopped treatment for a period of time, they may skip or delay filling a prescription, maybe they skip or delay a treatment, or they don't take the medication as prescribed to try and make it last longer. The reality is, the high cost of MS treatments create 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.

Solutions for people with MS

Drug prices, affordability and access are complex problems that will require multiple solutions and shared commitment by all stakeholders. There is no silver bullet solution and we have to look at solutions across the entire prescription drug supply chain. The Society has advocated for the states, and for Congress, to advance policies that will lower drug costs and improve access for those living with MS. The current trajectory is unsustainable for government, taxpayers, and those living with chronic conditions such as MS.

In 2016, the National MS Society released comprehensive recommendations to Make MS Medications Accessible (Recommendations), which call on all stakeholders across the healthcare and drug supply chain system to work together to make medications more affordable, and the process for getting them simple and transparent. We believe there is no single solution that can fully reverse the trend toward ever-increasing drug prices and payer policies that inhibit or delay access to medically necessary therapies. We have consistently called on all stakeholders to engage in conversations to drive solutions and to bring forward solutions for their industry. State legislatures are one of these stakeholders that must act.

We believe that SB 6088 has the potential to help address and even limit 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 tasked with reviewing prescription drug prices and supported by staff and community stakeholders. The board would have authority to review specific high-cost prescriptions and would conduct a full analysis on what price would allow those who need them to afford them. PDAB could then potentially set an upper payment limit for what the state is willing to pay for that medication, putting downward pressure on drug prices throughout the supply chain, for all payers, and for similar classes of drugs. This process is intended to be transparent and deliberative, giving all stakeholders opportunities to contribute and participate in setting a fair upper

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payment limit. We believe a board such as this one could help ensure greater accountability for significant drug price increases in the State of Washington.

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 Seth.Greiner@nmss.org or call 206-515-4563 if you have questions or would like additional information.

Sincerely,

A handwritten signature in blue ink, appearing to read "Seth Greiner". The signature is fluid and somewhat abstract, with overlapping loops and a long horizontal stroke at the bottom.

Seth Greiner
Sr. Mgr. of Advocacy
Washington State, Oregon, & Alaska
National MS Society

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.