

1 AN ACT concerning public health.

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 1 and by adding Sections 1.5 and 2.5 as follows:

6 (410 ILCS 420/1) (from Ch. 111 1/2, par. 2901)

7 Sec. 1. Definitions. As used in this Act, unless the  
8 context clearly requires otherwise:

9 (1) "Department" means the ~~Illinois~~ Department of  
10 Healthcare and Family Services ~~Public Aid~~.

11 (1.5) "Director" means the Director of Healthcare and  
12 Family Services and the Director of Insurance ~~Public Aid~~.

13 (2) (Blank).

14 (3) "Hemophilia" means a bleeding tendency resulting from a  
15 genetically determined deficiency in the blood.

16 (4) (Blank). ~~"Committee" means the Hemophilia Advisory~~  
17 ~~Committee created under this Act.~~

18 (5) "Eligible person" means any resident of the State  
19 suffering from hemophilia.

20 (6) "Family" means:

21 (a) In the case of a patient who is a dependent of  
22 another person or couple as defined by the Illinois Income  
23 Tax Act, all those persons for whom exemption is claimed in

1 the State income tax return of the person or couple whose  
2 dependent the eligible person is, and

3 (b) In all other cases, all those persons for whom  
4 exemption is claimed in the State income tax return of the  
5 eligible person, or of the eligible person and his spouse.

6 (7) "Eligible cost of hemophilia services" means the cost  
7 of blood transfusions, blood derivatives, and for outpatient  
8 services, of physician charges, medical supplies, and  
9 appliances, used in the treatment of eligible persons for  
10 hemophilia, plus one half of the cost of hospital inpatient  
11 care, minus any amount of such cost which is eligible for  
12 payment or reimbursement by any hospital or medical insurance  
13 program, by any other government medical or financial  
14 assistance program, or by any charitable assistance program.

15 (8) "Gross income" means the base income for State income  
16 tax purposes of all members of the family.

17 (9) "Available family income" means the lesser of:

18 (a) Gross income minus the sum of (1) \$5,500, and (2)  
19 \$3,500 times the number of persons in the family, or

20 (b) One half of gross income.

21 (10) "Board" means the Hemophilia Advisory Review Board.

22 (Source: P.A. 89-507, eff. 7-1-97; 90-587, eff. 7-1-98; revised  
23 12-15-05.)

24 (410 ILCS 420/1.5 new)

25 Sec. 1.5. Findings. The General Assembly finds all of the

1 following:

2 (1) Inherited hemophilia and other bleeding disorders  
3 are devastating health conditions that can cause serious  
4 financial, social, and emotional hardships for patients  
5 and their families. Hemophilia, which occurs predominantly  
6 in males, is a rare but well-known type of inherited  
7 bleeding disorder in which one of several proteins normally  
8 found in blood are either deficient or inactive, and  
9 causing pain, swelling, and permanent damage to joints and  
10 muscles. The disorder affects Americans of all racial and  
11 ethnic backgrounds. In about one-third of all cases, there  
12 is no known family history of the disorder. In these cases,  
13 the disease developed after a new or spontaneous gene  
14 mutation.

15 (2) Hemophilia is one of a spectrum of devastating  
16 chronic bleeding disorders impacting Americans. Von  
17 Willebrand Disease, another type of bleeding disorder, is  
18 caused by a deficiency on the von Willebrand protein.  
19 Persons with the disorder often bruise easily, have  
20 frequent nosebleeds, or bleed after tooth extraction,  
21 tonsillectomy, or other surgery. In some instances, women  
22 will have prolonged menstrual bleeding. The disorder  
23 occurs in about 1% to 2% of the U.S. population.

24 (3) Appropriate care and treatment are necessities for  
25 maintaining optimum health for persons afflicted with  
26 hemophilia and other bleeding disorders.

1           (4) While hemophilia and other bleeding disorders are  
2           incurable, advancements in drug therapies are allowing  
3           individuals greater latitude in managing their conditions,  
4           fostering independence, and minimizing chronic  
5           complications such as damage to the joints and muscles,  
6           blood-transmitted infectious diseases, and chronic liver  
7           diseases. At the same time, treatment for clotting  
8           disorders is saving more and more lives. The rarity of  
9           these disorders coupled with the delicate processes for  
10           producing factors, however, makes treating these disorders  
11           extremely costly. As a result, insurance coverage is a  
12           major concern for patients and their families.

13           (5) It is thus the intent of the General Assembly  
14           through implementation of this Act to establish an advisory  
15           board to provide expert advice to the State on health and  
16           insurance policies, plans, and public health programs that  
17           impact individuals with hemophilia and other bleeding  
18           disorders.

19           (410 ILCS 420/2.5 new)

20           Sec. 2.5. Hemophilia Advisory Review Board.

21           (a) The Director of Public Health in collaboration and in  
22           consultation with the Director of Insurance, shall establish an  
23           independent advisory board known as the Hemophilia Advisory  
24           Review Board. The Board shall review, may comment upon, and  
25           make recommendations to the Directors with regard to, but not

1 limited to the following:

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

6 (2) Standards of care and treatment for persons living  
7 with hemophilia and other bleeding disorders. In examining  
8 standards of care, the Board shall protect open access to  
9 any and all treatments for hemophilia and other bleeding  
10 disorders, in accordance with federal guidelines and  
11 standards of care guidelines developed by the Medical and  
12 Scientific Advisory Council (MASAC) of National Hemophilia  
13 Foundation (NHF), an internationally recognized body whose  
14 guidelines set the standards of care for hemophilia and  
15 other bleeding disorders around the world.

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

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

26 (5) Protecting the rights of people living with

1 hemophilia and other bleeding disorders to appropriate  
2 health insurance coverage be it under a private or  
3 State-sponsored health insurance provider.

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

10 (1) one board-certified physician licensed, practicing  
11 and currently treating individuals with hemophilia or  
12 other bleeding disorders;

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

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

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

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

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

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

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

9           No more than a majority of the voting members may be of the  
10          same political party. Members of the Board shall elect one of  
11          its members to act as chair for a term of 3 years. The chair  
12          shall retain all voting rights. If there is a vacancy on the  
13          Board, such position may be filled in the same manner as the  
14          original appointment. Members of the Board shall receive no  
15          compensation, but may be reimbursed for actual expenses  
16          incurred in the carrying out of their duties. The Board shall  
17          meet no less than 4 times per year and follow all policies and  
18          procedures of the State of Illinois Open Meetings Law.

19          (c) No later than 6 months after the date of enactment of  
20          this amendatory Act, the Board shall submit to the Governor and  
21          the General Assembly a report with recommendations for  
22          maintaining access to care and obtaining appropriate health  
23          insurance coverage for individuals with hemophilia and other  
24          bleeding disorders. The report shall be subject to public  
25          review and comment prior to adoption. No later than 6 months  
26          after adoption by the Governor and Legislature and annually

1 thereafter, the Director of Healthcare and Family Services  
2 shall issue a report, which shall be made available to the  
3 public, on the status of implementing the recommendations as  
4 proposed by the Board and on any state and national activities  
5 with regard to hemophilia and other bleeding disorders.

6 (410 ILCS 420/4 rep.)

7 Section 10. The Hemophilia Care Act is amended by repealing  
8 Section 4.