

**SENATE  
STATE OF MINNESOTA  
NINETY-THIRD SESSION**

**S.F. No. 1029**

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DATE  
02/01/2023

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Introduction and first reading  
Referred to Health and Human Services

OFFICIAL STATUS

1.1 A bill for an act  
1.2 relating to health; requiring unrestricted access to services for diagnosis, monitoring,  
1.3 and treatment of rare diseases; amending Minnesota Statutes 2022, section  
1.4 256B.0625, by adding a subdivision; proposing coding for new law in Minnesota  
1.5 Statutes, chapter 62Q.

1.6 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

1.7 Section 1. [62Q.451] UNRESTRICTED ACCESS TO SERVICES FOR THE  
1.8 DIAGNOSIS, MONITORING, AND TREATMENT OF RARE DISEASES.

1.9 (a) No health plan company may restrict the choice of an enrollee as to where the enrollee  
1.10 receives services from a licensed health care provider related to the diagnosis, monitoring,  
1.11 and treatment of a rare disease or condition. Except as provided in paragraph (c), for purposes  
1.12 of this section, "rare disease or condition" means any disease or condition:

1.13 (1) that affects fewer than 200,000 persons in the United States and is chronic, serious,  
1.14 life-altering, or life-threatening;

1.15 (2) that affects more than 200,000 persons in the United States and a drug for treatment  
1.16 has been designated as such pursuant to United States Code, title 21, section 360bb;

1.17 (3) that is labeled as a rare disease or condition on the Genetic and Rare Diseases  
1.18 Information Center list created by the National Institutes of Health; or

1.19 (4) for which a patient:

1.20 (i) has received two or more clinical consultations from a primary care provider or  
1.21 specialty provider that is specific to the presenting complaint;

2.1 (ii) has documentation in the patient's medical record of a developmental delay through  
2.2 standardized assessment, developmental regression, failure to thrive, or progressive  
2.3 multisystemic involvement; and

2.4 (iii) had laboratory or clinical testing that failed to provide a definitive diagnosis or  
2.5 resulted in conflicting diagnoses.

2.6 (b) Any services provided, referred for, or ordered by an out-of-network provider for a  
2.7 patient who, before receiving and being notified of a definitive diagnosis, satisfied the  
2.8 requirements in paragraph (a), clause (4), shall be governed by paragraph (d) even if the  
2.9 subsequent definitive diagnosis does not meet the definition of rare disease or condition in  
2.10 paragraph (a), clause (1), (2), or (3). Once the patient is definitively diagnosed with a disease  
2.11 or condition that does not meet the definition of rare disease or condition in paragraph (a),  
2.12 clause (1), (2), or (3), and the patient or a parent or guardian of a minor patient has been  
2.13 notified of the diagnosis, any services provided, referred for, or ordered by an out-of-network  
2.14 provider related to the diagnosis shall be governed by paragraph (d) for up to 60 days,  
2.15 providing time for care to be transferred to a qualified in-network provider and to schedule  
2.16 needed in-network appointments. After this 60-day period, subsequent services provided,  
2.17 referred for, or ordered by an out-of-network provider related to the diagnosis are no longer  
2.18 governed by paragraph (d).

2.19 (c) A rare disease or condition does not include an infectious disease that has widely  
2.20 available and known protocols for diagnosis and treatment and that is commonly treated in  
2.21 a primary care setting, even if it affects less than 200,000 persons in the United States.

2.22 (d) Cost-sharing requirements and benefit or services limitations for the diagnosis and  
2.23 treatment of a rare disease or condition must not place a greater financial burden on the  
2.24 enrollee or be more restrictive than those requirements for in-network medical treatment.

2.25 (e) A health plan company must provide enrollees with written information on the content  
2.26 and application of this section and must train customer service representatives on the content  
2.27 and application of this section.

2.28 (f) This section does not apply to medications obtained from a retail pharmacy.

2.29 **EFFECTIVE DATE.** This section is effective January 1, 2024, and applies to health  
2.30 plans offered, issued, or renewed on or after that date.

3.1 Sec. 2. Minnesota Statutes 2022, section 256B.0625, is amended by adding a subdivision  
3.2 to read:

3.3 Subd. 68. **Services for the diagnosis, monitoring, and treatment of rare**  
3.4 **diseases.** Medical assistance coverage for services related to the diagnosis, monitoring, and  
3.5 treatment of a rare disease or condition must meet the requirements in section 62Q.451.

3.6 **EFFECTIVE DATE.** This section is effective January 1, 2024.