## 3865

## 2011-2012 Regular Sessions

IN SENATE

March 8, 2011

Introduced by Sen. ROBACH -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, the social services law and the insurance law, in relation to providing that persons with hemophilia and other clotting protein deficiencies who are otherwise eligible for the Child Health Plus, Family Health Plus, and Healthy New York programs shall have access to reimbursement for outpatient blood clotting factor concentrates and other necessary treatments and services

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Legislative findings. Hemophilia is a rare hereditary 1 Section 1. 2 bleeding disorder resulting from a deficiency in blood proteins known as clotting factors. Without an adequate supply of clotting factors, indi-3 4 viduals can experience prolonged bleeding following routine medical and 5 dental procedures, trauma, and a range of physical activities. Addi-6 tionally, individuals with hemophilia often experience spontaneous internal bleeding that can cause severe joint damage, chronic pain, 7 and 8 even death.

9 Prior to the 1970s, individuals with hemophilia seldom lived beyond 10 the age of 30 years. Early treatment consisted of whole blood and plasma 11 transfusions at hospitals. These treatments were difficult, time consum-12 ing and only minimally effective. The advent of commercially prepared 13 blood clotting factors in the 1980s represented a major advance in 14 treatment, both in terms of efficacy and convenience. Most importantly, 15 these advances allowed for home infusion.

16 In addition to hemophilia, there are several other disorders resulting 17 from blood protein deficiencies. These include Von Willebrand Disease 18 (VWD), the most common bleeding disorder, affecting approximately two 19 million Americans. Individuals with the severest form of VWD rely on 20 clotting factor treatments similar to those used by individuals with 21 hemophilia.

EXPLANATION--Matter in ITALICS (underscored) is new; matter in brackets
[] is old law to be omitted.

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Clotting factor products produced today (derived from plasma or recombinant technology) are very safe and highly effective medications. 1 2 3 Access to therapies has vastly improved both the health outcomes and 4 quality of life for the majority of patients and their families. Many 5 patients today are on a prophylactic regimen to prevent bleeding 6 episodes. This preventative regimen together with the coordinated care 7 provided by hemophilia treatment centers have significantly reduced 8 visits to emergency rooms, hospitalizations and joint damage. Further, the ability to manage hemophilia and other bleeding disorders outside of 9 10 the hospital setting have helped improve attendance for school-aged 11 children, decreased absenteeism from work for adult patients and caregivers, vastly improved the ability of affected persons to join the work 12 force, and minimized life disruptions for the entire family. 13

Presently, Child Health Plus, Family Health Plus and Healthy New York to not cover clotting factors prescribed for use at home. Moreover, New York state is the only state in the U.S. preventing access to lifesaving outpatient clotting factor products for individuals that qualify for the State Children's Health Insurance Program.

19 The legislature finds that having a policy that prohibits otherwise eligible individuals from accessing lifesaving medications not only 20 21 violates the spirit of these very important programs, it discriminates 22 against a vulnerable group of individuals whose health care costs are deemed to be high and fundamentally undermines the programs' overall 23 goal of ensuring that low-income children and families have access to 24 25 quality health care. The legislature further finds that costs to the 26 state for allowing individuals who qualify for Child Health Plus, Family Health Plus, and Healthy New York to access the outpatient clotting products at home, the recommended model of care, will be much less than 27 28 29 the long-term costs the state will very likely end up paying through the 30 Medicaid program for individuals who later develop debilitating complications and are deemed unable to work. 31

This legislation is intended to modify existing state law by allowing for the coverage of lifesaving clotting factor products prescribed for use at home by persons with hemophilia and other clotting protein deficiencies who are eligible for the Child Health Plus, Family Health Plus, and Healthy New York programs.

37 S 2. Subdivision 7 of section 2510 of the public health law, as 38 amended by section 21 of part B of chapter 109 of the laws of 2010, is 39 amended to read as follows:

40 7. "Covered health care services" means: the services of physicians, optometrists, nurses, nurse practitioners, midwives and other related 41 professional personnel which are provided on an outpatient basis, 42 43 including routine well-child visits; diagnosis and treatment of illness 44 and injury; inpatient health care services; laboratory tests; diagnostic 45 x-rays; prescription and non-prescription drugs and durable medical equipment; radiation therapy; chemotherapy; hemodialysis; OUTPATIENT 46 47 PRODUCTS AND OTHER BLOOD CLOTTING FACTOR TREATMENTS AND SERVICES 48 FURNISHED IN CONNECTION WITH THECARE OF HEMOPHILIA AND OTHER BLOOD 49 CLOTTING PROTEIN DEFICIENCIES; emergency room services; hospice 50 emergency, preventive and routine dental care, including services; medically necessary orthodontia but excluding cosmetic surgery; emergen-51 cy, preventive and routine vision care, including eyeglasses; speech and 52 53 hearing services; and, inpatient and outpatient mental health, alcohol 54 and substance abuse services as defined by the commissioner in consulta-55 tion with the superintendent. "Covered health care services" shall not 56 include drugs, procedures and supplies for the treatment of erectile

dysfunction when provided to, or prescribed for use by, a person who is 1 2 required to register as a sex offender pursuant to article six-C of the 3 correction law, provided that any denial of coverage of such drugs, 4 procedures or supplies shall provide the patient with the means of 5 obtaining additional information concerning both the denial and the 6 means of challenging such denial.

7 S 3. Paragraph a of subdivision 7 of section 2510 of the public health 8 law, as amended by chapter 526 of the laws of 2002, is amended to read 9 as follows:

10 a. "Primary and preventive health care services" means: the services physicians, optometrists, nurses, nurse practitioners, midwives and 11 of other related professional personnel which are provided on an outpatient 12 basis, including routine well-child visits; diagnosis and treatment of 13 14 illness and injury; laboratory tests; diagnostic x-rays; prescription 15 drugs; radiation therapy; chemotherapy; hemodialysis; OUTPATIENT BLOOD CLOTTING FACTOR PRODUCTS AND OTHER TREATMENTS AND SERVICES FURNISHED IN 16 17 CONNECTION WITH THE CARE OF HEMOPHILIA AND OTHER BLOOD CLOTTING PROTEIN DEFICIENCIES; emergency room services; hospice services; and, outpatient 18 19 alcohol and substance abuse services as defined by the commissioner in 20 consultation with the superintendent.

21 S 4. Subparagraphs (xv) and (xvi) of paragraph (e) of subdivision 1 of 22 section 369-ee of the social services law, subparagraph (xv) as amended 23 and subparagraph (xvi) as added by chapter 526 of the laws of 2002, are 24 amended and a new paragraph (xvii) is added to read as follows:

25 (xv) services provided to meet the requirements of 42 U.S.C. 1396d(r); 26 [and] 27

(xvi) hospice services[.]; AND

28 (XVII) OUTPATIENT BLOOD CLOTTING FACTOR PRODUCTS AND OTHER TREATMENTS 29 SERVICES FURNISHED IN CONNECTION WITH THE CARE OF HEMOPHILIA AND AND OTHER BLOOD CLOTTING PROTEIN DEFICIENCIES AS DEFINED BY THE COMMISSIONER 30 OF HEALTH IN CONSULTATION WITH THE SUPERINTENDENT. 31

32 S 5. Paragraph 13 of subsection (d) of section 4326 of the insurance 33 added by chapter 1 of the laws of 1999, is amended to read as law, as 34 follows:

35 (13) blood and blood products furnished in connection with surgery or inpatient hospital services OR OUTPATIENT SERVICES FOR HEMOPHILIA AND 36 37 OTHER BLOOD CLOTTING PROTEIN DEFICIENCIES; and

S 6. This act shall take effect on the first of April next succeeding 38 39 the date upon which it shall have become a law, provided that the amend-40 ments to subdivision 7 of section 2510 of the public health law made by section two of this act shall be subject to the expiration and reversion 41 of such subdivision pursuant to subdivision 4 of section 47 of chapter 2 42 43 of the laws of 1998, as amended, when upon such date the provisions of 44 section three of this act shall take effect.