

Senate Bill 159

By: Senators Grant of the 25th, Unterman of the 45th and Thomas of the 54th

AS PASSED SENATE

**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 as 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 provision relative to health, is amended by adding a new Code section to read as
24 follows:

25 "31-1-10.

26 (a) The director of the Division of Public Health of the Department of Human Resources
27 in conjunction with the Commissioner of Insurance shall establish an independent advisory
28 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 Insurance 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 of Insurance, and shall serve a
35 three-year term:

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

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

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

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

45 (E) One member who is a representative of an organization established under the
46 Georgia Insurance Code for the purpose of providing health insurance;

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

50 (G) One member who is a person who has hemophilia;

51 (H) One member who is a caregiver of a person who has hemophilia; and

52 (I) One member who is a person who has a bleeding disorder other than hemophilia or
53 who is a caregiver of a person who has a bleeding disorder other than hemophilia.

54 (3) The Hemophilia Advisory Board may also have up to five additional nonvoting
55 members as determined appropriate by the director and the Commissioner of Insurance.

56 These nonvoting members may be persons with, or caregivers of a person with,
57 hemophilia or other bleeding disorder or persons experienced in the diagnosis, treatment,
58 care, and support of individuals with hemophilia or other bleeding disorders.

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

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

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

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

67 (d) The Hemophilia Advisory Board shall meet at least quarterly and at the call of the
68 director or the Commissioner of Insurance or the presiding officer and follow all policies
69 and procedures of Code Sections 50-14-1 through 50-14-6, relating to open and public
70 meetings.

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

73 (f) The Hemophilia Advisory Board shall review and make recommendations to the
74 director and the Commissioner of Insurance with regard to issues that affect the health and
75 wellness of persons living with hemophilia and other bleeding disorders, including, but not
76 limited to, the following:

77 (1) Proposed legislative or administrative changes to policies and programs that are
78 integral to the health and wellness of individuals with hemophilia and other bleeding
79 disorders, including access to appropriate health insurance or similar health coverage;

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

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

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

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

94 **SECTION 4.**

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