

Senate File 548 - Enrolled

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1 1 SENATE FILE 548
1 2
1 3 AN ACT
1 4 CREATING A HEMOPHILIA ADVISORY COMMITTEE AND PROVIDING A
1 5 CONTINGENT EFFECTIVE DATE.
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1 7 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:
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1 9 Section 1. NEW SECTION. 135N.1 SHORT TITLE.
1 10 This chapter shall be known and may be cited as the
1 11 "Hemophilia Advisory Committee Act".
1 12 Sec. 2. NEW SECTION. 135N.2 LEGISLATIVE INTENT AND
1 13 FINDINGS.
1 14 1. It is the intent of the general assembly to establish
1 15 an advisory committee to provide recommendations on
1 16 cost-effective treatment programs that enhance the quality of
1 17 life of those afflicted with hemophilia and contain the high
1 18 cost of that treatment.
1 19 2. The general assembly finds inherited hemophilia and
1 20 other bleeding and clotting disorders are devastating health
1 21 conditions that can cause serious financial, social, and
1 22 emotional hardships for patients and their families.
1 23 Hemophilia and other bleeding and clotting disorders are
1 24 incurable, so appropriate lifetime care and treatment are
1 25 necessities for maintaining optimum health. Advancements in
1 26 drug therapies are allowing individuals greater latitude in
1 27 managing their conditions, fostering independence, and
1 28 minimizing chronic complications. However, the rarity of
1 29 these disorders coupled with the delicate processes for
1 30 producing factors and administering anticoagulants makes
1 31 treating these disorders extremely costly.
1 32 Sec. 3. NEW SECTION. 135N.3 ESTABLISHMENT AND DUTIES OF
1 33 HEMOPHILIA ADVISORY COMMITTEE.
1 34 1. The director of the department of public health shall
1 35 establish an advisory committee known as the hemophilia
2 1 advisory committee.
2 2 2. The committee shall review and make recommendations to
2 3 the director concerning but not limited to the following:
2 4 a. Proposed legislative or administrative changes to
2 5 policies and programs that are integral to the health and
2 6 wellness of individuals with hemophilia and other bleeding and
2 7 clotting disorders.
2 8 b. Standards of care and treatment for persons living with
2 9 hemophilia and other bleeding and clotting disorders.
2 10 c. The development of community-based initiatives to
2 11 increase awareness of care and treatment for persons living
2 12 with hemophilia and other bleeding and clotting disorders.
2 13 d. Facilitating communication and cooperation between
2 14 persons with hemophilia and other bleeding and clotting
2 15 disorders.

2 16 Sec. 4. NEW SECTION. 135N.4 MEMBERSHIP.

2 17 1. The following persons shall serve as nonvoting members
2 18 of the committee:

2 19 a. The director of public health or a designee.

2 20 b. The director of the department of human services or a
2 21 designee.

2 22 c. The commissioner of insurance or a designee.

2 23 2. The following voting members shall be appointed by the
2 24 director, serving three-year terms:

2 25 a. One member who is a board-certified physician licensed,
2 26 practicing, and currently treating individuals with hemophilia
2 27 or other bleeding and clotting disorders.

2 28 b. One member who is a nurse licensed, practicing, and
2 29 currently treating individuals with hemophilia or other
2 30 bleeding and clotting disorders.

2 31 c. One member who is a social worker licensed, practicing,
2 32 and currently treating individuals with hemophilia or other
2 33 bleeding and clotting disorders.

2 34 d. One member who is a representative of a
2 35 federally-funded hemophilia treatment center.

3 1 e. One member who is a representative of an organization
3 2 established under the Iowa insurance code for the purpose of
3 3 providing health insurance.

3 4 f. One member who is a representative of a voluntary
3 5 health organization who currently services the hemophilia and
3 6 other bleeding and clotting disorders community.

3 7 g. One member who is a patient, or caregiver of a patient,
3 8 with hemophilia.

3 9 h. One member who is a patient, or caregiver of a patient,
3 10 with a bleeding disorder other than hemophilia.

3 11 i. One member who is a patient, or caregiver of a patient,
3 12 with a clotting disorder.

3 13 3. At least one of the appointments made pursuant to
3 14 subsection 2, paragraphs "g", "h", and "i" shall be a patient
3 15 with hemophilia, a bleeding disorder that is not hemophilia,
3 16 or a clotting disorder. The committee appointments may be
3 17 made notwithstanding sections 69.16 and 69.16A.

3 18 4. If there is a vacancy on the committee, such position
3 19 shall be filled in the same manner as the original
3 20 appointment.

3 21 Sec. 5. NEW SECTION. 135N.5 MEETINGS.

3 22 1. The committee shall meet no less than four times per
3 23 year and is subject to chapters 20 and 21 relating to open
3 24 meetings and public records.

3 25 2. Members of the committee shall receive no compensation,
3 26 but may be reimbursed for actual expenses incurred in the
3 27 carrying out of their duties.

3 28 Sec. 6. NEW SECTION. 135N.6 REPORT REQUIRED.

3 29 The committee shall, by January 15, 2008, and annually
3 30 thereafter, submit to the governor and the general assembly a
3 31 report with recommendations for maintaining and improving
3 32 access to care for individuals with hemophilia and other
3 33 bleeding and clotting disorders. Subsequent annual reports
3 34 shall report on the status of implementing the recommendations
3 35 as proposed by the committee and on any state and national
4 1 activities with regard to hemophilia and other bleeding and
4 2 clotting disorders.

4 3 Sec. 7. CONTINGENT EFFECTIVE DATE. This Act, being deemed
4 4 of immediate importance, takes effect upon enactment only if
4 5 an appropriation is made for the purposes of this Act.

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JOHN P. KIBBIE
President of the Senate

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PATRICK J. MURPHY
Speaker of the House

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4 17 I hereby certify that this bill originated in the Senate and
4 18 is known as Senate File 548, Eighty-second General Assembly.

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MICHAEL E. MARSHALL
Secretary of the Senate

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4 24 Approved _____, 2007

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4 28 CHESTER J. CULVER

4 29 Governor