National Multiple Sclerosis Society Submitted Comments on Ohio House Bill 469 June 2, 2020

Holly Pendell
Director, Advocacy & Activist Engagement
Holly.Pendell@nmss.org

The National Multiple Sclerosis Society appreciates the opportunity to submit comments in support of House Bill 469. We thank Representatives Manchester and West for introducing legislation that if passed, will assist people living with multiple sclerosis (MS) access the medications they need to live their best lives.

Multiple sclerosis 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 range from numbness and tingling to 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. MS affects more than 2.3 million people worldwide and one million people in United States.

Copay accumulators (or accumulator adjustment programs) began from the belief that drug manufacturers' patient assistance programs are discouraging patients and their doctors from choosing generics or less-costly prescription drug alternatives. These programs are used to prohibit prescription drug coupons or other forms of charitable assistance from applying towards a patient's annual deductible or out-of-pocket maximum amounts, though the insurers are receiving full payment for the medication.

For people living with MS copay accumulators make it more difficult to receive the disease modifying therapies (DMTs) they need. As many as 40% of people living with MS rely on some copay assistance to maintain access to their disease-modifying therapy. With the implementation of copay accumulator programs, people with MS are experiencing higher cost burdens as they struggle with unexpected expenses during their deductible period.

Such was the case for Nikki Snyder of Canfield, Ohio. Nikki agreed to let me share her story today. Nikki lives with MS, as does her mother, and in late fall of 2018 received a bill for \$2,326.24 for her most recent MRI. She thought the bill must have been a mistake. She had paperwork from her insurer showing she had met her deductible earlier that year. Nikki could not understand why she was being billed this large amount. She had always met her deductible with the cost of her monthly disease modifying therapy (DMT).

When Nikki reached out to her insurance company to ask about the bill, she was told that the financial assistance she had received from her drug company to help pay for DMT's was no longer being counted toward her deductible, even though the insurance was receiving the payment. The insurer said they had just realized she was using assistance and as a result, the amount counted toward her deductible was far less than had been included in her monthly statement. The change had been included in the fine print of

her health insurance policy. She was devastated. Just months earlier she had married and with her husband, she had recently purchased a home. Additional debt was not what she needed, but it is what she received.

Nikki is not alone in experiencing a copay accumulator unexpectedly. I have heard many stories from numerous enrollees across the state who were surprised to learn their assistance would no longer count towards their deductible. People with chronic and high-cost conditions like MS face significant financial hardship each year until their deductible has been met and the full relief of their health insurance applies. This hardship is made worse by copay accumulator programs preventing copay assistance from applying to a person's deductible. It means it takes them longer to reach the end of the deductible period and more must be paid out of pocket. In the long run, that means less adherence to drugs and diminished results.

DMT's and symptom management medications like what Nikki take are critical to slow the progression of MS. In 2020, the median price of these therapies was over \$90,000 a year. The three generics currently available cost between \$63,000 and \$65,000 per year. Of the eight products that cost more than the median price, more than half have been on the market for eight years or longer, some as long as 25 years.

Until we find real solutions to the challenges in our healthcare system that prevent people from affordably accessing the care and treatments they need, we cannot rip away the band-aids people have come to rely on—like copay assistance programs. Medications must be affordable, and the process for getting them simple and transparent. House Bill 469 offers provisions that will allow consumers to receive assistance of any kind to pay for their medications and for that assistance to count towards their deductible. Ohio lawmakers have an opportunity to address a significant drug price issue by passing House Bill 469. Thank you for your consideration of this legislation. Please let me know if I can be of assistance to you and your work in the future.