Bringing Care to Rare

MINNESOTA
RARE DISEASE

ADVISORY COUNCIL

Reducing the diagnostic odyssey, addressing health equity, and improving outcomes by allowing out-of-network access for the rare disease community.

HF384/SF1029

The rare disease patient journey is often lengthy and costly.

For many rare disease families, this is time and money they simply don't have.

We can change that.

Patients & Families living with a Rare Disease:

See an average of 8 CLINICIANS*

before getting their diagnosis



Have to wait an average of 7-8 YEARS*

before getting an accurate diagnosis



Receive an
average of
2-3
WRONG
DIAGNOSES*

40%
rated INITIAL
PROVIDER
rare disease
KNOWLEDGE
as POOR^

Report being

DENIED

out-of-network care:

19% OF ADULT PATIENTS^



Report being

DENIED

out-of-network care:

27% OF PEDIATRIC PATIENTS[^]

* www.globalgenes.com ^Bogart, et al. Orphanet J of Rare Diseases (2022) 17:196 Prepared: February 8, 2023

Contact: Erica Barnes, RDAC Executive Director erica.barnes@state.mn.us