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2013-2014 Regular Sessions

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 ASSEM-
BLY, DO ENACT AS FOLLOWS:

1 Section 1. Legislative findings. Hemophilia is a rare hereditary
2 bleeding disorder resulting from a deficiency in blood proteins known as
3 clotting factors. Without an adequate supply of clotting factors, indi-
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
7 internal bleeding that can cause severe joint damage, chronic pain, 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

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

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

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

16 Presently, New York state is the only state in the U.S. preventing
17 access to lifesaving outpatient clotting factor products for individuals
18 that qualify for the State Children's Health Insurance Program.

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

32 This legislation is intended to modify existing state law by allowing
33 for the coverage of lifesaving clotting factor products prescribed for
34 use at home by persons with hemophilia and other clotting protein defi-
35 ciencies who are eligible for the Child Health Plus or Family Health
36 Plus program.

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,
41 optometrists, nurses, nurse practitioners, midwives and other related
42 professional personnel which are provided on an outpatient basis,
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
46 equipment; radiation therapy; chemotherapy; hemodialysis; OUTPATIENT
47 BLOOD CLOTTING FACTOR PRODUCTS AND OTHER TREATMENTS AND SERVICES
48 FURNISHED IN CONNECTION WITH THE CARE OF HEMOPHILIA AND OTHER BLOOD
49 CLOTTING PROTEIN DEFICIENCIES; emergency room services; hospice
50 services; emergency, preventive and routine dental care, including
51 medically necessary orthodontia but excluding cosmetic surgery; emergen-
52 cy, preventive and routine vision care, including eyeglasses; speech and
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 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.