

SENATE No. 465

The Commonwealth of Massachusetts

PRESENTED BY:

Sal N. DiDomenico

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

An Act supporting individuals suffering with amyotrophic lateral sclerosis and their families.

PETITION OF:

NAME:

Sal N. DiDomenico

DISTRICT/ADDRESS:

Middlesex and Suffolk

SENATE No. 465

By Mr. DiDomenico, a petition (accompanied by bill, Senate, No. 465) of Sal N. DiDomenico for legislation to support individuals suffering with amyotrophic lateral sclerosis and their families. Elder Affairs.

The Commonwealth of Massachusetts

In the One Hundred and Ninety-Fourth General Court
(2025-2026)

An Act supporting individuals suffering with amyotrophic lateral sclerosis and their families.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

1 SECTION 1. The executive office of elder affairs, under authority granted in section 4 of
2 chapter 19A of Massachusetts general laws, shall amend the Massachusetts home care
3 regulations (651 CMR 3.00). Such amendment shall require home care program services be
4 made available to persons diagnosed with amyotrophic lateral sclerosis regardless of their age, if
5 they are otherwise eligible for such services. The secretary for health and human services shall
6 ensure that the relevant agencies under her purview promulgate regulations as necessary to
7 implement this act.

8 SECTION 2. Chapter 118E: DIVISION OF MEDICAL ASSISTANCE of the
9 Massachusetts General Laws, as appearing in the 2018 Official Edition, is hereby amended by
10 adding the following section:

11 Section 79: Patient-Centeredness

Section 79 (a) Standards for Patient-Centeredness in Research & Analysis. The Division of Medical Assistance shall ensure that any portfolio of research and analysis relied upon for decision-making, whether provided by a state agency or a third party, impacting enrollee access to healthcare treatments and services, meets standards of patient-centeredness. The Division of Medical Assistance shall publicly provide a summary of patient-centeredness standards for any such analysis that includes, but is not limited to:

1) Evaluation of a range of research and analysis that includes outcomes prioritized by patients and people with disabilities within a specific disease area. If necessary, the Division of Medical Assistance will commission a survey of patients to identify relevant outcomes within a disease area.

2) Evaluation of a range of research and analysis that looks at relevant patient subgroups to ensure consideration of important differences in preferences and clinical characteristics within patient subpopulations.

3) Scientific Rigor: The Division of Medical Assistance shall require research and analysis to comply with good research practices, defined as consideration of the full range of relevant, peer-reviewed evidence (e.g., real-world evidence, research from range of sponsors including manufacturers), avoid patient harm through over-interpretation of findings of “inconclusive” evidence of clinical differences and instead allow time for conduct of additional research.

(b) Prohibition on Reliance on Discriminatory Measures. The Division of Medical Assistance shall not develop or utilize, directly or indirectly through a contracted entity or other third-party, a dollars-per-quality adjusted life year or any similar measures or research in

determining whether a particular health care treatment is cost effective, recommended, the value of a treatment, or in determining coverage, reimbursement, appropriate payment amounts, cost-sharing, or incentive policies or programs.

(c) Appeals and Physician Override Mechanisms. The Division of Medical Assistance may not implement any policy limiting patient access to healthcare treatment and services which does not contain an appeals or physician override mechanism. Physicians may not be discriminated against or otherwise negatively impacted for utilizing available physician override mechanisms.

SECTION 3. Chapter 6D of the General Laws, as appearing in the 2018 Official Edition, is hereby amended by adding the following section:

Section 20. Patient-Centeredness Standards for Health Policy Commission Reviews

Section 20 (a) Standards for Patient-Centeredness in Research & Analysis. The Health Policy Commission shall ensure that any portfolio of research and analysis relied upon for determining the value of a healthcare treatment or service , whether provided by a state agency or a third party, impacting enrollee access to healthcare treatments and services, meets standards of patient-centeredness. The Health Policy Commission shall publicly provide a summary of patient-centeredness standards for any such analysis that includes, but is not limited to:

1) Evaluation of a range of research and analysis that includes outcomes prioritized by patients and people with disabilities within a specific disease area. If necessary, the Health Policy Commission will commission a survey of patients to identify relevant outcomes within a disease area.

2) Evaluation of a range of research and analysis that looks at relevant patient subgroups to ensure consideration of important differences in preferences and clinical characteristics within patient subpopulations.

3) Scientific Rigor: The Health Policy Commission shall require research and analysis to comply with good research practices, defined as consideration of the full range of relevant, peer-reviewed evidence (e.g., real-world evidence, research from range of sponsors including manufacturers), avoid patient harm through over-interpretation of findings of “inconclusive” evidence of clinical differences and instead allow time for conduct of additional research.

(b) Prohibition on Reliance on Discriminatory Measures. The Health Policy Commission shall not develop or utilize, directly or indirectly through a contracted entity or other third-party, a dollars-per-quality adjusted life year or any similar measures or research in determining whether a particular health care treatment is cost effective, recommended, the value of a treatment, or in determining coverage, reimbursement, appropriate payment amounts, cost-sharing, or incentive policies or programs.