

House Bill 378

By: Representatives Jerguson of the 22nd, Allison of the 8th, Harden of the 28th, and Dutton of the 166th

A BILL TO BE ENTITLED
AN ACT

1 To amend Article 1 of Chapter 1 of Title 31 of the Official Code of Georgia Annotated,
2 relating to general provisions relative to health, so as to create the Hemophilia Advisory
3 Board; to provide for a short title; to provide for legislative findings; to provide for duties,
4 reporting, membership, and the selection of officers; to provide for related matters; to repeal
5 conflicting laws; and for other purposes.

6 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

7 **SECTION 1.**

8 This Act shall be known and may be cited as the "Hemophilia Advisory Board Act."

9 **SECTION 2.**

10 The General Assembly finds that hemophilia and other bleeding disorders are devastating
11 health conditions that can cause serious financial, social, and emotional hardships for patients
12 and their families. Hemophilia and other bleeding disorders are incurable, so appropriate
13 lifetime care and treatment are necessities for maintaining optimum health. Advancements
14 in drug therapies are allowing individuals greater latitude in managing their conditions,
15 fostering independence, and minimizing chronic complications. As a result, individuals are
16 living longer and are healthier and more productive. However, the rarity of these disorders
17 coupled with the delicate processes of producing clotting factor concentrates makes treating
18 these disorders extremely costly. It is the intent of the General Assembly to establish an
19 advisory board to provide expert advice to the state on health and insurance policies, plans,
20 and programs that impact individuals with hemophilia and other bleeding disorders.

21 **SECTION 3.**

22 Article 1 of Chapter 1 of Title 31 of the Official Code of Georgia Annotated, relating to
23 general provisions relative to health, is amended by adding a new Code section to read as
24 follows:

25 "31-1-12.

26 (a) The director of the Division of Public Health of the Department of Community Health
 27 in conjunction with the commissioner of community health shall establish an independent
 28 advisory board known as the Hemophilia Advisory Board.

29 (b)(1) The following persons shall serve as nonvoting members of the Hemophilia
 30 Advisory Board:

31 (A) The director of the Division of Public Health or a designee; and

32 (B) The commissioner of community health or a designee.

33 (2) The following voting members shall be appointed by the director of the Division of
 34 Public Health, in consultation with the commissioner, and shall serve a three-year term:

35 (A) One member who is a board certified physician licensed, practicing, and currently
 36 treating individuals with hemophilia and other bleeding disorders and who specializes
 37 in the treatment of these individuals;

38 (B) One member who is a nurse licensed, practicing, and currently treating individuals
 39 with hemophilia and other bleeding disorders;

40 (C) One member who is a social worker licensed, practicing, and currently treating
 41 individuals with hemophilia and other bleeding disorders;

42 (D) One member who is a representative of a federally funded hemophilia treatment
 43 center in this state;

44 (E) One member who is a representative of a nonprofit organization that has, as its
 45 primary purpose, the provision of services to the population of this state with
 46 hemophilia and other bleeding disorders;

47 (F) One member who is a person who has hemophilia;

48 (G) One member who is a caregiver of a person who has hemophilia; and

49 (H) One member who is a person who has a bleeding disorder other than hemophilia
 50 or who is a caregiver of a person who has a bleeding disorder other than hemophilia.

51 (3) The Hemophilia Advisory Board may also have up to five additional nonvoting
 52 members as determined appropriate by the director and the commissioner. These
 53 nonvoting members may be persons with, or caregivers of a person with, hemophilia or
 54 other bleeding disorder or persons experienced in the diagnosis, treatment, care, and
 55 support of individuals with hemophilia or other bleeding disorders.

56 (c)(1) Board members shall elect from among the voting board members a presiding
 57 officer. The presiding officer retains all voting rights.

58 (2) A majority of the members shall constitute a quorum at any meeting held by the
 59 Hemophilia Advisory Board.

60 (3) If there is a vacancy on the Hemophilia Advisory Board, such position shall be filled
 61 in the same manner as the original appointment.

62 (4) Members of the Hemophilia Advisory Board shall receive no compensation for
63 service on the Hemophilia Advisory Board.

64 (d) The Hemophilia Advisory Board shall meet at least quarterly and at the call of the
65 director, the commissioner, or the presiding officer and follow all policies and procedures
66 of Chapter 14 of Title 50, relating to open and public meetings.

67 (e) The department shall provide reasonably necessary administrative support for
68 Hemophilia Advisory Board activities.

69 (f) The Hemophilia Advisory Board shall review and make recommendations to the
70 director and the commissioner with regard to issues that affect the health and wellness of
71 persons living with hemophilia and other bleeding disorders, including, but not limited to,
72 the following:

73 (1) Proposed legislative or administrative changes to policies and programs that are
74 integral to the health and wellness of individuals with hemophilia and other bleeding
75 disorders;

76 (2) Standards of care and treatment for persons living with hemophilia and other
77 bleeding disorders, taking into consideration the federal and state standards of care
78 guidelines developed by state and national organizations, including, but not limited to,
79 the Medical and Scientific Advisory Council of the National Hemophilia Foundation;

80 (3) The development of community based initiatives to increase awareness of care and
81 treatment for persons living with hemophilia and other bleeding disorders; and

82 (4) The coordination of public and private support networking systems.

83 (g) The Hemophilia Advisory Board shall, no later than six months after the effective date
84 of this Code section, and annually thereafter, submit to the Governor and the General
85 Assembly a report of its findings and recommendations. Annually thereafter, the director
86 of the Division of Public Health, in consultation with the commissioner, shall report to the
87 Governor and the General Assembly on the status of implementing the recommendations
88 as proposed by the Hemophilia Advisory Board. The reports shall be made public and
89 shall be subject to public review and comment."

90 **SECTION 4.**

91 All laws and parts of laws in conflict with this Act are repealed.