

**SENATE . . . . . No. 465**

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**The Commonwealth of Massachusetts**

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PRESENTED BY:

***Sal N. DiDomenico***

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*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.

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PETITION OF:

NAME:

*Sal N. DiDomenico*

DISTRICT/ADDRESS:

*Middlesex and Suffolk*

**SENATE . . . . . No. 465**

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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.

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**The Commonwealth of Massachusetts**

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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