

**FOR IMMEDIATE RELEASE**

**February 6, 2020**

**Statement on Behalf of The ALS Association – Massachusetts Chapter, Epilepsy Foundation New England, and Partnership to Improve Patient Care on Massachusetts Health Policy Commission Final Prescription Drug Regulations**

On February 5, 2020, the Massachusetts Health Policy Commission (HPC) finalized regulations outlining their approach to assessing the value of prescription drugs. As groups representing patients and people with disabilities, the affordability of health care is a significant priority. That being said, HPC's regulations put patient access at risk, and may ultimately do more harm than good for patients. They set the stage for third-party analyses by groups like the Institute for Clinical and Economic Review (ICER) and rely on international reference pricing, which relies on QALY-based assessments in determining the "value" of treatments.

Massachusetts has always been a leader in both health care and inclusion, and this regulation does not honor that legacy. A recent report by the National Council on Disability (NCD), an independent federal agency, concluded that QALYs place a lower value on treatments which extend the lives of people with chronic illnesses and disabilities and fail to fully measure health-related quality of life. NCD recommended that policymakers and insurers reject QALYs as a method of measuring cost-effectiveness for medical care and avoid referencing international pricing due to its reliance on QALYs.

The patient and disability community has long had concerns about the use of QALYs to determine cost effectiveness or "value" of treatments, and, historically, the QALY has been opposed for use in decision-making by the American public and policy makers. In fact, there is currently a ban on use of the QALY or similar metrics in Medicare, and, in 1992, a Republican administration established that use of a cost-effectiveness standard by a state Medicaid program would violate the Americans with Disabilities Act. Groups representing patients and people with disabilities shared this concern clearly to HPC and are disheartened they did not put protecting patients first and include a QALY ban in the regulation.

While we appreciate the expanded provisions requiring transparency and consideration of outcomes that matter to patients, without an explicit QALY ban, this approach fails to provide them with meaningful and needed protections. We will continue in our fight to ensure that both state and federal policymakers recognize that all lives, including those of patients and persons with disabilities, have equal value.

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