

SENATE No. 567

The Commonwealth of Massachusetts

In the Year Two Thousand Nine

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, as appearing in the 2006 Official
2 Edition, is hereby amended by striking sections 6A, 6B, and 6C an inserting in place thereof the
3 following:

4 Section 6A. Hemophilia Advisory Committee Act

5 The intent of the general court, through implementation of this act, is to reorganize the
6 hemophilia advisory committee to provide expert advice to the state on health and insurance
7 policies, plans, and programs that impact individuals with hemophilia and other inherited
8 bleeding and clotting disorders.

9 This act may be cited as the hemophilia advisory committee act.

10 Section 6B. Hemophilia Advisory Committee

11 The commissioner of public health, in coordination with the commissioner of insurance,
12 shall reorganize the hemophilia advisory committee to review the impact of legislation and
13 administrative actions on preserving the treatment and care of hemophilia and other inherited

14 bleeding and clotting disorders and advise on the establishment of programs for public
15 awareness, reporting and treatment of hemophilia and other inherited bleeding and clotting
16 disorders.

17 1) The hemophilia advisory committee shall advise said commissioners on:

18 A) Legislation and administrative changes to policies and programs that are integral
19 to the health and wellness of individuals with hemophilia and other inherited bleeding and
20 clotting disorders;

21 B) Coordination with other state agencies and private organizations to advance the
22 development of community-based initiatives to increase awareness of care and treatment for
23 persons living with hemophilia and other inherited bleeding and clotting disorders. The
24 department of public health may provide such services through cooperative agreements with
25 hemophilia treatment centers, medical facilities, schools, nonprofit organizations serving the
26 bleeding and clotting disorders community, or other appropriate means;

27 C) Dissemination of information on initiatives to constituency groups. The
28 department of public health may also extend assistance to the programs listed in paragraph (B)
29 above in order to facilitate linkages for persons with hemophilia or other bleeding and clotting
30 disorders;

31 D) Standards of care and treatment for persons living with hemophilia and other
32 inherited bleeding and clotting disorders, taking into consideration the federal and standards of
33 care guidelines developed by state and national organizations including, but not limited to, the
34 Medical and Scientific Advisory Council of the National Hemophilia Foundation;

35 E) Protection and promotion of open access to any and all treatments for hemophilia
36 and other bleeding and clotting disorders consistent with the standards of care set forth in
37 paragraph (D) above;

38 F) Assistance to persons living with hemophilia and other inherited bleeding and
39 clotting disorders to access appropriate health insurance coverage, whether said coverage is a
40 private or state sponsored health insurance provider;

41 G) Development of and participation in care and treatment programs for persons with
42 hemophilia and other inherited bleeding and clotting disorders, including self-administration,
43 home care, medical and dental procedures, and techniques designed to provide maximum control
44 over bleeding episodes typical in these disorders.

45 2) The commissioner of public health, in conjunction with the commissioner of
46 insurance, shall present a report to the governor and the leadership of the general court on or
47 before December 31, 2010 and annually thereafter on the status of care and treatment for persons
48 living with hemophilia and other related bleeding disorders. Said report shall include how the
49 state assisted in protecting the rights of people living with hemophilia.

50 3) The hemophilia advisory committee shall consist of eleven members. The
51 commissioner of public health and the commissioner of insurance, and/or their designees, shall
52 serve as non-voting members and as the co-chairs of the committee. The remaining members
53 shall be appointed by the governor and shall include persons who are experienced in the delivery
54 of diagnosis, treatment, care, and support services to individuals with hemophilia or related
55 bleeding disorders. Said members shall include:

56 a) One registered nurse who is licensed, practicing and currently treating individuals
57 with hemophilia or other related bleeding disorders;

58 b) One social worker who is licensed, practicing and currently treating individuals
59 with hemophilia or other related bleeding disorders;

60 c) One representative of a state based federally-funded hemophilia treatment center;

61 d) One representative of an organization established under state law for the purpose
62 of providing health insurance;

63 e) One representative of a voluntary health organization who currently services the
64 hemophilia and related bleeding disorders community;

65 f) One person, or caregiver of a person, who is living with hemophilia;

66 g) One person, or caregiver of a person, who is living with a bleeding disorder other
67 than hemophilia;

68 h) One person, or caregiver of a person, who is living with a clotting disorder, and;

69 i) One board-certified physician who is licensed, practicing, and currently treating
70 individuals with hemophilia or other related bleeding disorders.

71 4) Members of the committee shall receive no compensation, but may be reimbursed
72 for actual expenses incurred in the carrying of their duties. A majority of the members shall
73 constitute a quorum at any meeting held by the committee.

74 Section 6C. Hemophilia Advisory Committee Rules and Regulations

75 The department of public health shall promulgate all rules and regulations necessary to
76 effectuate the purposes of this section and sections 6A and 6B of this chapter.

77 SECTION 2. The act shall take effect upon its passage.