

STATE OF NEW YORK

2384

2025-2026 Regular Sessions

IN ASSEMBLY

January 16, 2025

Introduced by M. of A. EICHENSTEIN, WEPRIN, GALLAGHER -- 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 40 to read as follows:

3 (40) (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

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

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1 which coverage is sought pursuant to this paragraph. Provided however,
2 that nothing in this paragraph shall require such chosen provider to be
3 participating in the patient's network or located within the state;
4 provided further that nothing herein shall obligate to cover cost
5 related to travel to the chosen provider.

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

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

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

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

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

21 § 2. Subsection (k) of section 3221 of the insurance law is amended by
22 adding a new paragraph 24 to read as follows:

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

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

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

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

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

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

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

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

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

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

9 § 3. Section 4303 of the insurance law is amended by adding a new
10 subsection (ww) to read as follows:

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

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

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

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

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

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

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

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

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

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

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

54 § 4406-j. Extraordinary out-of-network coverage. No health maintenance
55 organization subject to this article shall, by contract, written policy,
56 or procedure, limit a patient enrollee's direct access to services from

1 a chosen provider for a rare disease, life-threatening condition or
2 disease, degenerative and disabling condition, or diagnosis involving a
3 medically fragile child if such services are covered pursuant to para-
4 graph forty of subsection (i) of section three thousand sixteen of the
5 insurance law, paragraph twenty-four of subsection (k) of section three
6 thousand two hundred twenty-one of the insurance law, or subsection (ww)
7 of section four thousand three hundred three of the insurance law;
8 provided, however, that such patient enrollee's access to such services
9 are otherwise subject to the terms and conditions of the plan under
10 which such patient enrollee is covered.

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