

# STATE OF NEW YORK

8957

## IN SENATE

April 2, 2024

Introduced by Sen. HOYLMAN-SIGAL -- 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 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.

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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-

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

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