

2186

2013-2014 Regular Sessions

I N S E N A T E

January 14, 2013

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 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:

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
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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1 Clotting factor products produced today (derived from plasma or recom-
2 binant technology) are very safe and highly effective medications.
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,
9 the ability to manage hemophilia and other bleeding disorders outside of
10 the hospital setting have helped improve attendance for school-aged
11 children, decreased absenteeism from work for adult patients and care-
12 givers, vastly improved the ability of affected persons to join the work
13 force, and minimized life disruptions for the entire family.

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

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

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

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

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

1 correction law, provided that any denial of coverage of such drugs,
2 procedures or supplies shall provide the patient with the means of
3 obtaining additional information concerning both the denial and the
4 means of challenging such denial.

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

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

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

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

25 (xvi) hospice services[.]; AND

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

30 S 5. This act shall take effect on the first of April next succeeding
31 the date upon which it shall have become a law, provided that the amend-
32 ments to subdivision 7 of section 2510 of the public health law made by
33 section two of this act shall be subject to the expiration and reversion
34 of such subdivision pursuant to subdivision 4 of section 47 of chapter 2
35 of the laws of 1998, as amended, when upon such date the provisions of
36 section three of this act shall take effect.