



Rep. Joseph M. Lyons

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1 AMENDMENT TO SENATE BILL 397

2 AMENDMENT NO. _____. Amend Senate Bill 397 by replacing
3 everything after the enacting clause with the following:

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

1 disorders.

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

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

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

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

26 (b) The Board shall consist of the Director of Healthcare

1 and Family Services and the Director of Insurance or their
2 designee, who shall serve as non-voting members, and 7 voting
3 members appointed by the Governor in consultation and in
4 collaboration with the Directors. The voting members shall be
5 selected from among the following member groups:

6 (1) one board-certified physician licensed, practicing
7 and currently treating individuals with hemophilia or
8 other bleeding disorders;

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

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

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

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

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

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

25 The Board may also have up to 5 additional nonvoting members as
26 determined appropriate by the Directors. Nonvoting members may

1 be persons with or caregivers of a patient with hemophilia or a
2 bleeding disorder other than hemophilia or persons experienced
3 in the diagnosis, treatment, care, and support of individuals
4 with hemophilia or other bleeding disorders.

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

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

1 with regard to hemophilia and other bleeding disorders.

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

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