HOUSE DOCKET, NO. 1843 FILED ON: 1/20/2011

HOUSE . . . . . No. 1526

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 adoption of the accompanying bill:

An Act relative to the hemophilia advisory committee.

PETITION OF:

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

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HOUSE . . . . . No. 1526

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:

SECTION 1. Chapter 111 of the General Laws is hereby amended by striking out sections 6B and 6C, as appearing in the 2008 Official Edition, and inserting in place thereof the following sections:--

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

29 (1) legislative or administrative changes to policies and programs integral to the health
30 and 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
32 development of community-based initiatives to increase the awareness of care and treatment of
33 persons living with hemophilia or other inherited bleeding and clotting disorders;

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

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

40 (5) protection and promotion of open access to any and all treatments for hemophilia and
41 other 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
45 disorders to access appropriate health insurance coverage through private or state-sponsored
46 health 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
70 than 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.