S T A T E  O F  N E W  Y O R K

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I N  A S S E M B L Y

(PREFILED)

January 9, 2013

Introduced by M. of A. KELLNER, CROUCH, FINCH -- Multi-Sponsored by -- M. of A. CURRAN, CUSICK, HEVESI, LUPARDO, MARKEY, WALTER -- read once and referred to the Committee on Health

AN ACT to amend the public health law and the social services law, in relation to providing that persons with hemophilia and other clotting protein deficiencies who are otherwise eligible for the Child Health Plus or Family Health Plus 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:

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

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

In addition to hemophilia, there are several other disorders resulting from blood protein deficiencies. These include Von Willebrand Disease (VWD), the most common bleeding disorder, affecting approximately two million Americans. Individuals with the severest form of VWD rely on

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

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clotting factor treatments similar to those used by individuals with hemophilia.

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

Presently, 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.

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

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 or Family Health Plus program.

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

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

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

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

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

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

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

(xvi) hospice services[.]; AND

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

S 5. This act shall take effect on the first of April next succeeding the date upon which it shall have become a law, provided that the amendments 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 of such subdivision pursuant to subdivision 4 of section 47 of chapter 2 of the laws of 1998, as amended, when upon such date the provisions of section three of this act shall take effect.