

**CHAPTER 31**

## HEMOPHILIA ADVISORY COMMITTEE

S.F. 548

**AN ACT** creating a hemophilia advisory committee and providing a contingent effective date.

*Be It Enacted by the General Assembly of the State of Iowa:*

Section 1. NEW SECTION. 135N.1 SHORT TITLE.

This chapter shall be known and may be cited as the “Hemophilia Advisory Committee Act”.

Sec. 2. NEW SECTION. 135N.2 LEGISLATIVE INTENT AND FINDINGS.

1. It is the intent of the general assembly to establish an advisory committee to provide recommendations on cost-effective treatment programs that enhance the quality of life of those afflicted with hemophilia and contain the high cost of that treatment.

2. The general assembly finds inherited hemophilia and other bleeding and clotting disorders are devastating health conditions that can cause serious financial, social, and emotional hardships for patients and their families. Hemophilia and other bleeding and clotting disorders are incurable, so appropriate lifetime care and treatment are necessities for maintaining optimum health. Advancements in drug therapies are allowing individuals greater latitude in managing their conditions, fostering independence, and minimizing chronic complications. However, the rarity of these disorders coupled with the delicate processes for producing factors and administering anticoagulants makes treating these disorders extremely costly.

Sec. 3. NEW SECTION. 135N.3 ESTABLISHMENT AND DUTIES OF HEMOPHILIA ADVISORY COMMITTEE.

1. The director of the department of public health shall establish an advisory committee known as the hemophilia advisory committee.

2. The committee shall review and make recommendations to the director concerning but not limited to the following:

a. Proposed legislative or administrative changes to policies and programs that are integral to the health and wellness of individuals with hemophilia and other bleeding and clotting disorders.

b. Standards of care and treatment for persons living with hemophilia and other bleeding and clotting disorders.

c. The development of community-based initiatives to increase awareness of care and treatment for persons living with hemophilia and other bleeding and clotting disorders.

d. Facilitating communication and cooperation between persons with hemophilia and other bleeding and clotting disorders.

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

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

a. The director of public health or a designee.

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

c. The commissioner of insurance or a designee.

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

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

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

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

- d. One member who is a representative of a federally-funded hemophilia treatment center.
  - e. One member who is a representative of an organization established under the Iowa insurance code for the purpose of providing health insurance.
  - f. One member who is a representative of a voluntary health organization who currently services the hemophilia and other bleeding and clotting disorders community.
  - g. One member who is a patient, or caregiver of a patient, with hemophilia.
  - h. One member who is a patient, or caregiver of a patient, with a bleeding disorder other than hemophilia.
  - i. One member who is a patient, or caregiver of a patient, with a clotting disorder.
3. At least one of the appointments made pursuant to subsection 2, paragraphs “g”, “h”, and “i” shall be a patient with hemophilia, a bleeding disorder that is not hemophilia, or a clotting disorder. The committee appointments may be made notwithstanding sections 69.16 and 69.16A.
  4. If there is a vacancy on the committee, such position shall be filled in the same manner as the original appointment.

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

1. The committee shall meet no less than four times per year and is subject to chapters 20 and 21 relating to open meetings and public records.
2. Members of the committee shall receive no compensation, but may be reimbursed for actual expenses incurred in the carrying out of their duties.

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

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

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

Approved March 30, 2007

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## CHAPTER 32

### STATEWIDE STUDENT INFORMATION SYSTEM — STUDY

H.F. 468

**AN ACT** requiring a study by the department of education relating to implementation of a statewide student information system.

*Be It Enacted by the General Assembly of the State of Iowa:*

Section 1. STATEWIDE STUDENT INFORMATION SYSTEM — STUDY. The department shall conduct a study regarding the student information systems currently in use in the state, the types of data collected, and the future needs for additional types of data at the kinder-