



September 19, 2023

Chairwoman Cindy F. Friedman
Joint Committee on Health Care Financing
24 Beacon Street
Room 313
Boston, MA 02133

Chairman John J. Lawn, Jr.
Joint Committee on Health Care Financing
24 Beacon Street
Room 236
Boston, MA 02133

RE: Support for H.1183/S.730 – Quality Adjusted Life Year Prohibition

Dear Chairwoman Friedman and Chairman Lawn,

On behalf of the Movement Disorders Policy Coalition, I am writing in support of H.1183/S.730. This legislation will ensure that the quality-adjusted life year (QALY), a controversial metric used to determine medication value, cannot be used by the Health Policy Commission or the Division of Medical Assistance in determining the value or coverage for health care treatments including citizens covered by MassHealth, the Commonwealth's Medicaid program.

The [Movement Disorders Policy Coalition](#) (MDPC) serves as a platform from which stakeholders, including health care providers and patients, can provide input on policy decisions impacting patient-centered care for those living with movement disorders. As a coalition of stakeholder groups across the movement disorders space, MDPC advocates at the federal, state, and health plan levels for key health reforms that increase access to personalized care for patients with movement disorders including tardive dyskinesia, Parkinson's disease, essential tremor, Tourette Syndrome, dystonia, ataxia and Huntington's disease.

The quality-adjusted life year (QALY) is a valuation metric that is used by health economists to determine the cost-effectiveness of a treatment, and it is sometimes used by health insurance providers in making coverage determinations. The QALY dramatically undervalues patients with disabilities and chronic conditions, discriminating against the most vulnerable patients who could benefit from life-changing treatments.

This undervaluation can lead to difficulty for many patients, including those with movement disorders, in accessing the therapies they need. Placing barriers between patients and the therapies prescribed by their healthcare provider interferes with patient care and undermines the

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primacy of the clinician-patient relationship, a relationship that serves as the foundation of our healthcare system. For patients with movement disorders who are managing already complex conditions and treatment regimens, use of the QALY can lead to less effective care and negatively impact both physical and mental health symptoms.

H.1183/S.730 are critical in ensuring that patients, and particularly those with serious, enduring conditions like many movement disorders, can receive treatment. This legislation is designed to ensure all residents of Massachusetts may receive appropriate health care without discrimination by prohibiting the use of the QALY metric used to determine cost effectiveness of treatments.

On behalf of the Movement Disorders Policy Coalition and our membership, thank you for your leadership on H.1183/S.730. If we can provide further details or answer any questions, please reach out to Josie Cooper at jcooper@allianceforpatientaccess.org.

Sincerely,

A handwritten signature in cursive script that reads "Josie Cooper".

Josie Cooper
Executive Director
Movement Disorders Policy Coalition