

Help us Improve Rare Disease Care in Nevada!

The Nevada Rare Disease Advisory Council (formation during the 2019 legislative session) is developing a statewide website for patients, clinicians, and community-based organizations to readily obtain contacts and resources. Currently, available resources such as insurance directories by specialties are often outdated and inadequate for patients to obtain information on providers in the state who care for rare disease. Additionally, current models for community assistance are often fragmented.

The Nevada Rare Disease Advisory Council is seeking your assistance in providing us your information and information regarding any rare disease conditions you currently treat, rare disease your foundation assists with, or resources you feel may best support this mission. Our hope is that this database will be searchable by diagnosis which will then link to a provider who has informed us they are accepting new patients for care. Additionally, they would be able to connect with local and statewide foundations offering services.

A lottery of individuals submitting their information will be held for an Amazon gift card.

If you currently treat any rare condition or provide any service for patients with rare conditions, please send your contact information and list of current rare diseases served to amber.federizo@htcnv.org.

We know more patients with rare disease or even clinicians looking for resources are out there. Let's find them Nevada!