

The House Committee on Health and Human Services offers the following substitute to HB 378:

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
5 provide for contingent effective dates and automatic repeal; to repeal conflicting laws; and
6 for other purposes.

7 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

PART I

SECTION 1-1.

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

SECTION 1-2.

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

23 **PART II**

24 **SECTION 2-1.**

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

28 "31-1-12.

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

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

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

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

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

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

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

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

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

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

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

52 (H) One member who is a person who has a bleeding disorder other than hemophilia
 53 or 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. These
 56 nonvoting members may be persons with, or caregivers of a person with, hemophilia or
 57 other bleeding disorder or persons experienced in the diagnosis, treatment, care, and
 58 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, the commissioner, or the presiding officer and follow all policies and procedures
69 of Chapter 14 of Title 50, relating to open and public meetings.
- 70 (e) The department shall provide reasonably necessary administrative support for
71 Hemophilia Advisory Board activities.
- 72 (f) The Hemophilia Advisory Board shall review and make recommendations to the
73 director and the commissioner with regard to issues that affect the health and wellness of
74 persons living with hemophilia and other bleeding disorders, including, but not limited to,
75 the following:
- 76 (1) Proposed legislative or administrative changes to policies and programs that are
77 integral to the health and wellness of individuals with hemophilia and other bleeding
78 disorders;
- 79 (2) Standards of care and treatment for persons living with hemophilia and other
80 bleeding disorders, taking into consideration the federal and state standards of care
81 guidelines developed by state and national organizations, including, but not limited to,
82 the Medical and Scientific Advisory Council of the National Hemophilia Foundation;
- 83 (3) The development of community based initiatives to increase awareness of care and
84 treatment for persons living with hemophilia and other bleeding disorders; and
- 85 (4) The coordination of public and private support networking systems.
- 86 (g) The Hemophilia Advisory Board shall, no later than six months after the effective date
87 of this Code section, and annually thereafter, submit to the Governor and the General
88 Assembly a report of its findings and recommendations. Annually thereafter, the director
89 of the Division of Public Health, in consultation with the commissioner, shall report to the
90 Governor and the General Assembly on the status of implementing the recommendations
91 as proposed by the Hemophilia Advisory Board. The reports shall be made public and
92 shall be subject to public review and comment."

93 **PART III**

94 **SECTION 3-1.**

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

98 "31-1-12.

99 (a) The commissioner of public health in conjunction with the commissioner of
100 community health shall establish an independent advisory board known as the Hemophilia
101 Advisory Board.

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

104 (A) The commissioner of public health or a designee; and

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

106 (2) The following voting members shall be appointed by the commissioner of public
107 health, in consultation with the commissioner of community health, and shall serve a
108 three-year term:

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

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

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

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

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

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

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

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

125 (3) The Hemophilia Advisory Board may also have up to five additional nonvoting
126 members as determined appropriate by the commissioner and the commissioner of
127 community health. These nonvoting members may be persons with, or caregivers of a
128 person with, hemophilia or other bleeding disorder or persons experienced in the

129 diagnosis, treatment, care, and support of individuals with hemophilia or other bleeding
 130 disorders.

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

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

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

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

139 (d) The Hemophilia Advisory Board shall meet at least quarterly and at the call of the
 140 commissioner, the commissioner of community health, or the presiding officer and follow
 141 all policies and procedures of Chapter 14 of Title 50, relating to open and public meetings.

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

144 (f) The Hemophilia Advisory Board shall review and make recommendations to the
 145 commissioner and the commissioner of community health with regard to issues that affect
 146 the health and wellness of persons living with hemophilia and other bleeding disorders,
 147 including, but not limited to, the following:

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

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

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

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

158 (g) The Hemophilia Advisory Board shall, no later than six months after the effective date
 159 of this Code section, and annually thereafter, submit to the Governor and the General
 160 Assembly a report of its findings and recommendations. Annually thereafter, the
 161 commissioner of public health, in consultation with the commissioner of community health,
 162 shall report to the Governor and the General Assembly on the status of implementing the
 163 recommendations as proposed by the Hemophilia Advisory Board. The reports shall be
 164 made public and shall be subject to public review and comment."

165

PART IV

166

SECTION 4-1.

167 (a) This Act shall become effective July 1, 2011, except as provided by subsection (b) of this
168 section.

169 (b) Part III of this Act shall become effective on July 1, 2011, only if HB 214 or similar Act
170 creating the Department of Public Health is enacted at the 2011 regular session of the
171 General Assembly and becomes law on July 1, 2011, in which event Part II of this Act shall
172 not become effective and shall stand repealed on that date. If such Act does not become law,
173 Part III of this Act shall not become effective and shall stand repealed on July 1, 2011.

174

SECTION 4-2.

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