

**HOUSE . . . . . No. 01526**

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The Commonwealth of Massachusetts

PRESENTED BY:

*Jeffrey Sánchez*

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 passage of the accompanying bill:

An Act relative to the hemophilia advisory committee.

PETITION OF:

NAME:	DISTRICT/ADDRESS:
<i>Jeffrey Sánchez</i>	<i>15th Suffolk</i>
<i>Viriato Manuel deMacedo</i>	<i>1st Plymouth</i>
<i>Gale D. Candaras</i>	<i>First Hampden and Hampshire</i>
<i>William N. Brownsberger</i>	<i>24th Middlesex</i>
<i>Anne M. Gobi</i>	<i>5th Worcester</i>
<i>Colleen M. Garry</i>	<i>36th Middlesex</i>
<i>Jay Kaufman</i>	<i>15th Middlesex</i>
<i>James B. Eldridge</i>	<i>Middlesex and Worcester</i>
<i>James Arciero</i>	<i>2nd Middlesex</i>

# HOUSE . . . . . No. 01526

By Mr. Sánchez of Boston, a petition (accompanied by bill, House, No. 1526) of Jeffrey Sánchez and others for legislation establishing a hemophilia advisory committee. Public Health.

## The Commonwealth of Massachusetts

In the Year Two Thousand Eleven

An Act relative to the hemophilia advisory committee.

*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. Chapter 111 of the General Laws is hereby amended by striking out sections 6B  
2 and 6C, as appearing in the 2008 Official Edition, and inserting in place thereof the following  
3 sections:--

4 Section 6B. (a) There is hereby established a hemophilia advisory committee which shall  
5 review administrative actions and the impact of legislation relative to the treatment and care of  
6 persons with hemophilia or other inherited bleeding and clotting disorders and to make  
7 recommendations to the commissioner of public health and the commissioner of insurance  
8 relative to the establishment of programs for public awareness, reporting and treatment of  
9 hemophilia and other inherited bleeding and clotting disorders and to make recommendations for  
10 legislation relative thereto. The committee shall consist of 11 members. The commissioner of  
11 public health or a designee thereof and the commissioner of insurance or a designee thereof shall  
12 serve as non-voting members and co-chairs of the committee. The remaining members shall be

13 appointed by the governor and include: 1 registered nurse, licensed, practicing and treating  
14 individuals with hemophilia or other inherited bleeding and clotting disorders; 1 social worker,  
15 licensed, practicing and treating individuals with hemophilia or other inherited bleeding or  
16 clotting disorders; 1 representative of a commonwealth-based, federally funded hemophilia  
17 treatment center; 1 representative of a commonwealth provider of health insurance, established  
18 by statute; 1 representative of a voluntary health organization that services persons with  
19 hemophilia or other bleeding and clotting disorders; 1 person with hemophilia or a caregiver  
20 thereof; 1 person with a bleeding disorder other than hemophilia or a caregiver thereof; 1 person  
21 with a clotting disorder or a caregiver thereof; and 1 board certified physician, licensed,  
22 practicing and treating persons with hemophilia or other inherited bleeding and clotting  
23 disorders. Members of the committee shall receive no compensation but may be reimbursed for  
24 actual expenses incurred in carrying out their official duties. Six members shall constitute a  
25 quorum and the affirmative vote of six members shall be necessary for any action taken by the  
26 committee.

27 (b) The hemophilia advisory committee shall make recommendations to the commissioners of  
28 public health and insurance relative to:

29 (1) legislative or administrative changes to policies and programs integral to the health and  
30 wellness of persons with hemophilia or other inherited bleeding and clotting disorders;

31 (2) coordination with other state agencies and private organizations to advance the development  
32 of community-based initiatives to increase the awareness of care and treatment of persons living  
33 with hemophilia or other inherited bleeding and clotting disorders;

34 (3) dissemination of information relative to initiatives of interest to persons with hemophilia or  
35 other inherited bleeding and clotting disorders;

36 (4) standards of care and treatment for persons with hemophilia or other inherited bleeding and  
37 clotting disorders, taking into consideration the federal and state standards of care guidelines  
38 developed by state and national organizations including but not limited to the Medical and  
39 Scientific Advisory Council of the National Hemophilia Foundation;

40 (5) protection and promotion of open access to any and all treatments for hemophilia and other  
41 inherited bleeding and clotting disorders consistent with the standards of care guidelines  
42 developed by state and national organizations including but not limited to the Medical and  
43 Scientific Advisory Council of the National Hemophilia Foundation;

44 (6) assistance to persons living with hemophilia or other inherited bleeding and clotting disorders  
45 to access appropriate health insurance coverage through private or state-sponsored health  
46 insurance providers; and

47 (7) development of, and participation in, care and treatment programs for persons with  
48 hemophilia or other inherited bleeding and clotting disorders, including self-administration,  
49 home care, medical and dental procedures and techniques designed to provide maximum control  
50 over bleeding episodes.

51 (c) The department of public health may coordinate with other state agencies and private  
52 organizations, through cooperative agreements with hemophilia treatment centers, medical  
53 facilities, schools and nonprofit organizations that serve persons living with hemophilia or other  
54 inherited bleeding and clotting disorders, in order to advance the development of community  
55 –based initiatives to increase the awareness of care and treatment for persons living with

56 hemophilia or other inherited bleeding and clotting disorders. The department of public health  
57 may also extend assistance to such agencies and organizations to facilitate connecting persons  
58 with hemophilia or other bleeding and clotting disorders with such agencies and programs.

59 Section 6C. The commissioner of public health, in consultation with the commissioner of  
60 insurance, shall annually submit a report to the joint committee on health care finance and the  
61 joint committee on public health on the status of care and treatment of persons with hemophilia  
62 or other inherited bleeding and clotting disorders. The report shall include information relative  
63 to the method and manner by which the commonwealth has protected the health and wellness of  
64 persons with hemophilia or other inherited bleeding and clotting disorders. A copy of said report  
65 shall also be submitted to the secretary of the executive health & human services and the director  
66 of the MassHealth program.

67 SECTION 2. The department of public health shall adopt such rules and regulations as  
68 necessary to effectuate the purposes of act.

69 SECTION 3. The initial report to be filed pursuant to section 2 shall be filed not later than  
70 December 31, 2011; and by inserting before the enacting clause the following emergency  
71 preamble:-

72 “Whereas, The deferred operation of this act would tend to defeat its purpose, which is to  
73 immediately reorganize the hemophilia advisory committee and authorize such committee to  
74 provide recommendations to the commonwealth relative to health insurance policies and health  
75 insurance plans and programs that impact individuals with hemophilia or other inherited  
76 bleeding and clotting disorders, therefore it is hereby declared to be an emergency law, necessary  
77 for the immediate preservation of the public convenience.