



Senator Christine Rolfes
Chair, Senate Ways & Means Committee
Washington State Legislature
303 John A. Cherberg Building
Olympia, WA 98504

Senator Lynda Wilson
Ranking Member, Senate Ways & Means Committee
Washington State Legislature
205 Irv Newhouse Building
Olympia, WA 98504

Chair Rolfes and Ranking Member Wilson:

On behalf of the 74,600 Washingtonians with epilepsy, we write to express concern with SB5020 and encourage you to pursue other ways of addressing the rising costs of prescription drugs.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of at least 3.4 million Americans with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. For people living with epilepsy, timely access to appropriate, physician-directed care, including epilepsy medications, is a critical concern. Epilepsy medications are the most common and cost-effective treatment for controlling and/or reducing seizures. To delay, change, limit, or deny access to medications could be extremely dangerous.

We are concerned that SB5020 relies on measures that discriminate against people with disabilities. Quality Adjusted Life Years (QALYs) are used by the Institute for Clinical and Economic Review (ICER), which is named in the bill, in their studies and determinations of whether price increases are supported by the evidence. QALYs have long been opposed by the disability community for discriminating against people with disabilities. QALYs place a number on the value on a year of human life, with relatively lower values for those with disabilities and chronic conditions. These values can then be used to deny access to care and treatments.

In 2019, the National Council on Disability, an independent federal agency, issued a report titled *Quality Adjusted Life Years and the Devaluation of Life with a Disability*.¹ NCD stated that they “found sufficient evidence of QALYS being discriminatory (or potentially discriminatory) to warrant concern”, and recommended the prohibition of the use of QALYs in Medicare and Medicaid. NCD also recommended the use of alternative value assessment mechanisms and provided examples for the federal government and states to use.

The use of QALYs may also violate federal law. Section 504 of the Rehabilitation Act ensures that people with

¹ https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf



disabilities will not be “excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination,” under any program offered by the federal government.² Title II of the Americans with Disabilities Act (ADA) extends this protection to programs and services offered by state and local governments.³ In 1992, the George H.W. Bush administration found that the use of QALYs in state Medicaid programs would violate the ADA and ruled against a request by the state of Oregon to use QALYs in determining coverage of services.

For these reasons, we encourage you to not pass this bill out of committee, and instead pursue alternative methods to lower the cost of prescription drugs for Washingtonians, including methods of value assessment that do not rely on QALYs. If you have any questions please do not hesitate to reach out to Laura Weidner, Vice President of Government Relations & Advocacy at lweidner@efa.org.

Sincerely,

Laura Thrall
President & CEO
Epilepsy Foundation

Kevin Koppes
Executive Director of Community Engagement
Epilepsy Foundation Washington

² 29 USC Sec 794, 2017.

³ 42 USC Sec 12131, 2017.