

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 please visit www.cbacrareisease.org



SPECIALISTS



PROVIDERS



DENTISTS

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



Over 75%

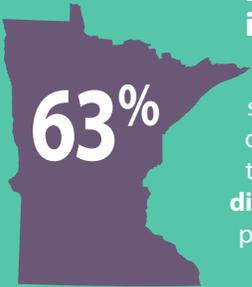
of clinicians are somewhat or not at all comfortable interpreting genetic testing results.



Receiving care in state

63%

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.

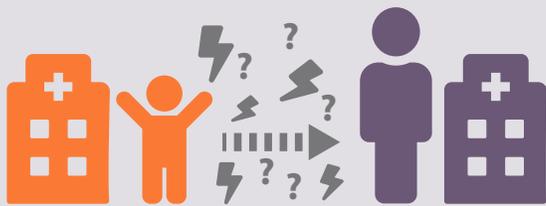


28%

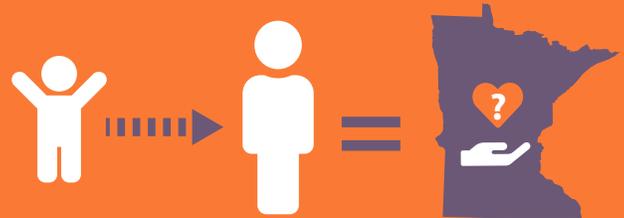
report that many times the type of insurance the patients carries has affected their ability to complete the recommended treatment plan.



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.