



Testimony of Holly Pendell
National Multiple Sclerosis Society
November 28, 2018
Ohio House Insurance Committee

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

On behalf of the over 20,000 Ohioans who live with multiple sclerosis, the National Multiple Sclerosis Society wishes to offer the following comment on Senate Bill 227, 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 than 2.3 million worldwide.

The National Multiple Sclerosis Society (the Society) has reviewed SB 227 and is deeply concerned over its potential implications for Ohioans living with MS or other high-cost health conditions. We are confident that greater transparency of health care costs and expenditures is possible without the unintended consequences we fear could manifest should this measure be enacted into law.

At its core, SB 227 advocates for greater transparency between insurers and business owners regarding claims data with the expectation that business owners, given this information, will be able to secure high quality insurance that will best meet the needs of their employees. Additionally, it has been stated that SB 227 may possibly increase competition within the insurance market and offer an opportunity for stabilization. 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. We fear the legislation as currently drafted may violate the spirit if not the letter of these critically important federal safeguards. 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.

In his sponsor testimony in the Senate, Senator Huffman notes HIPAA categorizes claims data information as “deidentified” information, if it neither identifies nor provides a reasonable basis to identify an individual. I argue that claims data alerting an employer that they have an employee with multiple sclerosis that has recently been added to their health plan or diagnosed, does in fact offer a reasonable identification of that employee. With little more than a Google search, a glance at HR records and simple observations, there’s a fair chance notification will lead to identification in that situation and medical privacy will have been lost. Also in his testimony, Senator Huffman offered that the disclosure of this information would be helpful to businesses considering joining possible association health plans in the future, that will likely not offer comprehensive benefits. The Society is still developing our position on Association Health Plans, but we are likely to follow the position of the National Association of Insurance Commissioners and other expert’s in expressing our grave concerns. Putting those concerns aside, the claims data that would be provided would only, in the very best-case scenarios, assist a company that has employees seeking very few comprehensive benefits; but it is of little help in predicting the future health care needs of those current or future employees that could include needed benefits such as specialty drugs, rehab therapy or maternity care.

Further, the Society believes that other sources of data on healthcare expenditures and claims costs are already available and used routinely by researchers, the media, lawmakers, professional associations and others. For this reason, we fail to see a compelling reason for requiring health plans to “release certain information to group plan policyholders”. The [National Medical Expenditure Data](#), [National Center on Health Statistics](#), [Employee Benefits Research Institute](#) and other publicly available data sources provide responsibly administered surveys and analyses of health care utilization and costs. We strongly urge proponents of SB 227 to utilize these resources instead of promoting new disclosure requirements that seem to conflict with the anti-discrimination measures cited above.

Finally, after reviewing all testimony provided by sponsors and proponents, I have found no argument as to why disease and pharmaceutical specific information is necessary to achieve any of the legislations goals as stated by the sponsor. Wouldn’t claims for treatment of catastrophic illnesses or specialty tier medications provide enough data to an employer to seek quality plans for their employees? Why must specific data be shared? I urge you to err on the side of the consumer today and of the protections given to them by the laws cited above. We must not tip the balance away from comprehensive benefits and medical privacy protections and return to era where employees live in fear of being outed due to their medical diagnosis.

I wish to thank the members of the House Insurance Committee for its consideration of my testimony.

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