

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.mnraredisease.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.

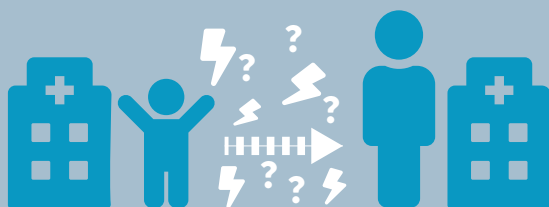


28%

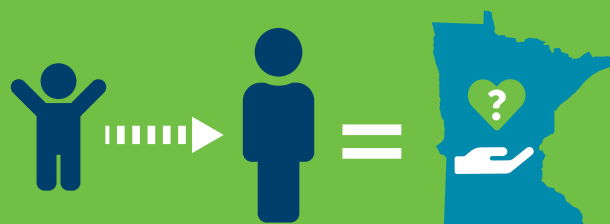
report that **many times**
the **type of insurance**
the patients carries has
affected their ability to
**complete the recommended
treatment plan.**



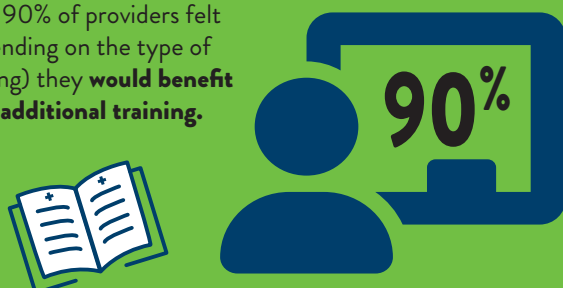
60% of providers and dentists identify **transitioning** care
from **pediatrics to adult** as **difficult.**



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.

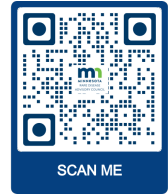


**77% because the disease
was too complex** and lesser
numbers reported time
constraints, out of the
scope, and/or ability of
their practice.

Healthcare access in rare disease: A PUBLIC HEALTH PRIORITY!

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The *2020 Rare Diseases Health Care Access Study* set out to learn more about rare disease patients' barriers to care. For more information on this study and the council, please scan the QR code or visit www.mnraredisease.org

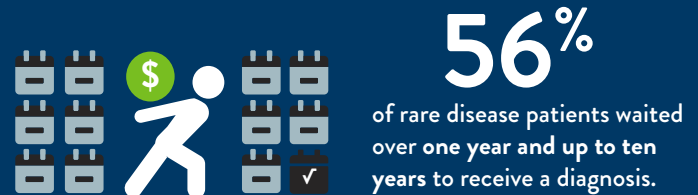


LOCAL CARE? ONLY FOR SOME.

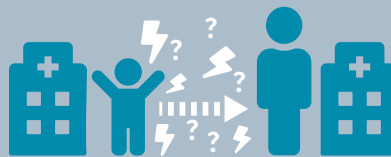
Participants living in outstate Minnesota were more likely to report traveling **over 60 miles** for rare disease care.



DELAYED TIME TO DIAGNOSIS



37% of patients saw
4-10 PROVIDERS
prior to receiving
a diagnosis.



44% of participants reported
problems with **transition from
pediatric to adult care.**

INVESTIGATIONAL DRUG ACCESS

72% MN adult
respondents
79% MN pediatric
respondents



reported delays or denials for use of an
investigational treatment.

CARE COORDINATORS: EQUALLY RARE



12%
of rare disease
patients surveyed have
a care coordinator.

TELEHEALTH'S USEFULNESS



58% of all participants reported
using telehealth visits for
specialist care appointments.

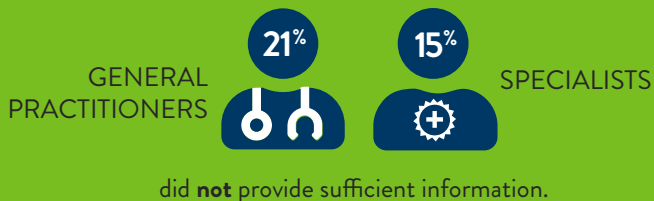
PERCEPTIONS OF PROVIDER KNOWLEDGE



40% rated the initial provider as
"poor" on their knowledge
of rare diseases.



INSUFFICIENT PATIENT EDUCATION FROM PROVIDERS



OUT OF NETWORK ACCESS



27% pediatric **19%** adult
Respondents reported being
initially denied seeing a specialist
due to that specialist being out
of network.

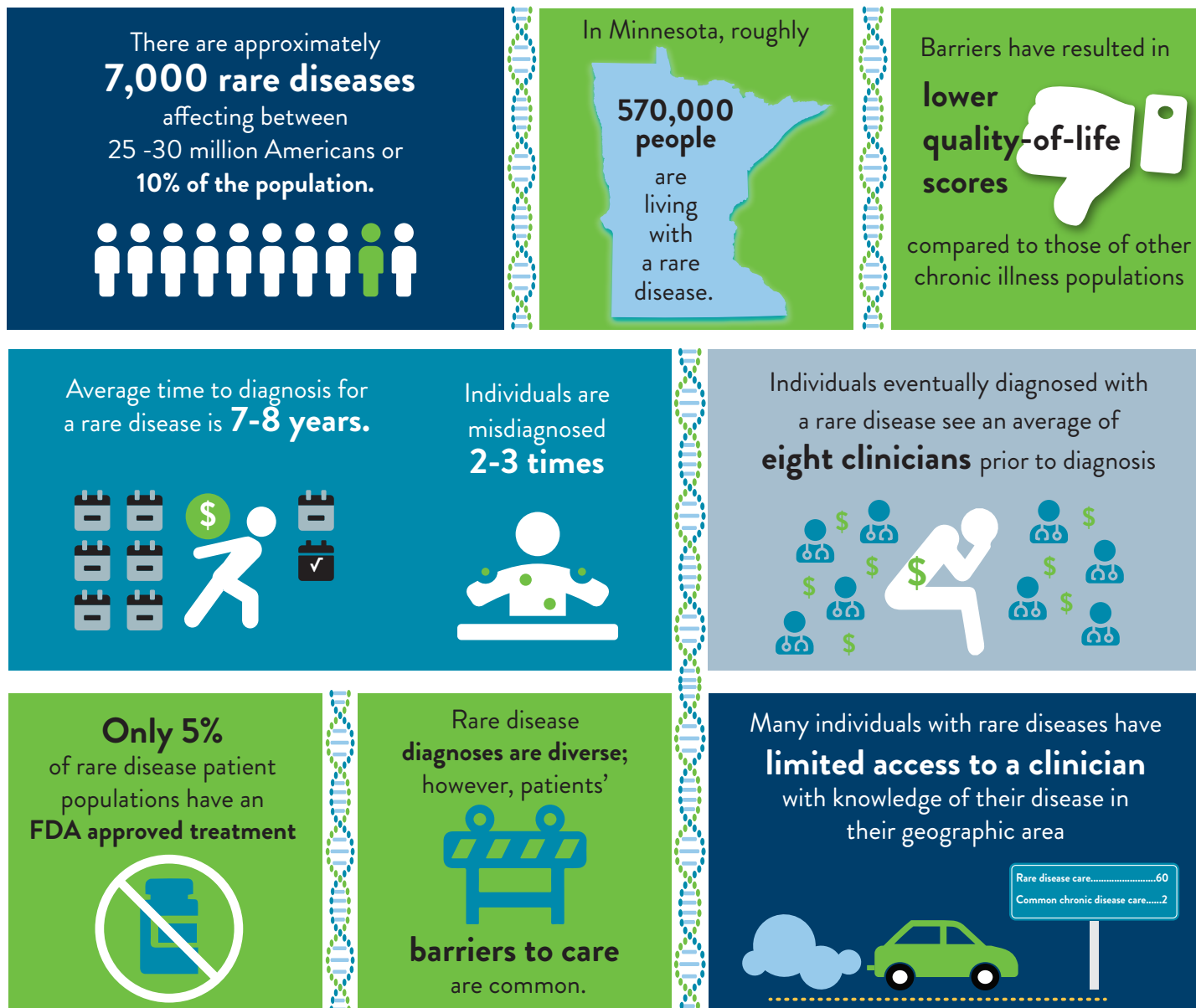
Rare isn't so rare.

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



The **Minnesota Rare Disease Advisory Council** is a newly established agency focused on providing comprehensive policy recommendations related to rare disease care, advising medical community, and engaging the rare disease community in an effort to address the persistent and unique barriers to care faced by individuals with rare diseases.

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



Research footnotes can be found at www.mnraredisease.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.*”