

1 AN ACT concerning State government.

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

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

6 (410 ILCS 420/2.5)

7 Sec. 2.5. Hemophilia Advisory Review Board.

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

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

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

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

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

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

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

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

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

1 other bleeding disorders;

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

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

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

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

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

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

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

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

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

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

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

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