

Rare Disease Frontline Providers Address Patients' Barriers to Care



There are over 7,000 rare diseases in existence with over 25 million patients affected. Yet, healthcare access and quality of life are elusive to many rare disease patients, and only 5% of rare disease patients have an approved treatment option. Even when compared to adults with common chronic diseases, adults in Minnesota with rare diseases had significantly worse stigma, physical function, fatigue, and depression, and marginally worse anxiety.

The *Frontline Provider Survey* was conducted to gain a healthcare professional's perspective on challenges to addressing the needs of the rare disease community. For more information on this study and the council, please scan the QR code or visit www.cbacrareddisease.org



Nearly a quarter of providers do not think
their knowledge of rare diseases meets the needs
of their practice.



Over 75%

of clinicians are somewhat or **not**
at all comfortable interpreting
genetic testing results.



63%

**Receiving care
in state**

say that they never
or **very rarely** have
to **refer difficult to
diagnose** rare disease
patients out of state.

**Rare disease
specialists are mainly
in the Twin Cities
metro area.**

There are a limited
number of specialists
to treat rare disease
outside the metro area.

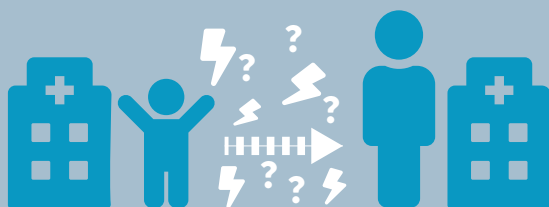


28%

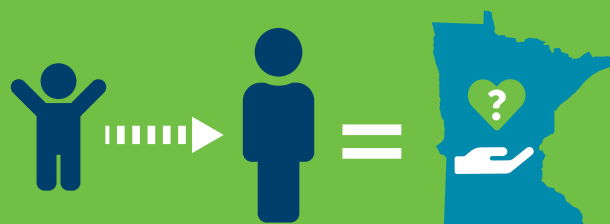
report that **many times**
the **type of insurance**
the patients carries has
affected their ability to
**complete the recommended
treatment plan.**



60% of providers and dentists identify **transitioning** care
from **pediatrics to adult** as difficult.



56% and 60% of medical and dental providers who
reported having **difficulty transitioning** their patients reported it was
due to a local practitioner being unwilling to take the patient.



Over 90% of providers felt
(depending on the type of
training) they **would benefit**
from **additional training.**



30% of medical and dental providers **did not feel** that they
had the **ability to care for rare disease** patients who have
contacted them.



**77% because the disease
was too complex** and lesser
numbers reported time
constraints, out of the
scope, and/or ability of
their practice.