

STATE OF NEW YORK

965

2025-2026 Regular Sessions

IN SENATE

(Prefiled)

January 8, 2025

Introduced by Sens. HOYLMAN-SIGAL, SALAZAR -- read twice and ordered printed, and when printed to be committed 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

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

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1 organization as having special expertise in treating, or has demon-
2 strated a clinical focus in the area of, the confirmed diagnosis for
3 which coverage is sought pursuant to this paragraph. Provided however,
4 that nothing in this paragraph shall require such chosen provider to be
5 participating in the patient's network or located within the state;
6 provided further that nothing herein shall obligate to cover cost
7 related to travel to the chosen provider.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 § 4406-j. Extraordinary out-of-network coverage. No health maintenance
2 organization subject to this article shall, by contract, written policy,
3 or procedure, limit a patient enrollee's direct access to services from
4 a chosen provider for a rare disease, life-threatening condition or
5 disease, degenerative and disabling condition, or diagnosis involving a
6 medically fragile child if such services are covered pursuant to para-
7 graph forty of subsection (i) of section three thousand sixteen of the
8 insurance law, paragraph twenty-four of subsection (k) of section three
9 thousand two hundred twenty-one of the insurance law, or subsection (ww)
10 of section four thousand three hundred three of the insurance law;
11 provided, however, that such patient enrollee's access to such services
12 are otherwise subject to the terms and conditions of the plan under
13 which such patient enrollee is covered.

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