

**HOUSE . . . . . No. 2395**

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**The Commonwealth of Massachusetts**

PRESENTED BY:

***David M. Rogers and Jon Santiago***

*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 relative to sickle cell disease.

PETITION OF:

| NAME:                         | DISTRICT/ADDRESS:     | DATE ADDED:      |
|-------------------------------|-----------------------|------------------|
| <i>David M. Rogers</i>        | <i>24th Middlesex</i> | <i>2/19/2021</i> |
| <i>Jon Santiago</i>           | <i>9th Suffolk</i>    | <i>2/26/2021</i> |
| <i>Maria Duaiame Robinson</i> | <i>6th Middlesex</i>  | <i>2/19/2021</i> |
| <i>Carlos González</i>        | <i>10th Hampden</i>   | <i>2/25/2021</i> |
| <i>Kay Khan</i>               | <i>11th Middlesex</i> | <i>2/25/2021</i> |
| <i>Elizabeth A. Malia</i>     | <i>11th Suffolk</i>   | <i>3/15/2021</i> |
| <i>David Allen Robertson</i>  | <i>19th Middlesex</i> | <i>3/16/2021</i> |

**HOUSE . . . . . No. 2395**

By Messrs. Rogers of Cambridge and Santiago of Boston, a petition (accompanied by bill, House, No. 2395) of David M. Rogers, Jon Santiago and others for legislation to establish a special commission (including members of the General Court) relative to sickle cell disease. Public Health.

**The Commonwealth of Massachusetts**

**In the One Hundred and Ninety-Second General Court  
(2021-2022)**

An Act relative to sickle cell disease.

*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. (a) There is hereby established a special legislative commission pursuant to  
2 section 2A of chapter 4 of the General Laws to examine and make recommendations regarding  
3 Sickle Cell Disease in the Commonwealth.

4 (b) The Commission shall consist of the following 20 members: the house and senate  
5 chairs of the joint committee on public health or their designees, who shall serve as co-chairs;  
6 three members of the general public affected by Sickle Cell Disease, at least one of whom must  
7 have the disease and two of whom must be the parent of a child with the disease ; one medical  
8 professional from each of the major Sickle Cell Disease treatment centers in the Commonwealth,  
9 including Massachusetts General Hospital, Brigham and Women’s Hospital, Boston Medical  
10 Center, Boston Children’s Hospital, and University of Massachusetts Memorial Health Center;  
11 the Executive Director of the Greater Boston Sickle Cell Association or their designee; the  
12 Executive Director of the Massachusetts Association of Community Health Workers or their

13 designee; the President of the Massachusetts Chapter of the National Association of Social  
14 Workers or their designee; two members appointed by the co-chairs, one of whom shall be an  
15 expert on the biology of the disease, and one of whom shall be an expert on the psycho-social  
16 aspect of the disease ; one member of the Black and Latino Caucus; one member of the Asian  
17 Caucus; and one representative appointed by the Governor with a background in racial health  
18 disparities. The co-chairs may appoint up to two additional members to fulfill the purpose and  
19 goals of the Commission.

20           Members of the special commission shall have evidence-based or lay knowledge,  
21 expertise or experience related to Sickle Cell Disease and racial health disparities and shall  
22 reflect broad racial and geographic diversity in the Commonwealth. All appointments shall be  
23 made not later than 30 days after the effective date of this act. The Commission shall convene its  
24 first meeting not later than 60 days after the effective date of this act.

25           (c) The Commission shall investigate and report on: (i) a standard of basic,  
26 multidisciplinary care for patients across the Commonwealth; (ii) the creation of a statewide  
27 resource website that would include disease information, information on how to access treatment  
28 centers and providers, listings of providers across the state representing multiple disciplines who  
29 have an expertise in the care of Sickle Cell Disease, a statewide hotline, and online  
30 communication options; (iii) the usage of Community-based Participatory Research to determine  
31 how many patients are living with Sickle Cell Disease, their level of access to medication,  
32 primary care, subspecialty care, morbidity and mortality rates, geographic distribution, access to  
33 transportation, other complications such as depression, anxiety, hypertension, low birth weight,  
34 infant mortality, heart disease, aging, advanced care planning, and any other information deemed  
35 important; (iv) resources for pediatric patients, including, but not limited to genetic counseling,

36 family planning and childcare resources for schools; (v) forging partnerships by building  
37 relationships with other healthcare centers specializing in Sickle Cell Disease within New  
38 England, setting a standard for a national approach to Sickle Cell Disease care and identifying  
39 and seeking out federal resources and support; (vi) the creation of an awareness campaign,  
40 including, but not limited to an initiative to promote Sickle Cell Disease information, resources  
41 and philanthropic sourcing and guidance; (vii) the availability of mental health care related to the  
42 disease, including, but not limited to, expanding access to social workers in clinical settings and  
43 a community social work pilot program ; (viii) community care, including, but not limited to,  
44 expanding access to community health workers in culturally appropriate settings and crisis  
45 response teams for acute care and; (ix) any other factors that the commission considers relevant,  
46 including but not limited to housing access, transportation resources, and education programs for  
47 students with Sickle Cell Disease.

48 (d) No later than 1 year after the effective date of this act, the Commission shall submit a  
49 report of its findings and recommendations, together with drafts of legislation necessary to carry  
50 out those recommendations, to the secretary of health and human services, and file the same with  
51 the clerks of the house of representatives and the senate, the house and senate committees on  
52 ways and means, the joint committee on health care financing and the joint committee on public  
53 health. The commission shall also, at all meetings, provide updates on the status of its findings  
54 and recommendations.

55 (e) The commission shall also oversee the establishment of three grant programs with the  
56 following goals: (i) for health care institutions to acquire resources for the purpose of meeting  
57 the standards established by the Commission and for the purpose of meeting the standards to  
58 ensure the same level of care across the Commonwealth. The funds shall also be used to bridge

59 the gap between outpatient and inpatient care, provide coordinated and comprehensive team-  
60 based, medical, behavioral health, mental health, and social support for patients with Sickle Cell  
61 Disease; (ii) to fund innovative research programs that will develop new treatments and promote  
62 development of new technologies for the treatment of Sickle Cell Disease; and (iii) for  
63 community investment that would create programs with educational resources, vocational  
64 training and support, housing, access to nutritional programs and youth mentorship for families  
65 affected by Sickle Cell Disease.