



Rep. Gary Hannig

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1 AMENDMENT TO SENATE BILL 1580

2 AMENDMENT NO. _____. Amend Senate Bill 1580 by replacing
3 everything after the enacting clause with the following:

4 "Section 1. Short title. This Act may be cited as the
5 FY2008 Budget Implementation (Human Services) Act.

6 Section 5. Purpose. It is the purpose of this Act to
7 implement the Governor's FY2008 budget recommendations
8 concerning human services.

9 Section 10. The Illinois Administrative Procedure Act is
10 amended by changing Section 5-45 as follows:

11 (5 ILCS 100/5-45) (from Ch. 127, par. 1005-45)

12 Sec. 5-45. Emergency rulemaking.

13 (a) "Emergency" means the existence of any situation that
14 any agency finds reasonably constitutes a threat to the public

1 interest, safety, or welfare.

2 (b) If any agency finds that an emergency exists that
3 requires adoption of a rule upon fewer days than is required by
4 Section 5-40 and states in writing its reasons for that
5 finding, the agency may adopt an emergency rule without prior
6 notice or hearing upon filing a notice of emergency rulemaking
7 with the Secretary of State under Section 5-70. The notice
8 shall include the text of the emergency rule and shall be
9 published in the Illinois Register. Consent orders or other
10 court orders adopting settlements negotiated by an agency may
11 be adopted under this Section. Subject to applicable
12 constitutional or statutory provisions, an emergency rule
13 becomes effective immediately upon filing under Section 5-65 or
14 at a stated date less than 10 days thereafter. The agency's
15 finding and a statement of the specific reasons for the finding
16 shall be filed with the rule. The agency shall take reasonable
17 and appropriate measures to make emergency rules known to the
18 persons who may be affected by them.

19 (c) An emergency rule may be effective for a period of not
20 longer than 150 days, but the agency's authority to adopt an
21 identical rule under Section 5-40 is not precluded. No
22 emergency rule may be adopted more than once in any 24 month
23 period, except that this limitation on the number of emergency
24 rules that may be adopted in a 24 month period does not apply
25 to (i) emergency rules that make additions to and deletions
26 from the Drug Manual under Section 5-5.16 of the Illinois

1 Public Aid Code or the generic drug formulary under Section
2 3.14 of the Illinois Food, Drug and Cosmetic Act, (ii)
3 emergency rules adopted by the Pollution Control Board before
4 July 1, 1997 to implement portions of the Livestock Management
5 Facilities Act, or (iii) emergency rules adopted by the
6 Illinois Department of Public Health under subsections (a)
7 through (i) of Section 2 of the Department of Public Health Act
8 when necessary to protect the public's health. Two or more
9 emergency rules having substantially the same purpose and
10 effect shall be deemed to be a single rule for purposes of this
11 Section.

12 (d) In order to provide for the expeditious and timely
13 implementation of the State's fiscal year 1999 budget,
14 emergency rules to implement any provision of Public Act 90-587
15 or 90-588 or any other budget initiative for fiscal year 1999
16 may be adopted in accordance with this Section by the agency
17 charged with administering that provision or initiative,
18 except that the 24-month limitation on the adoption of
19 emergency rules and the provisions of Sections 5-115 and 5-125
20 do not apply to rules adopted under this subsection (d). The
21 adoption of emergency rules authorized by this subsection (d)
22 shall be deemed to be necessary for the public interest,
23 safety, and welfare.

24 (e) In order to provide for the expeditious and timely
25 implementation of the State's fiscal year 2000 budget,
26 emergency rules to implement any provision of this amendatory

1 Act of the 91st General Assembly or any other budget initiative
2 for fiscal year 2000 may be adopted in accordance with this
3 Section by the agency charged with administering that provision
4 or initiative, except that the 24-month limitation on the
5 adoption of emergency rules and the provisions of Sections
6 5-115 and 5-125 do not apply to rules adopted under this
7 subsection (e). The adoption of emergency rules authorized by
8 this subsection (e) shall be deemed to be necessary for the
9 public interest, safety, and welfare.

10 (f) In order to provide for the expeditious and timely
11 implementation of the State's fiscal year 2001 budget,
12 emergency rules to implement any provision of this amendatory
13 Act of the 91st General Assembly or any other budget initiative
14 for fiscal year 2001 may be adopted in accordance with this
15 Section by the agency charged with administering that provision
16 or initiative, except that the 24-month limitation on the
17 adoption of emergency rules and the provisions of Sections
18 5-115 and 5-125 do not apply to rules adopted under this
19 subsection (f). The adoption of emergency rules authorized by
20 this subsection (f) shall be deemed to be necessary for the
21 public interest, safety, and welfare.

22 (g) In order to provide for the expeditious and timely
23 implementation of the State's fiscal year 2002 budget,
24 emergency rules to implement any provision of this amendatory
25 Act of the 92nd General Assembly or any other budget initiative
26 for fiscal year 2002 may be adopted in accordance with this

1 Section by the agency charged with administering that provision
2 or initiative, except that the 24-month limitation on the
3 adoption of emergency rules and the provisions of Sections
4 5-115 and 5-125 do not apply to rules adopted under this
5 subsection (g). The adoption of emergency rules authorized by
6 this subsection (g) shall be deemed to be necessary for the
7 public interest, safety, and welfare.

8 (h) In order to provide for the expeditious and timely
9 implementation of the State's fiscal year 2003 budget,
10 emergency rules to implement any provision of this amendatory
11 Act of the 92nd General Assembly or any other budget initiative
12 for fiscal year 2003 may be adopted in accordance with this
13 Section by the agency charged with administering that provision
14 or initiative, except that the 24-month limitation on the
15 adoption of emergency rules and the provisions of Sections
16 5-115 and 5-125 do not apply to rules adopted under this
17 subsection (h). The adoption of emergency rules authorized by
18 this subsection (h) shall be deemed to be necessary for the
19 public interest, safety, and welfare.

20 (i) In order to provide for the expeditious and timely
21 implementation of the State's fiscal year 2004 budget,
22 emergency rules to implement any provision of this amendatory
23 Act of the 93rd General Assembly or any other budget initiative
24 for fiscal year 2004 may be adopted in accordance with this
25 Section by the agency charged with administering that provision
26 or initiative, except that the 24-month limitation on the

1 adoption of emergency rules and the provisions of Sections
2 5-115 and 5-125 do not apply to rules adopted under this
3 subsection (i). The adoption of emergency rules authorized by
4 this subsection (i) shall be deemed to be necessary for the
5 public interest, safety, and welfare.

6 (j) In order to provide for the expeditious and timely
7 implementation of the provisions of the State's fiscal year
8 2005 budget as provided under the Fiscal Year 2005 Budget
9 Implementation (Human Services) Act, emergency rules to
10 implement any provision of the Fiscal Year 2005 Budget
11 Implementation (Human Services) Act may be adopted in
12 accordance with this Section by the agency charged with
13 administering that provision, except that the 24-month
14 limitation on the adoption of emergency rules and the
15 provisions of Sections 5-115 and 5-125 do not apply to rules
16 adopted under this subsection (j). The Department of Public Aid
17 may also adopt rules under this subsection (j) necessary to
18 administer the Illinois Public Aid Code and the Children's
19 Health Insurance Program Act. The adoption of emergency rules
20 authorized by this subsection (j) shall be deemed to be
21 necessary for the public interest, safety, and welfare.

22 (k) In order to provide for the expeditious and timely
23 implementation of the provisions of the State's fiscal year
24 2006 budget, emergency rules to implement any provision of this
25 amendatory Act of the 94th General Assembly or any other budget
26 initiative for fiscal year 2006 may be adopted in accordance

1 with this Section by the agency charged with administering that
2 provision or initiative, except that the 24-month limitation on
3 the adoption of emergency rules and the provisions of Sections
4 5-115 and 5-125 do not apply to rules adopted under this
5 subsection (k). The Department of Healthcare and Family
6 Services may also adopt rules under this subsection (k)
7 necessary to administer the Illinois Public Aid Code, the
8 Senior Citizens and Disabled Persons Property Tax Relief and
9 Pharmaceutical Assistance Act, the Senior Citizens and
10 Disabled Persons Prescription Drug Discount Program Act (now
11 the Illinois Prescription Drug Discount Program Act), and the
12 Children's Health Insurance Program Act. The adoption of
13 emergency rules authorized by this subsection (k) shall be
14 deemed to be necessary for the public interest, safety, and
15 welfare.

16 (1) In order to provide for the expeditious and timely
17 implementation of the provisions of the State's fiscal year
18 2007 budget, the Department of Healthcare and Family Services
19 may adopt emergency rules during fiscal year 2007, including
20 rules effective July 1, 2007, in accordance with this
21 subsection to the extent necessary to administer the
22 Department's responsibilities with respect to amendments to
23 the State plans and Illinois waivers approved by the federal
24 Centers for Medicare and Medicaid Services necessitated by the
25 requirements of Title XIX and Title XXI of the federal Social
26 Security Act. The adoption of emergency rules authorized by

1 this subsection (l) shall be deemed to be necessary for the
2 public interest, safety, and welfare.

3 (m) In order to provide for the expeditious and timely
4 implementation of the provisions of the State's fiscal year
5 2008 budget, the Department of Healthcare and Family Services
6 may adopt emergency rules during fiscal year 2008, including
7 rules effective July 1, 2008, in accordance with this
8 subsection to the extent necessary to administer the
9 Department's responsibilities with respect to amendments to
10 the State plans and Illinois waivers approved by the federal
11 Centers for Medicare and Medicaid Services necessitated by the
12 requirements of Title XIX and Title XXI of the federal Social
13 Security Act. The adoption of emergency rules authorized by
14 this subsection (m) shall be deemed to be necessary for the
15 public interest, safety, and welfare.

16 (Source: P.A. 93-20, eff. 6-20-03; 93-829, eff. 7-28-04;
17 93-841, eff. 7-30-04; 94-48, eff. 7-1-05; 94-838, eff. 6-6-06;
18 revised 10-19-06.)

19 Section 15. The Illinois Public Aid Code is amended by
20 changing Section 5-5.4 as follows:

21 (305 ILCS 5/5-5.4) (from Ch. 23, par. 5-5.4)

22 Sec. 5-5.4. Standards of Payment - Department of Healthcare
23 and Family Services. The Department of Healthcare and Family
24 Services shall develop standards of payment of skilled nursing

1 and intermediate care services in facilities providing such
2 services under this Article which:

3 (1) Provide for the determination of a facility's payment
4 for skilled nursing and intermediate care services on a
5 prospective basis. The amount of the payment rate for all
6 nursing facilities certified by the Department of Public Health
7 under the Nursing Home Care Act as Intermediate Care for the
8 Developmentally Disabled facilities, Long Term Care for Under
9 Age 22 facilities, Skilled Nursing facilities, or Intermediate
10 Care facilities under the medical assistance program shall be
11 prospectively established annually on the basis of historical,
12 financial, and statistical data reflecting actual costs from
13 prior years, which shall be applied to the current rate year
14 and updated for inflation, except that the capital cost element
15 for newly constructed facilities shall be based upon projected
16 budgets. The annually established payment rate shall take
17 effect on July 1 in 1984 and subsequent years. No rate increase
18 and no update for inflation shall be provided on or after July
19 1, 1994 and before July 1, 2008 ~~2007~~, unless specifically
20 provided for in this Section. The changes made by Public Act
21 93-841 extending the duration of the prohibition against a rate
22 increase or update for inflation are effective retroactive to
23 July 1, 2004.

24 For facilities licensed by the Department of Public Health
25 under the Nursing Home Care Act as Intermediate Care for the
26 Developmentally Disabled facilities or Long Term Care for Under

1 Age 22 facilities, the rates taking effect on July 1, 1998
2 shall include an increase of 3%. For facilities licensed by the
3 Department of Public Health under the Nursing Home Care Act as
4 Skilled Nursing facilities or Intermediate Care facilities,
5 the rates taking effect on July 1, 1998 shall include an
6 increase of 3% plus \$1.10 per resident-day, as defined by the
7 Department. For facilities licensed by the Department of Public
8 Health under the Nursing Home Care Act as Intermediate Care
9 Facilities for the Developmentally Disabled or Long Term Care
10 for Under Age 22 facilities, the rates taking effect on January
11 1, 2006 shall include an increase of 3%.

12 For facilities licensed by the Department of Public Health
13 under the Nursing Home Care Act as Intermediate Care for the
14 Developmentally Disabled facilities or Long Term Care for Under
15 Age 22 facilities, the rates taking effect on July 1, 1999
16 shall include an increase of 1.6% plus \$3.00 per resident-day,
17 as defined by the Department. For facilities licensed by the
18 Department of Public Health under the Nursing Home Care Act as
19 Skilled Nursing facilities or Intermediate Care facilities,
20 the rates taking effect on July 1, 1999 shall include an
21 increase of 1.6% and, for services provided on or after October
22 1, 1999, shall be increased by \$4.00 per resident-day, as
23 defined by the Department.

24 For facilities licensed by the Department of Public Health
25 under the Nursing Home Care Act as Intermediate Care for the
26 Developmentally Disabled facilities or Long Term Care for Under

1 Age 22 facilities, the rates taking effect on July 1, 2000
2 shall include an increase of 2.5% per resident-day, as defined
3 by the Department. For facilities licensed by the Department of
4 Public Health under the Nursing Home Care Act as Skilled
5 Nursing facilities or Intermediate Care facilities, the rates
6 taking effect on July 1, 2000 shall include an increase of 2.5%
7 per resident-day, as defined by the Department.

8 For facilities licensed by the Department of Public Health
9 under the Nursing Home Care Act as skilled nursing facilities
10 or intermediate care facilities, a new payment methodology must
11 be implemented for the nursing component of the rate effective
12 July 1, 2003. The Department of Public Aid (now Healthcare and
13 Family Services) shall develop the new payment methodology
14 using the Minimum Data Set (MDS) as the instrument to collect
15 information concerning nursing home resident condition
16 necessary to compute the rate. The Department shall develop the
17 new payment methodology to meet the unique needs of Illinois
18 nursing home residents while remaining subject to the
19 appropriations provided by the General Assembly. A transition
20 period from the payment methodology in effect on June 30, 2003
21 to the payment methodology in effect on July 1, 2003 shall be
22 provided for a period not exceeding 3 years and 184 days after
23 implementation of the new payment methodology as follows:

24 (A) For a facility that would receive a lower nursing
25 component rate per patient day under the new system than
26 the facility received effective on the date immediately

1 preceding the date that the Department implements the new
2 payment methodology, the nursing component rate per
3 patient day for the facility shall be held at the level in
4 effect on the date immediately preceding the date that the
5 Department implements the new payment methodology until a
6 higher nursing component rate of reimbursement is achieved
7 by that facility.

8 (B) For a facility that would receive a higher nursing
9 component rate per patient day under the payment
10 methodology in effect on July 1, 2003 than the facility
11 received effective on the date immediately preceding the
12 date that the Department implements the new payment
13 methodology, the nursing component rate per patient day for
14 the facility shall be adjusted.

15 (C) Notwithstanding paragraphs (A) and (B), the
16 nursing component rate per patient day for the facility
17 shall be adjusted subject to appropriations provided by the
18 General Assembly.

19 For facilities licensed by the Department of Public Health
20 under the Nursing Home Care Act as Intermediate Care for the
21 Developmentally Disabled facilities or Long Term Care for Under
22 Age 22 facilities, the rates taking effect on March 1, 2001
23 shall include a statewide increase of 7.85%, as defined by the
24 Department.

25 For facilities licensed by the Department of Public Health
26 under the Nursing Home Care Act as Intermediate Care for the

1 Developmentally Disabled facilities or Long Term Care for Under
2 Age 22 facilities, the rates taking effect on April 1, 2002
3 shall include a statewide increase of 2.0%, as defined by the
4 Department. This increase terminates on July 1, 2002; beginning
5 July 1, 2002 these rates are reduced to the level of the rates
6 in effect on March 31, 2002, as defined by the Department.

7 For facilities licensed by the Department of Public Health
8 under the Nursing Home Care Act as skilled nursing facilities
9 or intermediate care facilities, the rates taking effect on
10 July 1, 2001 shall be computed using the most recent cost
11 reports on file with the Department of Public Aid no later than
12 April 1, 2000, updated for inflation to January 1, 2001. For
13 rates effective July 1, 2001 only, rates shall be the greater
14 of the rate computed for July 1, 2001 or the rate effective on
15 June 30, 2001.

16 Notwithstanding any other provision of this Section, for
17 facilities licensed by the Department of Public Health under
18 the Nursing Home Care Act as skilled nursing facilities or
19 intermediate care facilities, the Illinois Department shall
20 determine by rule the rates taking effect on July 1, 2002,
21 which shall be 5.9% less than the rates in effect on June 30,
22 2002.

23 Notwithstanding any other provision of this Section, for
24 facilities licensed by the Department of Public Health under
25 the Nursing Home Care Act as skilled nursing facilities or
26 intermediate care facilities, if the payment methodologies

1 required under Section 5A-12 and the waiver granted under 42
2 CFR 433.68 are approved by the United States Centers for
3 Medicare and Medicaid Services, the rates taking effect on July
4 1, 2004 shall be 3.0% greater than the rates in effect on June
5 30, 2004. These rates shall take effect only upon approval and
6 implementation of the payment methodologies required under
7 Section 5A-12.

8 Notwithstanding any other provisions of this Section, for
9 facilities licensed by the Department of Public Health under
10 the Nursing Home Care Act as skilled nursing facilities or
11 intermediate care facilities, the rates taking effect on
12 January 1, 2005 shall be 3% more than the rates in effect on
13 December 31, 2004.

14 Notwithstanding any other provisions of this Section, for
15 facilities licensed by the Department of Public Health under
16 the Nursing Home Care Act as intermediate care facilities that
17 are federally defined as Institutions for Mental Disease, a
18 socio-development component rate equal to 6.6% of the
19 facility's nursing component rate as of January 1, 2006 shall
20 be established and paid effective July 1, 2006. The Illinois
21 Department may by rule adjust these socio-development
22 component rates, but in no case may such rates be diminished.

23 For facilities licensed by the Department of Public Health
24 under the Nursing Home Care Act as Intermediate Care for the
25 Developmentally Disabled facilities or as long-term care
26 facilities for residents under 22 years of age, the rates

1 taking effect on July 1, 2003 shall include a statewide
2 increase of 4%, as defined by the Department.

3 Notwithstanding any other provision of this Section, for
4 facilities licensed by the Department of Public Health under
5 the Nursing Home Care Act as skilled nursing facilities or
6 intermediate care facilities, effective January 1, 2005,
7 facility rates shall be increased by the difference between (i)
8 a facility's per diem property, liability, and malpractice
9 insurance costs as reported in the cost report filed with the
10 Department of Public Aid and used to establish rates effective
11 July 1, 2001 and (ii) those same costs as reported in the
12 facility's 2002 cost report. These costs shall be passed
13 through to the facility without caps or limitations, except for
14 adjustments required under normal auditing procedures.

15 Rates established effective each July 1 shall govern
16 payment for services rendered throughout that fiscal year,
17 except that rates established on July 1, 1996 shall be
18 increased by 6.8% for services provided on or after January 1,
19 1997. Such rates will be based upon the rates calculated for
20 the year beginning July 1, 1990, and for subsequent years
21 thereafter until June 30, 2001 shall be based on the facility
22 cost reports for the facility fiscal year ending at any point
23 in time during the previous calendar year, updated to the
24 midpoint of the rate year. The cost report shall be on file
25 with the Department no later than April 1 of the current rate
26 year. Should the cost report not be on file by April 1, the

1 Department shall base the rate on the latest cost report filed
2 by each skilled care facility and intermediate care facility,
3 updated to the midpoint of the current rate year. In
4 determining rates for services rendered on and after July 1,
5 1985, fixed time shall not be computed at less than zero. The
6 Department shall not make any alterations of regulations which
7 would reduce any component of the Medicaid rate to a level
8 below what that component would have been utilizing in the rate
9 effective on July 1, 1984.

10 (2) Shall take into account the actual costs incurred by
11 facilities in providing services for recipients of skilled
12 nursing and intermediate care services under the medical
13 assistance program.

14 (3) Shall take into account the medical and psycho-social
15 characteristics and needs of the patients.

16 (4) Shall take into account the actual costs incurred by
17 facilities in meeting licensing and certification standards
18 imposed and prescribed by the State of Illinois, any of its
19 political subdivisions or municipalities and by the U.S.
20 Department of Health and Human Services pursuant to Title XIX
21 of the Social Security Act.

22 The Department of Healthcare and Family Services shall
23 develop precise standards for payments to reimburse nursing
24 facilities for any utilization of appropriate rehabilitative
25 personnel for the provision of rehabilitative services which is
26 authorized by federal regulations, including reimbursement for

1 services provided by qualified therapists or qualified
2 assistants, and which is in accordance with accepted
3 professional practices. Reimbursement also may be made for
4 utilization of other supportive personnel under appropriate
5 supervision.

6 (Source: P.A. 93-20, eff. 6-20-03; 93-649, eff. 1-8-04; 93-659,
7 eff. 2-3-04; 93-841, eff. 7-30-04; 93-1087, eff. 2-28-05;
8 94-48, eff. 7-1-05; 94-85, eff. 6-28-05; 94-697, eff. 11-21-05;
9 94-838, eff. 6-6-06; 94-964, eff. 6-28-06; revised 8-3-06.)

10 Section 20. The Hemophilia Care Act is amended by changing
11 Section 1 and by adding Sections 1.5 and 2.5 as follows:

12 (410 ILCS 420/1) (from Ch. 111 1/2, par. 2901)

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

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

17 (1.5) "Director" means the Director of Healthcare and
18 Family Services and the Director of Insurance ~~Public Aid~~.

19 (2) (Blank).

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

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

24 (5) "Eligible person" means any resident of the State

1 suffering from hemophilia.

2 (6) "Family" means:

3 (a) In the case of a patient who is a dependent of
4 another person or couple as defined by the Illinois Income
5 Tax Act, all those persons for whom exemption is claimed in
6 the State income tax return of the person or couple whose
7 dependent the eligible person is, and

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

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

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

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

23 (a) Gross income minus the sum of (1) \$5,500, and (2)
24 \$3,500 times the number of persons in the family, or

25 (b) One half of gross income.

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

1 (Source: P.A. 89-507, eff. 7-1-97; 90-587, eff. 7-1-98; revised
2 12-15-05.)

3 (410 ILCS 420/1.5 new)

4 Sec. 1.5. Findings. The General Assembly finds all of the
5 following:

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

19 (2) Hemophilia is one of a spectrum of devastating
20 chronic bleeding disorders impacting Americans. Von
21 Willebrand Disease, another type of bleeding disorder, is
22 caused by a deficiency on the von Willebrand protein.
23 Persons with the disorder often bruise easily, have
24 frequent nosebleeds, or bleed after tooth extraction,
25 tonsillectomy, or other surgery. In some instances, women

1 will have prolonged menstrual bleeding. The disorder
2 occurs in about 1% to 2% of the U.S. population.

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

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

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

24 (410 ILCS 420/2.5 new)

25 Sec. 2.5. Hemophilia Advisory Review Board.

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

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

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

21 (3) The development of community-based initiatives to
22 increase awareness of care and treatment for persons living
23 with hemophilia and other bleeding disorders. The
24 Department of Health may provide such services through
25 cooperative agreements with Hemophilia Treatment Centers,
26 medical facilities, schools, nonprofit organizations

1 servicing the bleeding disorder community, or other
2 appropriate means.

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

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

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

15 (1) one board-certified physician licensed, practicing
16 and currently treating individuals with hemophilia or
17 other bleeding disorders;

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

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

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

26 (5) one representative of an organization established

1 under the Illinois Insurance Code for the purpose of
2 providing health insurance;

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

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

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

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

24 (c) No later than 6 months after the date of enactment of
25 this amendatory Act, the Board shall submit to the Governor and
26 the General Assembly a report with recommendations for

1 maintaining access to care and obtaining appropriate health
2 insurance coverage for individuals with hemophilia and other
3 bleeding disorders. The report shall be subject to public
4 review and comment prior to adoption. No later than 6 months
5 after adoption by the Governor and Legislature and annually
6 thereafter, the Director of Healthcare and Family Services
7 shall issue a report, which shall be made available to the
8 public, on the status of implementing the recommendations as
9 proposed by the Board and on any state and national activities
10 with regard to hemophilia and other bleeding disorders.

11 (410 ILCS 420/4 rep.)

12 Section 21. The Hemophilia Care Act is amended by repealing
13 Section 4.

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