


Rare isn't so rare.


Any disease, disorder, illness, or condition affecting fewer than 200,000 people in the U.S. is considered **rare**.

Minnesota Rare Disease Advisory Council is a result of the grassroots efforts of Minnesota patients and families whose lives have been affected by rare disease. The Council was established in 2019 by the Minnesota state legislature to ensure that every patient diagnosed with a rare disease has access to a timely diagnosis, appropriate care, and an effective treatment. The Council consists of rare disease experts from across health systems and aligned disciplines who work tirelessly to create a strong responsive, rare disease community.


There are approximately **7,000 rare diseases** affecting between 25 -30 million Americans or **10% of the population.**



In Minnesota, roughly **570,000 people** are living with a rare disease.



Barriers have resulted in **lower quality-of-life scores** compared to those of other chronic illness populations



Average time to diagnosis for a rare disease is **7-8 years.**




Individuals are misdiagnosed **2-3 times**




Individuals eventually diagnosed with a rare disease see an average of **eight clinicians** prior to diagnosis




Only 5% of rare disease patient populations have an FDA approved treatment



Rare disease diagnoses are diverse; however, patients' **barriers to care** are common.



Many individuals with rare diseases have **limited access to a clinician** with knowledge of their disease in their geographic area



Rare disease care.....60
Common chronic disease care.....2

Research footnotes can be found at www.cbacrareddisease.org

“Envisioning a world where every Minnesota citizen living with a rare disease has access to a timely diagnosis, comprehensive care, and an effective treatment.”