

STATE OF NEW YORK

9539

IN ASSEMBLY

March 20, 2024

Introduced by M. of A. EICHENSTEIN -- read once and referred to the Committee on Insurance

AN ACT to amend the insurance law and the public health law, in relation to providing insurance coverage for rare diseases, life-threatening conditions or diseases, degenerative and disabling conditions, or diagnoses involving medically fragile children

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

1 Section 1. Subsection (i) of section 3216 of the insurance law is
2 amended by adding a new paragraph 39 to read as follows:

3 (39) (A) Every policy which provides hospital, surgical, medical or
4 major medical coverage shall provide coverage for medically necessary
5 services from a chosen provider for a confirmed diagnosis that is deemed
6 to be a rare disease, life-threatening condition or disease, degenera-
7 tive and disabling condition, or involves a medically fragile child,
8 with no restriction to a plan network, if the following conditions are
9 met:

10 (i) (A) The costs of the chosen provider are equal to or less than the
11 average cost that would have otherwise been paid to a local network
12 provider who possesses a similar subspecialty as such chosen provider;
13 and

14 (B) the patient's treating specialist or primary care provider
15 provides a written statement to recommend the chosen provider for the
16 particular disease.

17 (ii) The chosen provider or the patient's primary care physician
18 provides advance notice to such patient's network plan prior to a
19 planned procedure covered pursuant to this paragraph.

20 (iii) The chosen provider is accredited or designated by the depart-
21 ment of health, the federal government, or a voluntary national health
22 organization as having special expertise in treating, or has demon-
23 strated a clinical focus in the area of, the confirmed diagnosis for
24 which coverage is sought pursuant to this paragraph. Provided however,
25 that nothing in this paragraph shall require such chosen provider to be
26 participating in the patient's network or located within the state;

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

LBD14125-05-4

1 provided further that nothing herein shall obligate to cover cost
2 related to travel to the chosen provider.

3 (B) For the purposes of this paragraph, the following terms shall have
4 the following meanings:

5 (i) "Rare disease" shall have the same meaning as set forth in subdivi-
6 vision seven-g of section forty-nine hundred of the public health law.

7 (ii) "Life-threatening condition or disease" shall have the same mean-
8 ing as set forth in subdivision seven-a of section forty-nine hundred of
9 the public health law.

10 (iii) "Degenerative and disabling condition" shall mean a condition or
11 disease which (a) requires specialized medical care over a prolonged
12 period of time, or (b) qualifies the patient as a disabled person, as
13 defined by subdivision five of section two hundred eight of the social
14 services law.

15 (iv) "Medically fragile child" shall have the same meaning as set
16 forth in subdivision nine of section forty-four hundred one of the
17 public health law.

18 § 2. Subsection (k) of section 3221 of the insurance law is amended by
19 adding a new paragraph 23 to read as follows:

20 (23) (A) Every policy which provides hospital, surgical, medical or
21 major medical coverage shall provide coverage for medically necessary
22 services from a chosen provider for a confirmed diagnosis that is deemed
23 to be a rare disease, life-threatening condition or disease, degenera-
24 tive and disabling condition, or involves a medically fragile child,
25 with no restriction to a plan network, if the following conditions are
26 met:

27 (i) (I) The costs of the chosen provider are equal to or less than the
28 average cost that would have otherwise been paid to a local network
29 provider who possesses a similar subspecialty as such chosen provider;
30 and

31 (II) the patient's treating specialist or primary care provider
32 provides a written statement to recommend the chosen provider for the
33 particular disease.

34 (ii) The chosen provider or the patient's primary care physician
35 provides advance notice to such patient's network plan prior to a
36 planned procedure covered pursuant to this paragraph.

37 (iii) The chosen provider is accredited or designated by the depart-
38 ment of health, the federal government, or a voluntary national health
39 organization as having special expertise in treating, or has demon-
40 strated a clinical focus in the area of, the confirmed diagnosis for
41 which coverage is sought pursuant to this paragraph. Provided however,
42 that nothing in this paragraph shall require such chosen provider to be
43 participating in the patient's network or located within the state;
44 provided further that nothing herein shall obligate to cover cost
45 related to travel to the chosen provider.

46 (B) For the purposes of this paragraph, the following terms shall have
47 the following meanings:

48 (i) "Rare disease" shall have the same meaning as set forth in subdivi-
49 vision seven-g of section forty-nine hundred of the public health law.

50 (ii) "Life-threatening condition or disease" shall have the same mean-
51 ing as set forth in subdivision seven-a of section forty-nine hundred of
52 the public health law.

53 (iii) "Degenerative and disabling condition" shall mean a condition or
54 disease which (a) requires specialized medical care over a prolonged
55 period of time, or (b) qualifies the patient as a disabled person, as

1 defined by subdivision five of section two hundred eight of the social
2 services law.

3 (iv) "Medically fragile child" shall have the same meaning as set
4 forth in subdivision nine of section forty-four hundred one of the
5 public health law.

6 § 3. Section 4303 of the insurance law is amended by adding a new
7 subsection (vv) to read as follows:

8 (vv) (1) Every policy which provides hospital, surgical, medical or
9 major medical coverage shall provide coverage for medically necessary
10 services from a chosen provider for a confirmed diagnosis that is deemed
11 to be a rare disease, life-threatening condition or disease, degenera-
12 tive and disabling condition, or involves a medically fragile child,
13 with no restriction to a plan network, if the following conditions are
14 met:

15 (A) (i) The costs of the chosen provider are equal to or less than the
16 average cost that would have otherwise been paid to a local network
17 provider who possesses a similar subspecialty as such chosen provider;
18 and

19 (ii) the patient's treating specialist or primary care provider
20 provides a written statement to recommend the chosen provider for the
21 particular disease.

22 (B) The chosen provider or the patient's primary care physician
23 provides advance notice to such patient's network plan prior to a
24 planned procedure covered pursuant to this subsection.

25 (C) The chosen provider is accredited or designated by the department
26 of health, the federal government, or a voluntary national health organ-
27 ization as having special expertise in treating, or has demonstrated a
28 clinical focus in the area of, the confirmed diagnosis for which cover-
29 age is sought pursuant to this subsection. Provided however, that noth-
30 ing in this subsection shall require such chosen provider to be partic-
31 ipating in the patient's network or located within the state; provided
32 further that nothing herein shall obligate to cover cost related to
33 travel to the chosen provider.

34 (2) For the purposes of this subsection, the following terms shall
35 have the following meanings:

36 (A) "Rare disease" shall have the same meaning as set forth in subdi-
37 vision seven-g of section forty-nine hundred of the public health law.

38 (B) "Life-threatening condition or disease" shall have the same mean-
39 ing as set forth in subdivision seven-a of section forty-nine hundred of
40 the public health law.

41 (C) "Degenerative and disabling condition" shall mean a condition or
42 disease which (i) requires specialized medical care over a prolonged
43 period of time, or (ii) qualifies the patient as a disabled person, as
44 defined by subdivision five of section two hundred eight of the social
45 services law.

46 (D) "Medically fragile child" shall have the same meaning as set forth
47 in subdivision nine of section forty-four hundred one of the public
48 health law.

49 § 4. The public health law is amended by adding a new section 4406-j
50 to read as follows:

51 § 4406-j. Extraordinary out-of-network coverage. No health maintenance
52 organization subject to this article shall, by contract, written policy,
53 or procedure, limit a patient enrollee's direct access to services from
54 a chosen provider for a rare disease, life-threatening condition or
55 disease, degenerative and disabling condition, or diagnosis involving a
56 medically fragile child if such services are covered pursuant to para-

1 graph thirty-nine of subsection (i) of section three thousand sixteen of
2 the insurance law, paragraph twenty-three of subsection (k) of section
3 three thousand two hundred twenty-one of the insurance law, or
4 subsection (vv) of section four thousand three hundred three of the
5 insurance law; provided, however, that such patient enrollee's access to
6 such services are otherwise subject to the terms and conditions of the
7 plan under which such patient enrollee is covered.

8 § 5. This act shall take effect on the ninetieth day after it shall
9 have become a law and shall apply to all insurance policies and
10 contracts issued, renewed, modified, altered, or amended on or after
11 such effective date.