

## NEW POLICIES THAT SUPPORT THE RARE DISEASE COMMUNITY IN MINNESOTA: WHAT YOU SHOULD KNOW

### Minnesota Rare Disease Advisory Council Budget Request (HF 1501 / SF 2037)

The Minnesota Rare Disease Advisory Council (MNRDAC) was established by the Minnesota Legislature in 2019 to represent rare disease patient communities, which, while individually rare, collectively impact 1 in 10 people. Originally housed at the University of Minnesota, the Council transitioned to a state agency in 2022, similar to the Minnesota Council on Disability. In the 2023 legislative session, the MNRDAC's base operational budget was established; however, only a portion of the budget was established as an ongoing appropriation with the remaining being a one-time appropriation. This significantly limits the MNRDAC's ability to meet its mandate and support Minnesota's rare disease community.

#### BACKGROUND

##### Rare Disease Patients Face Unique Challenges

- The average time to diagnosis is 7-8 years.
- Patients typically receive 2-3 misdiagnoses before an accurate diagnosis.
- Less than 9% of the approximately 10,000 rare diseases have an FDA-approved treatment.
- The healthcare system is not built for patients with rare diseases, leading to inefficiencies and increased suffering.

##### Council Budget and Need for Full Appropriation

- The Council operates with some support from the Minnesota Council on Disability (MDH) but is its own state agency.
- This level of funding is significantly below agencies of comparable scope and function.
- The MNRDAC is requesting the full base budget amount be appropriated this session to fulfill compliance requirements and to execute on its role as an advisory to policy makers and other state agencies.

#### KEY FACTS

- The MNRDAC is a national leader, and its structure and function is seen as a model for other states.
- The MNRDAC advises MDH, DHS, and other state agencies on best practices for treating patients with rare diseases.
- Adequate funding allows the MNRDAC to help state agencies - identify more efficient ways to improve care for the rare disease community, saving money and ensuring that Minnesota's most vulnerable populations receive appropriate care.

#### CONCLUSION

The requested appropriation will allow MNRDAC to fulfill its legislative mandate, improve healthcare efficiency, and ensure that rare disease patients in Minnesota receive the care they need. Investing in the MNRDAC's work is an investment in better health outcomes and cost-effective policy solutions for the state.