



Testimony of Holly Pendell
National Multiple Sclerosis Society
May 7, 2019

Ohio House of Representative Insurance Committee

Good afternoon Chairman Brinkman, Vice Chairman Antani, Ranking Member Rep. Boggs and committee members. My name is Holly Pendell and I represent the National Multiple Sclerosis Society.

On behalf of the thousands of Ohioans who live with multiple sclerosis, the National Multiple Sclerosis Society wishes to offer the following comment on Senate Bill 9, which will require health plan issuers to release certain claim information to group plan policyholders.

I would like to begin with a bit of information about multiple sclerosis. Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system, it interrupts 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 moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease. MS affects more approximately 1 million individuals in the United States.

The National Multiple Sclerosis Society (the Society) is pleased with the changes that were made since last year's version of this legislation, which we strongly opposed. Yet one specific concern remains. You will note that the current legislation allows for diagnosis and condition to be shared data in cases where the claim is over \$30,000. We are confident that greater transparency of health care costs and expenditures is possible without the unintended consequences we fear could manifest should this information be shared by law.

Except for unplanned life events that may result in complicated hospital stays, cancer, arthritis and multiple sclerosis are the diagnosis's that will be shared for claims over \$30,000. A study just last week, identified these conditions as the three most expensive conditions in the United States to treat. The most recent data provided regarding the occurrence of multiple sclerosis suggests that 1 in every 300 individuals is living with MS. In a company of between 50 and 100 employees, there is unlikely to be no more than one employee or employee family member living with MS. As a result the claim information linking the over \$30,000 cost to the condition of MS will likely identify that employee and their prescribed treatment or procedure to their employer. We fear repeatedly associating large medical costs with a select few employees can create an unintended bias against that employee or the condition.

After reviewing all testimony provided by sponsors and proponents, I have found no argument as to why disease specific information is necessary to achieve any of the legislation's goals as stated by the sponsor. The Society advocates for greater transparency of health care and coverage costs in the firm belief that it can lower and restrain them while promoting accountability among providers of health care services and insurance, as well as manufacturers of medicines, equipment and supplies. However, we also strive to protect the privacy and confidentiality of those living with MS in all relationships through strong anti-discrimination protections such as those within the Rehabilitation Act, the American with Disabilities Act, the Health Insurance Portability and Accountability Act (HIPAA), and the Patient Protection and Affordable Care Act. Even with these measures, real or perceived discrimination against employees with MS is a constant source of concern among people living with the disease who contact us for help. Protecting against discrimination in employment and many other aspects of American life has been a core component of the education and understanding of MS the Society has promoted since our establishment.

I urge this committee to err on the side of the consumer today and remove the line in reference before passage of SB 9. I wish to thank the members of the House Insurance Committee for its time today and I'm happy to answer any questions.

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