

HOUSE No. 2071

By Mr. Coughlin of Dedham, petition of Robert K. Coughlin and others relative to the Hemophilia Advisory Committee. Public Health.

The Commonwealth of Massachusetts

PETITION OF:

Robert K. Coughlin	Frank I. Smizik
William C. Galvin	Alice Hanlon Peisch
Christine E. Canavan	Jennifer M. Callahan
Richard T. Moore	James E. Timilty
Kay Khan	Geoffrey D. Hall
Kathi-Anne Reinstein	Anne M. Gobi

In the Year Two Thousand and Seven.

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
2 by striking sections 6, 6A, and 6B and inserting in place thereof the
3 following:—

4 Section 6A. Hemophilia Advisory Committee Act.

5 The general court finds that hemophilia and related bleeding dis-
6 orders are devastating health conditions that afflict many citizens of
7 the commonwealth. The general court also finds hemophilia is an
8 inherited bleeding disorder, predominantly affecting males. Hemo-
9 philia and other bleeding disorders exist when it is hard for a person
10 to stop bleeding. Although a predominately hereditary disease,
11 hemophilia and other related bleeding disorders also affect people
12 with no family history. Up to one third of all new cases have no pre-
13 vious family history of the disease. In these cases, the disease devel-
14 oped after a new or spontaneous gene mutation.

15 People living with hemophilia and other related bleeding disor-
16 ders require attentive compliance and adherence to scheduled regi-
17 mens. The appropriate care and treatment of hemophilia and other

18 related bleeding disorders is a necessity for daily life of any person
19 afflicted with these diseases. Cost of care and treatment for these
20 rare genetic disorders necessitates both private and state sponsored
21 or licensed health insurance coverage.

22 It is the opinion of the general court that hemophilia and related
23 bleeding disorders can cause serious financial, social and emotional
24 hardships for patients and their families of such a major conse-
25 quences that it is essential for the State to develop and implement
26 policies, plans and programs to guarantee continued quality of life
27 for these patients.

28 It is the intent of the general court through implementation of this
29 act to reorganize the hemophilia advisory committee to provide
30 expert advice on the patient impact of health and insurance polices
31 that impact individuals impacted by hemophilia and other related
32 bleeding disorders.

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

34 Section 6B. Hemophilia Advisory Committee.

35 The commissioner in coordination with the commissioner of
36 insurance shall appoint a hemophilia advisory committee to review
37 the impact of legislation and administrative actions in preserving the
38 treatment and care of hemophilia and related bleeding and establish
39 programs for public awareness, reporting and treatment of hemo-
40 philia and other related bleeding disorders.

41 (1) The hemophilia advisory committee shall:—

42 A) Advise the Departments on the impact of proposed legislation
43 and administrative changes to policies and programs that are integral
44 to the health and wellness of individuals with hemophilia and other
45 related bleeding disorders.

46 B) Assist in the development and institute a statewide awareness
47 initiative among health care professionals, teachers, school adminis-
48 trators, public health departments, and families including the dis-
49 semination of information and the conducting of educational
50 programs to assist in the appropriate assistance, care and treatment
51 of hemophilia and other related bleeding disorders.

52 C) Extend assistance to the programs listed in (B) in order to
53 facilitate linkages for persons with hemophilia or other related
54 bleeding disorders.

55 D) Identify standards of care and treatment for persons living with
56 hemophilia and other related bleeding disorders to protect open

57 access to any and all treatments for hemophilia and related bleeding
58 disorders.

59 E) Assist in protecting the rights of people living with hemophilia
60 and related bleeding disorders to appropriate health insurance cov-
61 erage, be it under a private or state sponsored health insurance
62 provider.

63 F) Develop or participate in the development of care and treat-
64 ment programs for such persons, including self-administration, home
65 care and medical and dental procedures and techniques designed to
66 provide maximum control over bleeding episodes typical in such
67 persons.

68 2) The commissioner may provide community based awareness
69 programs on hemophilia and other related bleeding disorders to ele-
70 vate awareness of care and treatment of persons living with hemo-
71 philia and other related bleeding disorders. The commissioner may
72 provide such services through cooperative agreements with medical
73 facilities or other appropriate means.

74 3) The commissioner in conjunction with the commissioner of
75 insurance shall present a report to the governor and the leadership of
76 the general court on or before December 1, 2007 and annually there-
77 after on the status of care and treatment for persons living with
78 hemophilia and other related bleeding disorders. Said report shall
79 include how the state assisted in protecting the rights of people
80 living with hemophilia and related bleeding disorders by protecting
81 open access to any and all treatments and obtaining appropriate
82 health insurance coverage, be it private, state sponsored or licensed
83 health insurance coverage.

84 4) The hemophilia advisory committee shall consist of the com-
85 missioner of public health and the commissioner of insurance and/or
86 their designees, who shall serve as non-voting members and shall be
87 co-chairs of the committee, and seven voting members appointed by
88 the governor. The voting members shall include persons who are
89 experienced in the delivery of diagnosis, treatment, care and support
90 services to individuals with hemophilia or related bleeding disorders.
91 The voting members shall include:—

92 a) one board-certified physician who is licensed, practicing and
93 currently treating individuals with hemophilia or other related
94 bleeding disorders;

95 b) one registered nurse who is licensed, practicing and currently
96 treating individuals with hemophilia or other related bleeding disor-
97 ders;

98 c) one social worker who is licensed, practicing and currently
99 treating individuals with hemophilia or other related bleeding disor-
100 ders;

101 d) one representative of a state based hemophilia treatment center;

102 e) one representative of an organization established under state
103 law for the purpose of providing health insurance;

104 f) one representative of a voluntary health organization who cur-
105 rently services the hemophilia and related bleeding disorders com-
106 munity; and

107 g) one patient or caregiver of a patient who is living with hemo-
108 philia or a related bleeding disorder.

109 5) Members of the committee shall receive no compensation, but
110 may be reimbursed for actual expenses incurred in the carrying out
111 of their duties. No more than a majority of the voting members may
112 be of the same political party.

113 Section 6C. Hemophilia Advisory Committee Rules and Regula-
114 tions.

115 The department shall promulgate all rules and regulations neces-
116 sary to effectuate the purposes of this section and sections six A and
117 six B of this chapter.

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