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:

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

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

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

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

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

(iii) The chosen provider is accredited or designated by the department of health, the federal government, or a voluntary national health organization as having special expertise in treating, or has demonstrated a clinical focus in the area of, the confirmed diagnosis for which coverage is sought pursuant to this paragraph. Provided however, that nothing in this paragraph shall require such chosen provider to be 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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provided further that nothing herein shall obligate to cover cost related to travel to the chosen provider.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(C) The chosen provider is accredited or designated by the department of health, the federal government, or a voluntary national health organization as having special expertise in treating, or has demonstrated a clinical focus in the area of, the confirmed diagnosis for which coverage is sought pursuant to this subsection. Provided however, that nothing in this subsection shall require such chosen provider to be participating in the patient's network or located within the state; provided further that nothing herein shall obligate to cover cost related to travel to the chosen provider.

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

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

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

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

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

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

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

<u>**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.**</u>

§ 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.