

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 1. Short title. This Act may be cited as the FY2008
5 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
15 interest, safety, or welfare.

16 (b) If any agency finds that an emergency exists that
17 requires adoption of a rule upon fewer days than is required by
18 Section 5-40 and states in writing its reasons for that
19 finding, the agency may adopt an emergency rule without prior
20 notice or hearing upon filing a notice of emergency rulemaking
21 with the Secretary of State under Section 5-70. The notice

1 shall include the text of the emergency rule and shall be
2 published in the Illinois Register. Consent orders or other
3 court orders adopting settlements negotiated by an agency may
4 be adopted under this Section. Subject to applicable
5 constitutional or statutory provisions, an emergency rule
6 becomes effective immediately upon filing under Section 5-65 or
7 at a stated date less than 10 days thereafter. The agency's
8 finding and a statement of the specific reasons for the finding
9 shall be filed with the rule. The agency shall take reasonable
10 and appropriate measures to make emergency rules known to the
11 persons who may be affected by them.

12 (c) An emergency rule may be effective for a period of not
13 longer than 150 days, but the agency's authority to adopt an
14 identical rule under Section 5-40 is not precluded. No
15 emergency rule may be adopted more than once in any 24 month
16 period, except that this limitation on the number of emergency
17 rules that may be adopted in a 24 month period does not apply
18 to (i) emergency rules that make additions to and deletions
19 from the Drug Manual under Section 5-5.16 of the Illinois
20 Public Aid Code or the generic drug formulary under Section
21 3.14 of the Illinois Food, Drug and Cosmetic Act, (ii)
22 emergency rules adopted by the Pollution Control Board before
23 July 1, 1997 to implement portions of the Livestock Management
24 Facilities Act, or (iii) emergency rules adopted by the
25 Illinois Department of Public Health under subsections (a)
26 through (i) of Section 2 of the Department of Public Health Act

1 when necessary to protect the public's health. Two or more
2 emergency rules having substantially the same purpose and
3 effect shall be deemed to be a single rule for purposes of this
4 Section.

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

17 (e) In order to provide for the expeditious and timely
18 implementation of the State's fiscal year 2000 budget,
19 emergency rules to implement any provision of this amendatory
20 Act of the 91st General Assembly or any other budget initiative
21 for fiscal year 2000 may be adopted in accordance with this
22 Section by the agency charged with administering that provision
23 or initiative, except that the 24-month limitation on the
24 adoption of emergency rules and the provisions of Sections
25 5-115 and 5-125 do not apply to rules adopted under this
26 subsection (e). The adoption of emergency rules authorized by

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

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

15 (g) In order to provide for the expeditious and timely
16 implementation of the State's fiscal year 2002 budget,
17 emergency rules to implement any provision of this amendatory
18 Act of the 92nd General Assembly or any other budget initiative
19 for fiscal year 2002 may be adopted in accordance with this
20 Section by the agency charged with administering that provision
21 or initiative, except that the 24-month limitation on the
22 adoption of emergency rules and the provisions of Sections
23 5-115 and 5-125 do not apply to rules adopted under this
24 subsection (g). The adoption of emergency rules authorized by
25 this subsection (g) shall be deemed to be necessary for the
26 public interest, safety, and welfare.

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

13 (i) In order to provide for the expeditious and timely
14 implementation of the State's fiscal year 2004 budget,
15 emergency rules to implement any provision of this amendatory
16 Act of the 93rd General Assembly or any other budget initiative
17 for fiscal year 2004 may be adopted in accordance with this
18 Section by the agency charged with administering that provision
19 or initiative, except that the 24-month limitation on the
20 adoption of emergency rules and the provisions of Sections
21 5-115 and 5-125 do not apply to rules adopted under this
22 subsection (i). The adoption of emergency rules authorized by
23 this subsection (i) shall be deemed to be necessary for the
24 public interest, safety, and welfare.

25 (j) In order to provide for the expeditious and timely
26 implementation of the provisions of the State's fiscal year

1 2005 budget as provided under the Fiscal Year 2005 Budget
2 Implementation (Human Services) Act, emergency rules to
3 implement any provision of the Fiscal Year 2005 Budget
4 Implementation (Human Services) Act may be adopted in
5 accordance with this Section by the agency charged with
6 administering that provision, except that the 24-month
7 limitation on the adoption of emergency rules and the
8 provisions of Sections 5-115 and 5-125 do not apply to rules
9 adopted under this subsection (j). The Department of Public Aid
10 may also adopt rules under this subsection (j) necessary to
11 administer the Illinois Public Aid Code and the Children's
12 Health Insurance Program Act. The adoption of emergency rules
13 authorized by this subsection (j) shall be deemed to be
14 necessary for the public interest, safety, and welfare.

15 (k) In order to provide for the expeditious and timely
16 implementation of the provisions of the State's fiscal year
17 2006 budget, emergency rules to implement any provision of this
18 amendatory Act of the 94th General Assembly or any other budget
19 initiative for fiscal year 2006 may be adopted in accordance
20 with this Section by the agency charged with administering that
21 provision or initiative, except that the 24-month limitation on
22 the adoption of emergency rules and the provisions of Sections
23 5-115 and 5-125 do not apply to rules adopted under this
24 subsection (k). The Department of Healthcare and Family
25 Services may also adopt rules under this subsection (k)
26 necessary to administer the Illinois Public Aid Code, the

1 Senior Citizens and Disabled Persons Property Tax Relief and
2 Pharmaceutical Assistance Act, the Senior Citizens and
3 Disabled Persons Prescription Drug Discount Program Act (now
4 the Illinois Prescription Drug Discount Program Act), and the
5 Children's Health Insurance Program Act. The adoption of
6 emergency rules authorized by this subsection (k) shall be
7 deemed to be necessary for the public interest, safety, and
8 welfare.

9 (l) In order to provide for the expeditious and timely
10 implementation of the provisions of the State's fiscal year
11 2007 budget, the Department of Healthcare and Family Services
12 may adopt emergency rules during fiscal year 2007, including
13 rules effective July 1, 2007, in accordance with this
14 subsection to the extent necessary to administer the
15 Department's responsibilities with respect to amendments to
16 the State plans and Illinois waivers approved by the federal
17 Centers for Medicare and Medicaid Services necessitated by the
18 requirements of Title XIX and Title XXI of the federal Social
19 Security Act. The adoption of emergency rules authorized by
20 this subsection (l) shall be deemed to be necessary for the
21 public interest, safety, and welfare.

22 (m) In order to provide for the expeditious and timely
23 implementation of the provisions of the State's fiscal year
24 2008 budget, the Department of Healthcare and Family Services
25 may adopt emergency rules during fiscal year 2008, including
26 rules effective July 1, 2008, in accordance with this

1 subsection to the extent necessary to administer the
2 Department's responsibilities with respect to amendments to
3 the State plans and Illinois waivers approved by the federal
4 Centers for Medicare and Medicaid Services necessitated by the
5 requirements of Title XIX and Title XXI of the federal Social
6 Security Act. The adoption of emergency rules authorized by
7 this subsection (m) shall be deemed to be necessary for the
8 public interest, safety, and welfare.

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

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

14 (305 ILCS 5/5-5.4) (from Ch. 23, par. 5-5.4)

15 Sec. 5-5.4. Standards of Payment - Department of Healthcare
16 and Family Services. The Department of Healthcare and Family
17 Services shall develop standards of payment of skilled nursing
18 and intermediate care services in facilities providing such
19 services under this Article which:

20 (1) Provide for the determination of a facility's payment
21 for skilled nursing and intermediate care services on a
22 prospective basis. The amount of the payment rate for all
23 nursing facilities certified by the Department of Public Health
24 under the Nursing Home Care Act as Intermediate Care for the

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

17 For facilities licensed by the Department of Public Health
18 under the Nursing Home Care Act as Intermediate Care for the
19 Developmentally Disabled facilities or Long Term Care for Under
20 Age 22 facilities, the rates taking effect on July 1, 1998
21 shall include an increase of 3%. For facilities licensed by the
22 Department of Public Health under the Nursing Home Care Act as
23 Skilled Nursing facilities or Intermediate Care facilities,
24 the rates taking effect on July 1, 1998 shall include an
25 increase of 3% plus \$1.10 per resident-day, as defined by the
26 Department. For facilities licensed by the Department of Public

1 Health under the Nursing Home Care Act as Intermediate Care
2 Facilities for the Developmentally Disabled or Long Term Care
3 for Under Age 22 facilities, the rates taking effect on January
4 1, 2006 shall include an increase of 3%.

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

17 For facilities licensed by the Department of Public Health
18 under the Nursing Home Care Act as Intermediate Care for the
19 Developmentally Disabled facilities or Long Term Care for Under
20 Age 22 facilities, the rates taking effect on July 1, 2000
21 shall include an increase of 2.5% per resident-day, as defined
22 by the Department. For facilities licensed by the Department of
23 Public Health under the Nursing Home Care Act as Skilled
24 Nursing facilities or Intermediate Care facilities, the rates
25 taking effect on July 1, 2000 shall include an increase of 2.5%
26 per resident-day, as defined by the Department.

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

17 (A) For a facility that would receive a lower nursing
18 component rate per patient day under the new system than
19 the facility received effective on the date immediately
20 preceding the date that the Department implements the new
21 payment methodology, the nursing component rate per
22 patient day for the facility shall be held at the level in
23 effect on the date immediately preceding the date that the
24 Department implements the new payment methodology until a
25 higher nursing component rate of reimbursement is achieved
26 by that facility.

1 (B) For a facility that would receive a higher nursing
2 component rate per patient day under the payment
3 methodology in effect on July 1, 2003 than the facility
4 received effective on the date immediately preceding the
5 date that the Department implements the new payment
6 methodology, the nursing component rate per patient day for
7 the facility shall be adjusted.

8 (C) Notwithstanding paragraphs (A) and (B), the
9 nursing component rate per patient day for the facility
10 shall be adjusted subject to appropriations provided by the
11 General Assembly.

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 March 1, 2001
16 shall include a statewide increase of 7.85%, as defined by the
17 Department.

18 For facilities licensed by the Department of Public Health
19 under the Nursing Home Care Act as Intermediate Care for the
20 Developmentally Disabled facilities or Long Term Care for Under
21 Age 22 facilities, the rates taking effect on April 1, 2002
22 shall include a statewide increase of 2.0%, as defined by the
23 Department. This increase terminates on July 1, 2002; beginning
24 July 1, 2002 these rates are reduced to the level of the rates
25 in effect on March 31, 2002, as defined by the Department.

26 For facilities licensed by the Department of Public Health

1 under the Nursing Home Care Act as skilled nursing facilities
2 or intermediate care facilities, the rates taking effect on
3 July 1, 2001 shall be computed using the most recent cost
4 reports on file with the Department of Public Aid no later than
5 April 1, 2000, updated for inflation to January 1, 2001. For
6 rates effective July 1, 2001 only, rates shall be the greater
7 of the rate computed for July 1, 2001 or the rate effective on
8 June 30, 2001.

9 Notwithstanding any other provision of this Section, for
10 facilities licensed by the Department of Public Health under
11 the Nursing Home Care Act as skilled nursing facilities or
12 intermediate care facilities, the Illinois Department shall
13 determine by rule the rates taking effect on July 1, 2002,
14 which shall be 5.9% less than the rates in effect on June 30,
15 2002.

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, if the payment methodologies
20 required under Section 5A-12 and the waiver granted under 42
21 CFR 433.68 are approved by the United States Centers for
22 Medicare and Medicaid Services, the rates taking effect on July
23 1, 2004 shall be 3.0% greater than the rates in effect on June
24 30, 2004. These rates shall take effect only upon approval and
25 implementation of the payment methodologies required under
26 Section 5A-12.

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

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

16 For facilities licensed by the Department of Public Health
17 under the Nursing Home Care Act as Intermediate Care for the
18 Developmentally Disabled facilities or as long-term care
19 facilities for residents under 22 years of age, the rates
20 taking effect on July 1, 2003 shall include a statewide
21 increase of 4%, as defined by the Department.

22 Notwithstanding any other provision of this Section, for
23 facilities licensed by the Department of Public Health under
24 the Nursing Home Care Act as skilled nursing facilities or
25 intermediate care facilities, effective January 1, 2005,
26 facility rates shall be increased by the difference between (i)

1 a facility's per diem property, liability, and malpractice
2 insurance costs as reported in the cost report filed with the
3 Department of Public Aid and used to establish rates effective
4 July 1, 2001 and (ii) those same costs as reported in the
5 facility's 2002 cost report. These costs shall be passed
6 through to the facility without caps or limitations, except for
7 adjustments required under normal auditing procedures.

8 Rates established effective each July 1 shall govern
9 payment for services rendered throughout that fiscal year,
10 except that rates established on July 1, 1996 shall be
11 increased by 6.8% for services provided on or after January 1,
12 1997. Such rates will be based upon the rates calculated for
13 the year beginning July 1, 1990, and for subsequent years
14 thereafter until June 30, 2001 shall be based on the facility
15 cost reports for the facility fiscal year ending at any point
16 in time during the previous calendar year, updated to the
17 midpoint of the rate year. The cost report shall be on file
18 with the Department no later than April 1 of the current rate
19 year. Should the cost report not be on file by April 1, the
20 Department shall base the rate on the latest cost report filed
21 by each skilled care facility and intermediate care facility,
22 updated to the midpoint of the current rate year. In
23 determining rates for services rendered on and after July 1,
24 1985, fixed time shall not be computed at less than zero. The
25 Department shall not make any alterations of regulations which
26 would reduce any component of the Medicaid rate to a level

1 below what that component would have been utilizing in the rate
2 effective on July 1, 1984.

3 (2) Shall take into account the actual costs incurred by
4 facilities in providing services for recipients of skilled
5 nursing and intermediate care services under the medical
6 assistance program.

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

9 (4) Shall take into account the actual costs incurred by
10 facilities in meeting licensing and certification standards
11 imposed and prescribed by the State of Illinois, any of its
12 political subdivisions or municipalities and by the U.S.
13 Department of Health and Human Services pursuant to Title XIX
14 of the Social Security Act.

15 The Department of Healthcare and Family Services shall
16 develop precise standards for payments to reimburse nursing
17 facilities for any utilization of appropriate rehabilitative
18 personnel for the provision of rehabilitative services which is
19 authorized by federal regulations, including reimbursement for
20 services provided by qualified therapists or qualified
21 assistants, and which is in accordance with accepted
22 professional practices. Reimbursement also may be made for
23 utilization of other supportive personnel under appropriate
24 supervision.

25 (Source: P.A. 93-20, eff. 6-20-03; 93-649, eff. 1-8-04; 93-659,
26 eff. 2-3-04; 93-841, eff. 7-30-04; 93-1087, eff. 2-28-05;

1 94-48, eff. 7-1-05; 94-85, eff. 6-28-05; 94-697, eff. 11-21-05;
2 94-838, eff. 6-6-06; 94-964, eff. 6-28-06; revised 8-3-06.)

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

5 (410 ILCS 420/1) (from Ch. 111 1/2, par. 2901)

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

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

10 (1.5) "Director" means the Director of Healthcare and
11 Family Services and the Director of Insurance ~~Public Aid~~.

12 (2) (Blank).

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

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

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

19 (6) "Family" means:

20 (a) In the case of a patient who is a dependent of
21 another person or couple as defined by the Illinois Income
22 Tax Act, all those persons for whom exemption is claimed in
23 the State income tax return of the person or couple whose
24 dependent the eligible person is, and

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

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

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

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

16 (a) Gross income minus the sum of (1) \$5,500, and (2)
17 \$3,500 times the number of persons in the family, or

18 (b) One half of gross income.

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

20 (Source: P.A. 89-507, eff. 7-1-97; 90-587, eff. 7-1-98; revised
21 12-15-05.)

22 (410 ILCS 420/1.5 new)

23 Sec. 1.5. Findings. The General Assembly finds all of the
24 following:

25 (1) Inherited hemophilia and other bleeding disorders

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

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

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

25 (4) While hemophilia and other bleeding disorders are
26 incurable, advancements in drug therapies are allowing

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

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

17 (410 ILCS 420/2.5 new)

18 Sec. 2.5. Hemophilia Advisory Review Board.

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

25 (1) Proposed legislative or administrative changes to

1 policies and programs that are integral to the health and
2 wellness of individuals with hemophilia and other bleeding
3 disorders.

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

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

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

24 (5) Protecting the rights of people living with
25 hemophilia and other bleeding disorders to appropriate
26 health insurance coverage be it under a private or

1 State-sponsored health insurance provider.

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

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

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

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

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

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

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

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

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

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

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

1 public, on the status of implementing the recommendations as
2 proposed by the Board and on any state and national activities
3 with regard to hemophilia and other bleeding disorders.

4 (410 ILCS 420/4 rep.)

5 Section 21. The Hemophilia Care Act is amended by repealing
6 Section 4.

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