

AN ACT concerning State government.

**Be it enacted by the People of the State of Illinois,  
represented in the General Assembly:**

Section 5. The Hemophilia Care Act is amended by changing Section 2.5 as follows:

(410 ILCS 420/2.5)

Sec. 2.5. Hemophilia Advisory Review Board.

(a) The Director of Healthcare and Family Services ~~Public Health~~ in collaboration and in consultation with the Director of Insurance, shall establish an independent advisory board known as the Hemophilia Advisory Review Board. The Board shall review, may comment upon, and make recommendations to the Directors with regard to, but not limited to the following:

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

(2) Standards of care and treatment for persons living with hemophilia and other bleeding disorders. In examining standards of care, the Board shall protect open access to any and all treatments for hemophilia and other bleeding disorders, in accordance with federal guidelines and standards of care guidelines developed by the Medical and

Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF), an internationally recognized body whose guidelines set the standards of care for hemophilia and other bleeding disorders around the world.

(3) The development of community-based initiatives to increase awareness of care and treatment for persons living with hemophilia and other bleeding disorders. The Department of Healthcare and Family Services ~~Health~~ may provide such services through cooperative agreements with Hemophilia Treatment Centers, medical facilities, schools, nonprofit organizations servicing the bleeding disorder community, or other appropriate means.

(4) Facilitating linkages for persons with hemophilia and other bleeding disorders.

(5) Protecting the rights of people living with hemophilia and other bleeding disorders to appropriate health insurance coverage be it under a private or State-sponsored health insurance provider.

(b) The Board shall consist of the Director of Healthcare and Family Services and the Director of Insurance or their designee, who shall serve as non-voting members, and 7 voting members appointed by the Governor in consultation and in collaboration with the Directors. The voting members shall be selected from among the following member groups:

(1) one board-certified physician licensed, practicing and currently treating individuals with hemophilia or

other bleeding disorders;

(2) one nurse licensed, practicing and currently treating individuals with hemophilia or other bleeding disorders;

(3) one social worker licensed, practicing and currently treating individuals with hemophilia or other bleeding disorders;

(4) one representative of a federally funded Hemophilia Treatment Center;

(5) one representative of an organization established under the Illinois Insurance Code for the purpose of providing health insurance;

(6) one representative of a voluntary health organization that currently services the hemophilia and other bleeding disorders community; and

(7) one patient or caregiver of a patient with hemophilia or other bleeding disorder.

The Board may also have up to 5 additional nonvoting members as determined appropriate by the Directors. Nonvoting members may be persons with or caregivers of a patient with hemophilia or a bleeding disorder other than hemophilia or persons experienced in the diagnosis, treatment, care, and support of individuals with hemophilia or other bleeding disorders.

~~No more than a majority of the voting members may be of the same political party.~~ Members of the Board shall elect one of its members to act as chair for a term of 3 years. The chair

shall retain all voting rights. If there is a vacancy on the Board, such position may be filled in the same manner as the original appointment. Members of the Board shall receive no compensation, but may be reimbursed for actual expenses incurred in the carrying out of their duties. The Board shall meet no less than 4 times per year and follow all policies and procedures of the State of Illinois Open Meetings Law.

(c) No later than 6 months after the date of enactment of this amendatory Act, the Board shall submit to the Governor and the General Assembly a report with recommendations for maintaining access to care and obtaining appropriate health insurance coverage for individuals with hemophilia and other bleeding disorders. The report shall be subject to public review and comment prior to adoption. No later than 6 months after adoption by the Governor and Legislature and annually thereafter, the Director of Healthcare and Family Services shall issue a report, which shall be made available to the public, on the status of implementing the recommendations as proposed by the Board and on any state and national activities with regard to hemophilia and other bleeding disorders.

(Source: P.A. 95-12, eff. 7-2-07; revised 10-23-08.)

Section 99. Effective date. This Act takes effect upon becoming law.