



January 27, 2023

The Honorable Cathy McMorris-Rodgers  
Chair  
Energy and Commerce Committee  
US House of Representatives  
Washington DC 20510

The Honorable Frank Pallone Jr.  
Ranking Member  
Energy and Commerce Committee  
US House of Representatives  
Washington DC 20510

The Epilepsy Foundation writes to show our support for the Protecting All Health Care for Patients Act, to prohibit the use of Quality-Adjusted-Life-Years (QALYs) and similar measures in coverage and payment determinations under federal health care programs. This is an issue that impacts all levels of health care and prohibiting the use of these measures will positively impact the lives of millions of Americans.

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 well-being 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, and people living with epilepsy must have meaningful and timely access to physician-directed care and specialists, to avoid breakthrough seizures and related complications and costs.

The logic inherent in the QALY is concerning on its face: it is designed to measure the extent to which a year of life with a disability is of lower quality and lower value than life without a disability. The disability rights movement seeks to show that not only do people with disabilities have a right to participate in society, but that they can have high quality lives. QALY-based assessments also do not account for outcomes that matter to people living with the relevant health condition. When applied to health care decision-making, the results can mean that people with disabilities and chronic illnesses, including older adults, are deemed not worth the cost to treat. We agree with the conclusions of the National Council on Disability, an independent federal agency, that Congress should disallow QALYs in state and federal health care programs.

The Protecting All Health Care for Patients Act will solidify a decades-long bipartisan track record of supporting disability rights in federal programs. Section 504 of the Rehabilitation Act of 1973, signed by President Nixon, ensures that people with disabilities will not be “excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination,” under any program offered by any Executive Agency. Title II of the Americans with Disabilities Act of 1990, signed by President H.W. Bush, extended this protection to programs and services offered by state and local governments. In 2010, the Affordable Care Act, signed by President Obama, stated that the Secretary of Health and Human Services (HHS) has no authority to deny coverage of items or services “solely on the basis of comparative effectiveness research” nor to use such research in a manner that would attribute a lower value to extending the lives of older adults, people with disabilities or people with a terminal illness. Finally the Inflation Reduction Act, signed by President Biden, prohibits the use of measures that devalue the lives of



people with disabilities and others in Medicare prescription drug negotiations. Under both the Trump and Biden administrations, the HHS Office for Civil Rights has taken action on discriminatory allocation of health care resources.

The Epilepsy Foundation urges you to support this important legislation and join the decades-long bipartisan initiative to advance the rights of people with disabilities.

Please contact Rachel Patterson at [rpatterson@efa.org](mailto:rpatterson@efa.org) with any questions or follow-up.

Sincerely,

Allison Zetterquist  
Acting Chief Executive Officer  
Epilepsy Foundation