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# Rare Disease Advisory Council

# Minnesota Rare Disease Advisory Council Agency Profile

https://www.cbacraredisease.org/

## AT A GLANCE

- The Minnesota Rare Disease Advisory Council (MNRDAC) advocates for the one in ten Minnesotans affected by rare diseases. There are over 7,000 rare diseases, with only 5% having an FDA approved treatment.
- The rare disease community faces several unique barriers to care such as extreme delay in diagnosis, reduced access to a clinician knowledgeable about their specific rare disease, and lack of formal data to inform care and research.
- Quality of life measures for these citizens fall below that of even chronically ill patients diagnosed with more common diseases.
- Since inception in 2019, MNRDAC has sought to define the current state of rare disease care in Minnesota by completing extensive research studies of rare disease patients and healthcare providers across the State.
- MNRDAC was originally housed in the University of Minnesota Medical School; however, in July of 2022 the legislature expanded the scope of the Council to explicitly include engaging in policy at which time the Council transitioned to a state agency with the support and mentorship of the Minnesota Council on Disability.
- MNRDAC currently operates with a staffing compliment of 1.00 full-time equivalent (FTE) and an annual appropriation of $150,000 through FY2023.
- MNRDAC is advised by a diverse, cross-sector Council. It’s 25 members represent leaders in non-profit, private, and public entities throughout the state of Minnesota.

## PURPOSE

The Minnesota Rare Disease Advisory Council (MNRDAC) exists to improve care for the rare disease community by ensuring that every Minnesota citizen living with a rare disease has access to a timely diagnosis, expert/coordinated care, as well as individualized treatment, management, and support throughout their lifespan. MNRDAC realizes this purpose by providing advice on research, diagnosis, treatment, and education related to rare diseases to patients and family, healthcare providers, national, state and local governments and the private sector including employers, pharmaceutical companies and insurance companies.

## BUDGET

RDAC was created in FY23, so therefore there is no historical budget data.

## 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 all stakeholders that have engagement with the rare disease community.* The Council builds coalitions and engages in collaborative activities that deepen our understanding of the barriers to care individuals with rare diseases encounter. The Council then seeks to shape policy through communicating the unique healthcare disparities faced by the rare disease community and solutions to address these disparities to policy makers, state agencies, the medical community, and the public. The Council utilizes a bi-directional communication strategy which includes presentations at medical conferences and grand rounds, hosting roundtables and listening sessions, and participating in several consortia and committees.

- *Support and empower the rare disease patient community to advocate for improved quality of life.* The rare disease community is a fragmented patient population in a fragmented healthcare system. The Council seeks to increase collaboration 1.) across disease specific patient populations to increase resource sharing and reduce duplication of efforts 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 promoting Rare Disease Day events and activities across all rare disease communities 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 seeks to make education and resources available 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.

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 of care for the rare disease community.

## RESULTS

| *Type of Measure* | *Name of Measure* | *Previous Value* | *Date* | *Current Value* | *Date* |
|---|---|---|---|---|---|
| Quantity | The Council will provide **consultations and recommendations to relevant stakeholders** through avenues such as letters of support for advocacy groups, policy recommendations to state agencies and legislators, expert advice, and participation in coalitions in order to reduce the identified disparities in healthcare experienced by the rare disease community | | | | |
| Quantity | The Council will engage in **educational and knowledge dissemination activities** to medical associations, advocacy organizations, the general public through methods such as presentations, roundtables, listening sessions, and trainings in order to reduce the knowledge gap between individuals with expertise in rare disease care management and other care professionals | | | | |

| ***Type of Measure*** | ***Name of Measure*** | ***Previous Value*** | ***Date*** | ***Current Value*** | ***Date*** |
|---|---|---|---|---|---|
| Quantity | The Council will **increase the number of identified professionals and organizations** able to provide competent care to individuals with rare diseases through the managing of a clinician contact registry in order to reduce time spent by rare disease patients and medical professionals in seeking appropriate care | | | | |
| Quantity, Quality | The Council will **demonstrate its value as a central information resource for rare diseases** by increasing website visits in order to support patients and clinicians seeking information about rare diseases | | | | |

***(Dollars in Thousands)***

| | Actual FY20 | Actual FY21 | Actual FY22 | Estimate FY23 | Forecast Base FY24 | Forecast Base FY25 | Enacted Budget FY24 | Enacted Budget FY25 |
|---|---|---|---|---|---|---|---|---|
| ***Expenditures by Fund*** | | | | | | | | |
| 1000 - General | | | | 287 | | | 314 | 326 |
| **Total** | | | | **287** | | | **314** | **326** |
| Biennial Change | | | | 287 | | (287) | | 353 |
| Biennial % Change | | | | | | | | |
| Enacted Budget Change from Base | | | | | | | | 640 |
| Enacted Budget % Change from Base | | | | | | | | |

***(Dollars in Thousands)***

| | Actual | Actual | Actual | Estimate | Forecast Base | | Enacted Budget | |
|---|---|---|---|---|---|---|---|---|
| | **FY20** | **FY21** | **FY22** | **FY23** | **FY24** | **FY25** | **FY24** | **FY25** |
| **1000 - General** | | | | | | | | |
| Direct Appropriation | | | | | | | 314 | 326 |
| Transfers In | | | | 287 | | | | |
| **Expenditures** | | | | **287** | | | **314** | **326** |
| Biennial Change in Expenditures | | | | 287 | | (287) | | 353 |
| Biennial % Change in Expenditures | | | | | | | | |
| Enacted Budget Change from Base | | | | | | | | 640 |
| Enacted Budget % Change from Base | | | | | | | | |

*(Dollars in Thousands)*

| | FY23 | FY24 | FY25 | Biennium 2024-25 |
|---|---|---|---|---|
| ***Direct*** | | | | |
| **Fund: 1000 - General** | | | | |
| **Change Items** | | | | |
| Maintain Current Service Levels | | 7 | 15 | 22 |
| Establish Base Budget | | 307 | 311 | 618 |
| **Total Enacted Budget** | | **314** | **326** | **640** |

*(Dollars in Thousands)*

## Maintain Current Service Levels

This provision provides additional operating funds to maintain the current level of service delivery at the Minnesota Rare Disease Advisory Council.

| | FY23 | FY24 | FY25 | Biennium 2024-25 | FY26 | FY27 | Biennium 2026-27 |
|---|---|---|---|---|---|---|---|
| **1000 - General Fund Cost (Savings)** | **0** | **7** | **15** | **22** | **15** | **15** | **30** |
| Expenditures | 0 | 7 | 15 | 22 | 15 | 15 | 30 |

## Establish Base Budget

This provision establishes ongoing base funding for the newly formed state agency, the Minnesota Rare Disease Advisory Council. Funding will be used to hire an Executive Director and Executive Administrative Assistant, and cover operating costs including rent, utilities, and IT costs.

| | FY23 | FY24 | FY25 | Biennium 2024-25 | FY26 | FY27 | Biennium 2026-27 |
|---|---|---|---|---|---|---|---|
| **1000 - General Fund Cost (Savings)** | **0** | **307** | **311** | **618** | **311** | **311** | **622** |
| Expenditures | 0 | 307 | 311 | 618 | 311 | 311 | 622 |