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Minnesota Rare Disease Advisory Council

Minnesota Rare Disease Advisory Council Agency Profile

https://mnraredisease.org/

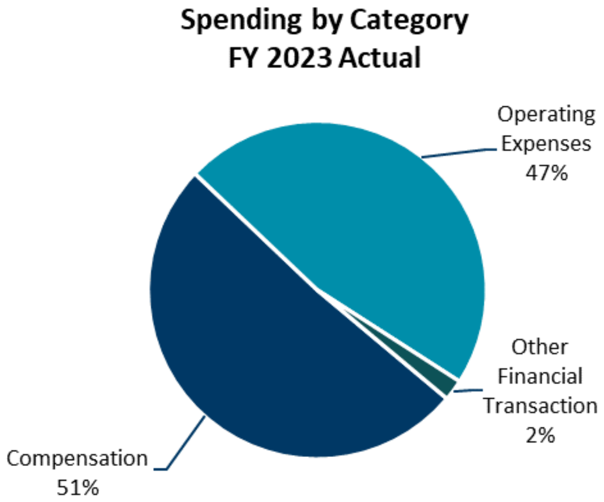
AT A GLANCE

- 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 an 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 citizens fall below that of even chronically ill patients diagnosed with more common diseases.
- Since inception in 2019, MNRDAC has defined baseline data, successfully passed legislation, and influenced policy to improve care and delivery for the rare disease community.
- MNRDAC currently operates with a staffing compliment of 1.8 full-time equivalent (FTE), an annual base appropriation of $326,000, and an additional $342,000 onetime appropriation available through FY27.
- MNRDAC is advised by a diverse, cross-sector Council. Its membership is composed of patients, clinicians, hospital administration, industry, and legislators.

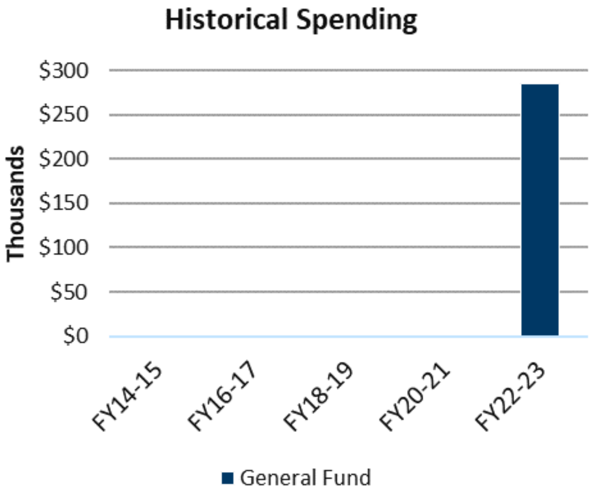
PURPOSE

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 seeks to address the structural inequities over and above those faced by individuals with common diseases by taking a systems approach and focusing efforts on the common barriers to accessing healthcare that crosscut all rare disease patient 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***. 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 consortia and committees.
- ***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 by 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 Advocacy Day events and community 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

Measure name	Measure type	Measure data source	Historical trend	Most recent data
Comprehensive policy resource for state policy makers in order to reduce the identified disparities in healthcare experienced by the rare disease community	Quantity, result	Measured through number of bills supported that successfully passed, number of letters of support provided to collaborative partners, number of recommendations made to MDH/DHS on specific topics, number of boards participated in	No baseline established, new agency	38 (breakdown of types of recommendations/ consultation can be found in annual reports)

Measure name	Measure type	Measure data source	Historical trend	Most recent data
Raise awareness of and provide education for rare disease in order to reduce the knowledge gap between individuals with expertise in rare disease care management and other care professionals	Quantity, result	Number of educational and knowledge dissemination activities to medical associations, academic institutions, advocacy organizations, the general public engaged in (presentations, roundtables, listening sessions, and trainings)	No baseline established, new agency	32 (specific information can be found in annual reports)
Central information resource for the rare disease patient community	Quantity	Newsletter subscriptions order to support stakeholders seeking information about rare diseases	No baseline established; newsletter launched in 2023	2,802 subscribers since launch

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

Rare Disease Advisory Council

Agency Expenditure Overview

(Dollars in Thousands)

	Actual FY22	Actual FY23	Actual FY24	Estimate FY25	Forecast Base FY26	 FY27
Expenditures by Fund						
1000 - General		285	305	677	326	326
Total		**285**	**305**	**677**	**326**	**326**
Biennial Change				698		(330)
Biennial % Change						(34)
Expenditures by Program						
Rare Disease Advisory Council		285	305	677	326	326
Total		**285**	**305**	**677**	**326**	**326**
Expenditures by Category						
Compensation		146	212	354	249	255
Operating Expenses		133	87	316	70	64
Other Financial Transaction		7	7	7	7	7
Total		**285**	**305**	**677**	**326**	**326**
Full-Time Equivalents		**1.24**	**1.93**	**3.30**	**2.00**	**2.00**

(Dollars in Thousands)

1000 - General

	Actual FY22	Actual FY23	Actual FY24	Estimate FY25	Forecast Base FY26	Forecast Base FY27
Balance Forward In				9		
Direct Appropriation			314	668	326	326
Transfers In		287				
Cancellations		2				
Balance Forward Out			9			
Expenditures		**285**	**305**	**677**	**326**	**326**
Biennial Change in Expenditures				698		(330)
Biennial % Change in Expenditures						(34)
Full-Time Equivalents		1.24	1.93	3.30	2.00	2.00

(Dollars in Thousands)

	FY25	FY26	FY27	Biennium 2026-27
Direct				
Fund: 1000 - General				
FY2025 Appropriations	**668**	**668**	**668**	**1,336**
Base Adjustments				
All Other One-Time Appropriations		(342)	(342)	(684)
Forecast Base	**668**	**326**	**326**	**652**