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Minnesota Rare Disease Advisory Council

Agency Profile 1

Minnesota Rare Disease Advisory Council — Agency Profile

https://mnraredisease.org/

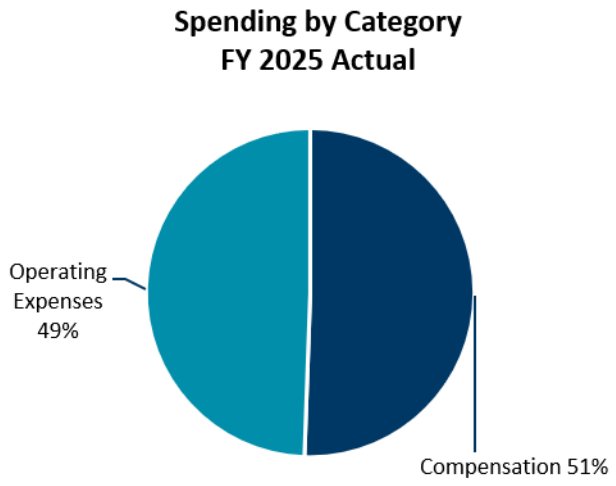
AT A GLANCE

- The Minnesota Rare Disease Advisory Council (MNRDAC) advocates for the one in ten Minnesotans affected by rare diseases. There are roughly 10,000 rare diseases, with only 5% having FDA approved treatment.
- The rare disease community faces unique barriers to care, such as extreme delay in diagnosis, reduced access to providers knowledgeable about their specific rare disease, and lack of formal data to inform care and research. Quality of life measures for these individuals fall below that of even chronically ill patients diagnosed with more common diseases.
- MNRDAC is advised by a diverse, cross-sector Council. Its membership is composed of patients, clinicians, researchers, hospital administration, industry, and legislators.
- MNRDAC currently operates with a staffing complement of 3.6 full-time equivalent (FTE), an annual base appropriation of $679,000.
- MNRDAC provides policy recommendations, engages patient communities in policy and research, and equips the medical community with tools for best practice in rare disease diagnosis and management.
- The majority of identified RDAC policies enjoyed bipartisan support (85%) and RDAC-facilitated input affected change across state agencies (42% increase in prior authorization modifications for specialty drugs following RDAC facilitated comment).
- 84% of clinicians reported RDAC education provided (Project ECHO) is likely to influence their clinical practice.

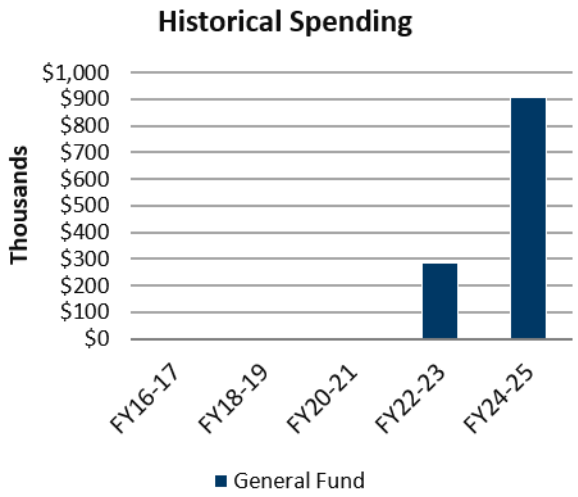
PURPOSE

The Minnesota Rare Disease Advisory Council (MNRDAC) exists to improve care for Minnesotans with rare diseases by ensuring access to timely diagnoses, coordinated expert care, and individualized support and management across the lifespan. MNRDAC works to reduce the unique structural inequities experienced by rare disease patients by using a systems approach and focusing on the common barriers to healthcare that affect all rare disease populations.

BUDGET



Source: Budget Planning & Analysis System (BPAS)



Source: Consolidated Fund Statement

STRATEGIES

In order to achieve its mission, the Council has defined the following goals:

- Be a comprehensive policy and information resource in the state of Minnesota for the legislature, other state agencies, and all entities of State government. To improve healthcare outcomes for rare disease patients, the state of Minnesota must enact innovative policies at every level of state government. The Council influences policy through participation in task forces and other collaborative initiatives in state agencies such as the Department of Human Services, the Minnesota Department of Health, and the Department of Commerce. In addition, the Council uses a deliberative process to collect stakeholder input and identify an annual policy and legislative platform. With support from our four voting legislative members, the Council seeks to enact legislation when appropriate to address the gaps in care for the rare disease community.
- Support and empower the rare disease patient community. The rare disease community is a fragmented patient population in a fragmented healthcare system. Often, patient organizations are parent-founded and lack resources of organizations that represent more common diseases. The Council seeks to increase collaboration 1.) across disease specific patient populations to increase resource sharing, reduce duplication of efforts, identify shared policy goals and 2.) between the rare disease community and researchers, clinicians, and industry to accelerate research and promote clinical trial readiness. The Council executes on this through hosting community events and forums as well as being a hub of information and resources related to rare disease care.
- Support and equip the medical community to better address the unique needs of the rare disease community to reduce health disparities. Knowledge and information related to rare disease diagnosis and treatment can be difficult to find. The Council provides education and support tools to clinicians that identify and promote best practices and increase the ease of getting individuals with rare diseases access to appropriate care. In addition, the Council seeks to influence the next generation of medical professionals by sponsoring clubs such as “Students for Rare” and guest lecturing in various academic classes and medical associations.

Abbey Meyers, founder of the National Organization for Rare Disorders (NORD) said, “Families affected by rare diseases represent a medically disenfranchised population that falls through the cracks of every healthcare system in the world.” By increasing society’s recognition that the rare disease community is a subset of the healthcare population with unique and well-defined barriers to care, the Council seeks to increase equity and access for all individuals living with a rare disease.

RESULTS

Part A: Performance Data

Measure	Measure type	Measure data source	Historical trend	Most recent data
(Legislature) Percent of bills introduced by RDAC with more than 2 cosigners from both political parties	Quantity, result	Bills introduced by RDAC in 2025-26 legislative session		85% (6/7)
(DHS) Number of letters of support/policy recommendations solicited from community, and modifications made by DFC in response	Quantity, result	Letters of comment submitted to Drug Formulary Committee	42% increase in prior authorization modifications since 6/2025	24 total commenters for 20 rare drugs, resulting in 51 specific recommendations from subject matter experts. 22% of prior authorization criteria changed based on RDAC-solicited expert comment
Clinicians will have confidence in engaging with rare disease patients and determining next steps for diagnosis and treatment	Quality, result	Percent of providers who attended an RDAC educational event report anticipated change to clinical practice based on RDAC training	Program implemented in FY 2025 after submission of previous profile report	15 Project ECHO educational sessions since FY25 with 347 registrants 84+% of participants indicate ECHOs are likely to influence clinical change 39% say they can care for rare disease patients better
Rare disease communities receive appropriate support and resources	Quantity	Number of events where RDAC guest spoke, sponsored, co-sponsored, or exhibited	32 events last biennium	26 events (to date) in FY26-FY27
Central information resource for the rare disease patient community	Quantity	Newsletter subscriptions	2,802 subscribers on last report	9,490 current newsletter subscribers

Part B: Evidence of Effectiveness (Required)

This council does not currently implement or directly fund a specific practice, program, or intervention model that has been evaluated for effectiveness using randomized controlled trials, quasi-experimental methods, or other recognized research designs.

M.S. 256.4835 (https://www.revisor.mn.gov/statutes/cite/256.4835) provides the legal authority for MNRDAC.