

AN ACT concerning public health.

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

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

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

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

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

Sec. 5-45. Emergency rulemaking.

(a) "Emergency" means the existence of any situation that any agency finds reasonably constitutes a threat to the public interest, safety, or welfare.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

For facilities licensed by the Department of Public Health

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

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

Notwithstanding any other provision of this Section, for facilities licensed by the Department of Public Health under the Nursing Home Care Act as skilled nursing facilities or intermediate care facilities, if the payment methodologies required under Section 5A-12 and the waiver granted under 42 CFR 433.68 are approved by the United States Centers for Medicare and Medicaid Services, the rates taking effect on July 1, 2004 shall be 3.0% greater than the rates in effect on June 30, 2004. These rates shall take effect only upon approval and implementation of the payment methodologies required under Section 5A-12.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(2) (Blank).

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

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

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

(6) "Family" means:

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

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

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

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

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

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

(b) One half of gross income.

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

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

(410 ILCS 420/1.5 new)

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

(1) Inherited hemophilia and other bleeding disorders

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

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

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

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

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

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

(410 ILCS 420/2.5 new)

Sec. 2.5. Hemophilia Advisory Review Board.

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

(1) Proposed legislative or administrative changes to

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

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

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

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

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

State-sponsored health insurance provider.

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

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

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

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

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

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

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

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

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

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

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

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

(410 ILCS 420/4 rep.)

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

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