

FOR IMMEDIATE RELEASE

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The ALS Association – Massachusetts Chapter and Epilepsy Foundation New England issue a statement on behalf of patients and people with disabilities on the importance of the patient protections included in H. 201.

Boston, Massachusetts - We are pleased to see that H. 201, An Act Advancing Health Care Research and Decision-Making Centered on Patients and People with Disabilities, will be receiving a hearing before the Joint Committee on Health Care Financing on Tuesday, November 9.

We support policymakers' goals to lower the cost of health care for residents of the Commonwealth, but as policymakers have sought solutions this issue, we have been concerned to see them considering policies that rely on the Quality-Adjusted Life Year (QALY), which discriminates against people with disabilities and chronic illnesses. For this reason, a statutory ban on the use of the QALY in Medicare was included in the Affordable Care Act; and the National Council on Disability, an independent federal agency advising the administration and Congress on disability policy, found in 2019 that the use of the QALY would be contrary to United States civil rights laws and disability policy.

Despite this clear precedent, the Massachusetts Health Policy Commission has signed a contract with the Institute for Clinical and Economic Review (ICER), and organization that deems the QALY the "gold standard." For this reason, it is imperative that appropriate patient protections, like those included in H. 201, are codified into law to assure patients and people with disabilities maintain access to treatments prescribed by their physicians and do not experience discrimination.

Bill Murphy, Epilepsy Foundation New England said, "Massachusetts historically has been both a leader in health care and the fight for equality for all people. Policies that rely on the Quality-Adjusted Life Year would be a stain on that record. I urge policymakers to pass H. 201 so we can maintain our leadership in both health care and equal rights."

Jenn McNary, a mother of two sons with Duchenne Muscular Dystrophy said, "I have seen firsthand the harm that QALY-based decision-making in health care causes patients. My son has been denied access to a drug that works well for him and greatly improves my entire family's quality of life due to payer policies based on these discriminatory assessments. I urge policymakers to pass H. 201 so my sons and all patients can have timely access to the treatments they need."

John Hedstrom, Executive Director of ALS Massachusetts Chapter said, "Patients with ALS have fundraised tirelessly for research and fought hard to help bring treatments to patients. Now that we are seeing new treatments for the first time in decades, it is imperative patients are able to access them, instead of being denied because they are considered too expensive or too sick to treat."

Contacts: Bill Murphy - wmurphy@epilepsynewengland.org; John Hedstrom – john.hedstrom@als-ma.org

