

# STATE OF NEW YORK

2384--A

Cal. No. 86

2025-2026 Regular Sessions

## IN ASSEMBLY

January 16, 2025

Introduced by M. of A. EICHENSTEIN, WEPRIN, GALLAGHER, REYES, DILAN, ROSENTHAL, WIEDER, STECK, ALVAREZ, KAY, LASHER, SANTABARBARA, TORRES, TAPIA, GALLAHAN, JACOBSON, GRIFFIN, E. BROWN, OTIS, COLTON, BLUMENCRANZ, BLANKENBUSH, BUTTENSCHON -- read once and referred to the Committee on Insurance -- ordered to a third reading, amended and ordered reprinted, retaining its place in the order of third reading

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 42 to read as follows:

3 (42) (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.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

55 (i) "Rare disease" shall have the same meaning as set forth in subdi-  
56 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 (xx) to read as follows:

14 (xx) (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-two of subsection (i) of section three thousand sixteen of  
8 the insurance law, paragraph twenty-four of subsection (k) of section  
9 three thousand two hundred twenty-one of the insurance law, or  
10 subsection (xx) of section four thousand three hundred three of the  
11 insurance law; provided, however, that such patient enrollee's access to  
12 such services are otherwise subject to the terms and conditions of the  
13 plan under 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.