HOUSE . . . . . No. 3960

The Commonwealth of Massachusetts

In the Year Two Thousand Twelve

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.

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; 1 representative of a voluntary

18 health organization that services persons with hemophilia or other bleeding and clotting
19 disorders; 1 person with hemophilia or a caregiver thereof; 1 person with a bleeding disorder
20 other than hemophilia or a caregiver thereof; 1 person with a clotting disorder or a caregiver
21 thereof; and 1 board certified physician, licensed, practicing and treating persons with
22 hemophilia or other inherited bleeding and clotting disorders. Members of the committee shall
23 receive no compensation but may be reimbursed for actual expenses incurred in carrying out
24 their official duties. A majority of members shall constitute a quorum at any meeting held by the
25 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 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 community
54 –based initiatives to increase the awareness of care and treatment for persons living with
55 hemophilia or other inherited bleeding and clotting disorders. The department of public health
56 may also extend assistance to such agencies and organizations to facilitate connecting persons
57 with hemophilia or other bleeding and clotting disorders with such agencies and programs.

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

66 SECTION 2. The department of public health shall adopt such rules and regulations as
67 necessary to effectuate the purposes of section 1 of this act.

68 SECTION 3. The initial report to be filed pursuant to section 1 shall be filed not later
69 than May 30, 2013.