

HOUSE No. 2073

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>Christine E. Canavan</i>	<i>10th Plymouth</i>
<i>Eileen M. Donoghue</i>	<i>First Middlesex</i>
<i>James B. Eldridge</i>	<i>Middlesex and Worcester</i>
<i>Colleen M. Garry</i>	<i>36th Middlesex</i>
<i>Kay Khan</i>	<i>11th Middlesex</i>

HOUSE No. 2073

By Mr. Sánchez of Boston, a petition (accompanied by bill, House, No. 2073) of Jeffrey Sánchez and others for legislation establishing a hemophilia advisory committee. Public Health.

[SIMILAR MATTER FILED IN PREVIOUS SESSION
SEE

HOUSE
 , NO. 1526 OF 2011-2012.]

The Commonwealth of Massachusetts

In the Year Two Thousand Thirteen

An Act relative to the hemophilia advisory committee.

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

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
2 sections 6B and 6C, as appearing in the 2010 Official Edition, and inserting in place thereof the
3 following 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 commercial health insurer, established by statute; 1
18 representative of a voluntary health organization that services persons with hemophilia or other
19 bleeding and clotting disorders; 1 person with hemophilia or a caregiver thereof; 1 person with a
20 bleeding disorder other than hemophilia or a caregiver thereof; 1 person with a clotting disorder
21 or a caregiver thereof; and 1 board certified physician, licensed, practicing and treating persons
22 with hemophilia or other inherited bleeding and clotting disorders. Members of the committee
23 shall receive no compensation but may be reimbursed for actual expenses incurred in carrying
24 out their official duties. A majority of members shall constitute a quorum at any meeting held by
25 the committee.

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

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

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

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

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

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

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

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

50 (c) The department of public health may coordinate with other state agencies and private
51 organizations, through cooperative agreements with hemophilia treatment centers, medical
52 facilities, schools and nonprofit organizations that serve persons living with hemophilia or other
53 inherited bleeding and clotting disorders, in order to advance the development of
54 community-based initiatives to increase the awareness of care and treatment for persons living
55 with hemophilia or other inherited bleeding and clotting disorders. The department of public
56 health may also extend assistance to such agencies and organizations to facilitate connecting
57 persons with hemophilia or other bleeding and clotting disorders with such agencies and
58 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 financing 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 office of health & human services and
66 the director 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 section 1 of this act.

69 SECTION 3. The initial report to be filed pursuant to section 2 shall be filed not later
70 than December 31, 2014.