

Senate Study Bill 1294

SENATE FILE _____
BY (PROPOSED COMMITTEE ON
HUMAN RESOURCES BILL BY
CHAIRPERSON RAGAN)

Passed Senate, Date _____ Passed House, Date _____
Vote: Ayes _____ Nays _____ Vote: Ayes _____ Nays _____
Approved _____

A BILL FOR

1 An Act creating a hemophilia advisory committee and providing an
2 effective date.
3 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:
4 TLSB 2808SC 82
5 jr/es/88

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

2 19 or other bleeding and clotting disorders.
2 20 b. One member who is a nurse licensed, practicing, and
2 21 currently treating individuals with hemophilia or other
2 22 bleeding and clotting disorders.
2 23 c. One member who is a social worker licensed, practicing,
2 24 and currently treating individuals with hemophilia or other
2 25 bleeding and clotting disorders.
2 26 d. One member who is a representative of a
2 27 federally-funded hemophilia treatment center.
2 28 e. One member who is a representative of an organization
2 29 established under the Iowa insurance code for the purpose of
2 30 providing health insurance.
2 31 f. One member who is a representative of a voluntary
2 32 health organization who currently services the hemophilia and
2 33 other bleeding and clotting disorders community.
2 34 g. One member who is a patient, or caregiver of a patient,
2 35 with hemophilia.
3 1 h. One member who is a patient, or caregiver of a patient,
3 2 with a bleeding disorder other than hemophilia.
3 3 i. One member who is a patient, or caregiver of a patient,
3 4 with a clotting disorder.
3 5 3. The committee appointments may be made notwithstanding
3 6 sections 69.16 and 69.16A.
3 7 4. If there is a vacancy on the committee, such position
3 8 shall be filled in the same manner as the original
3 9 appointment.

3 10 Sec. 5. NEW SECTION. 135N.5 MEETINGS.
3 11 1. The committee shall meet no less than four times per
3 12 year and is subject to chapters 20 and 21 relating to open
3 13 meetings and public records.
3 14 2. Members of the committee shall receive no compensation,
3 15 but may be reimbursed for actual expenses incurred in the
3 16 carrying out of their duties.

3 17 Sec. 6. NEW SECTION. 135N.6 REPORT REQUIRED.
3 18 The committee shall, by January 15, 2008, and annually
3 19 thereafter, submit to the governor and the general assembly a
3 20 report with recommendations for maintaining and improving
3 21 access to care for individuals with hemophilia and other
3 22 bleeding and clotting disorders. Subsequent annual reports
3 23 shall report on the status of implementing the recommendations
3 24 as proposed by the committee and on any state and national
3 25 activities with regard to hemophilia and other bleeding and
3 26 clotting disorders.

3 27 Sec. 7. EFFECTIVE DATE. This Act, being deemed of
3 28 immediate importance, takes effect upon enactment.

3 29 EXPLANATION

3 30 This bill creates a hemophilia advisory committee within
3 31 the department of public health. The committee may advise the
3 32 director of public health on a variety of matters, including
3 33 proposed legislative or administrative changes relating to
3 34 hemophilia, standards of care and treatment, the development
3 35 of community-based initiatives to increase awareness of care
4 1 and treatment for persons living with hemophilia and other
4 2 bleeding and clotting disorders, and facilitating linkages for
4 3 persons with hemophilia and other bleeding and clotting
4 4 disorders.

4 5 The committee has 12 members, with the director of public
4 6 health, the director of the department of human services, and
4 7 the commissioner of insurance, or their designees, serving as
4 8 nonvoting members. The director of public health will appoint
4 9 nine voting members representing a variety of stakeholder
4 10 interests.

4 11 The bill has an immediate effective date.

4 12 LSB 2808SC 82

4 13 jr:nh/es/88