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Minnesota 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				

Agency Expenditure Overview

(Dollars in Thousands)

	Actual	Actual	Actual	Estimate	Forecast Base		Governor's Recommendation	
	FY20	FY21	FY22	FY23	FY24	FY25	FY24	FY25

Expenditures by Fund

	FY20	FY21	FY22	FY23	FY24	FY25	FY24	FY25
1000 - General				287			654	602
Total				**287**			**654**	**602**
Biennial Change				287		(287)		969
Biennial % Change								
Governor's Change from Base								1,256
Governor's % Change from Base								

Expenditures by Program

	FY20	FY21	FY22	FY23	FY24	FY25	FY24	FY25
Rare Disease Advisory Council				287			654	602
Total				**287**			**654**	**602**

Expenditures by Category

	FY20	FY21	FY22	FY23	FY24	FY25	FY24	FY25
Compensation				184			439	457
Operating Expenses				103			215	145
Total				**287**			**654**	**602**

	FY20	FY21	FY22	FY23	FY24	FY25	FY24	FY25
Full-Time Equivalents				**1.50**			**4.00**	**4.00**

(Dollars in Thousands)

	Actual FY20	Actual FY21	Actual FY22	Estimate FY23	Forecast Base FY24	Forecast Base FY25	Governor's Recommendation FY24	Governor's Recommendation FY25
1000 - General								
Direct Appropriation							654	602
Transfers In				287				
Expenditures				**287**			**654**	**602**
Biennial Change in Expenditures				287		(287)		969
Biennial % Change in Expenditures								
Governor's Change from Base								1,256
Governor's % Change from Base								
Full-Time Equivalents				1.50			4.00	4.00

Agency Change Summary

(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
Establishing Program Capacity		340	276	616
Total Governor's Recommendations		**654**	**602**	**1,256**

Minnesota Rare Disease Advisory Council

FY 2024-25 Biennial Budget Change Item

Change Item Title: Maintain Current Service Levels

Fiscal Impact ($000s)	**FY 2024**	**FY 2025**	**FY 2026**	**FY 2027**
General Fund				
Expenditures	7	15	15	15
Revenues	0	0	0	0
Other Funds				
Expenditures	0	0	0	0
Revenues	0	0	0	0
Net Fiscal Impact = (Expenditures – Revenues)	7	15	15	15
FTEs	**0**	**0**	**0**	**0**

Recommendation:

The Governor recommends additional funding of $7 thousand in FY 2024 and $15 thousand in each subsequent year from the general fund to maintain the current level of service delivery at the Rare Disease Advisory Council.

Rationale/Background:

Each year, the cost of doing business rises—employer-paid health care contributions, FICA and Medicare, along with other salary and compensation-related costs increase. Other operating costs, like rent and lease, fuel and utilities, and IT and legal services also grow. This cost growth puts pressure on agency operating budgets that remain flat from year to year. For the Rare Disease Advisory Council, operating cost pressures exist in multiple categories—increases in compensation and insurance costs at the agency, increasing costs to maintain our current staff complement in a challenging labor market, and increasing IT costs.

Agencies face challenging decisions to manage these costs within existing budgets, while maintaining the services Minnesotans expect. The Rare Disease Advisory Council is supported through the general fund and does not collect fees.

Proposal:

The Governor recommends increasing agency operating budgets to support maintaining the delivery of current services. For the Rare Disease Advisory Council, this funding will cover inflationary pressure related to employee compensation and other operating expenses.

Results:

This proposal is intended to allow the Rare Disease Advisory Council to continue to provide current levels of service and information to the public.

Minnesota Rare Disease Advisory Council

FY 2024-25 Biennial Budget Change Item

Change Item Title: Establish Base Budget

Fiscal Impact ($000s)	FY 2024	FY 2025	FY 2026	FY 2027
General Fund				
Expenditures	307	311	311	311
Revenues	0	0	0	0
Other Funds				
Expenditures	0	0	0	0
Revenues	0	0	0	0
Net Fiscal Impact = (Expenditures – Revenues)	307	311	311	311
FTEs	**2**	**2**	**2**	**2**

Recommendation:

The Governor recommends $307 thousand in FY 2024 and $311 thousand in FY 2025 and ongoing to establish the base general fund appropriation for the Rare Disease Advisory Council (RDAC). Funds will be used to fund 2.0 FTE (executive director and an executive administrative support position) and to establish the operations of the newly formed state agency.

This recommendation provides the operational funding needed to establish the RDAC as a state agency, as opposed to an entity housed in the medical school at the U of M. The RDAC was previously a departmental entity of the University of Minnesota (U of M) Medical School reporting to the Board of Regents and funded through a general fund appropriation. This statute sunsets at the end of FY 2023.

Rationale/Background:

Rationale:

- Previous funds appropriated to the U of M were used to fund 1 FTE, minimal operational and business expenses, and council meetings and did not include programming dollars. Placing the RDAC at the U of M provided several no-cost supports that now must be funded to efficiently operate.
- The U of M provided operational support, including human resources, information technology, financial services, subject matter experts, research, and staffing support by the dean of the Medical School. Thus, operational and programming funding were not considered in the original appropriation.
- Prior to the establishment of the RDAC as a state agency, it operated as an adjunct advisory council to the U of M Medical School with a time sensitive, limited scope mandate which was to identify barriers to accessing care for the rare disease community and the associated disparities created by these barriers.
- Satisfying the intent of the original legislative mandate, the RDAC sought to be established as a state agency. During that legislative process, the scope of the agency was expanded as the RDAC was mandated to begin implementation of solutions to identified barriers in collaboration with relevant stakeholders.

Background:

- A rare disease is defined as “a disease or condition that affects less than 200,000 people in the United States”; there are approximately 7,000 rare diseases affecting between 25 and 30 million Americans or 10 percent of the population. In Minnesota, roughly 570,000 people are living with a rare disease.
- Rare disease diagnoses are diverse; however, the barriers to care for those patients face are common.

- Average time to diagnosis for a rare disease is seven to eight years and individuals are typically misdiagnosed two to three times
- Individuals eventually diagnosed with a rare disease see an average of eight clinicians prior to diagnosis
- Only five percent of rare disease patient populations have an FDA approved treatment

Proposal:

This recommendation is to establish the Rare Disease Advisory Council as a state agency. Previous funding sunsets at the end of FY 2023. Additionally, the legislature strengthened the scope and duties of the RDAC when it initially established the entity as a state agency. This recommendation intends to:

- Establish the administrative and operational capacity for the newly formed state agency.
- Operate efficiently and lawfully in compliance with state of Minnesota standards, regulations, policies, and statutory obligations while serving the rare disease community's patients, caregivers, insurers, and the state.

Summary of Proposed Costs

Category	*FY 2024*	*FY 2025*	*FY 2026*	*FY 2027*	*FY 2028*	*FY 2029*
Payroll	224	229	229	229	244	249
FTE is 1 Executive Director and 1 Council Executive Administrative Assistant						
Professional/Technical Contracts	60	60	60	60	60	60
The PT Line above includes $30K per year for contracting with the Department of Administration (SmART) $5K is for website management (a MN.IT related item noted in the IT table below) $25K is to contract for services not included in the FTE complement such as communications and enterprise business operations, including office and storage space						
Equipment, Supplies, Printing, Marketing, Travel	11	9	9	9	9	9
These are costs associated with upstarting an agency; branding, printing, outreach, travel, and purchasing capital equipment, such as desks, printers, AV equipment, etc.						
Training & Employee development	3	4	4	4	4	4
MNIT Enterprise Services (also reflected below)	9	9	9	9	9	9
Total	**307**	**311**	**311**	**311**	**326**	**331**
Agency FTEs	2	2	2	2	2	2

Intended Results

- The intended result of this proposal is to establish adequate base funding that supports effective and compliant operations of a state agency, acknowledging that the supporting resources previously provided by the U of M are no longer available.
- This proposal will fund staffing sufficient to operate the agency's executive functions and its administrative requirements. This requires 1 FTE as Executive Director and 1 FTE as an Executive Admirative Assistant.

- With proper staffing, this recommendation addresses the critical need to provide expertise to support the state of Minnesota's leadership as it makes complex and interconnected policy decisions to address the economic challenges the state faces as the FDA approves new and effective treatments to save the lives of and improve the quality of life for the rare disease patient and support the rare disease medical providers.
- This proposal addresses the policy development limitations that were incidental to being a U of M entity, in that the U of M does not typically endorse or develop public policy opinions or proposals, thus, some duties in the founding legislation were constrained.
- The requested amount is a necessary first step for the Council to reach the goals of empowering the rare disease patient community to advocate for improved quality of life, supporting and equipping the medical community to better address the unique needs of the rare disease community to reduce health disparities as well as the Council's function as policy advisor to the state and legislature.
- Relevant cost drivers for what appears to be an increase in costs is the replacement of the value of services that came with being an associate council entity of the U of M Dean of Medical School's Office. These factors drive the cost to operate:
    - A subject matter expert goes from being a no-cost phone call away at the U of M to a procurement that involves putting the cost of providing services out for bid and the negotiation of a contract and administrative functions to manage the contract.
    - Staffing goes from no cost graduate students and tenured professors who were eager to contribute to research projects for professional advancement to hiring professionals, either by contract or by FTE permanent positions.
    - All business functions provided for no cost such as human resources and financial management are estimated to cost $50,000 annually to remain complaint with state standards.
    - Council meetings held in the research and medical sector had no expectation to comply with open meeting law or data practices requirements that govern public engagement as a state agency.
    - Furnishings, office and storage space, office equipment such as IT/AV and conferencing equipment all provided at no cost at the U of M need to be procured.

While no other agency has rare disease-specific charge, several agencies are undertaking efforts to address the general challenges in healthcare access and delivery. Individuals with rare disease experience these challenges in specific and often unique ways and the RDAC is respected, recognized, and well positioned to function as an advisor. Current state entities that the RDAC advises:

- The Children & Youth with Special Health Needs Program, Community & Family Health, MN Dept Health- addressing inequities in transitioning children from pediatric to adult care.
- The Minnesota Council on Disability partners with RDAC as not every disability is a rare disease, while every rare disease has a disability aspect. These two agencies see efficiencies in partnering to provide stakeholders with necessary resources.
- Opioid Prescribing Improvement Program-(and workgroup) consulted RDAC to assist in developing specific policy solutions for the 2022 legislative session requiring opioid restrictions take into account the unique challenges in pain management experienced by the rare disease community
- Advisory Committee on Heritable and Congenital Disorders (also called the Newborn Screening Advisory Committee)- often deliberates on the addition of rare diseases to the state's newborn screening program
- Drug Utilization Review Board and Drug Formulary Committee recommends the drugs covered by Medicaid and MinnesotaCare through the uniform preferred drug list, some of which are indicated for use in the rare disease patient population

Adequate funding for RDAC establishes a comprehensive policy and information resource for Minnesota stakeholders that have engagement with the rare disease community. The outcome will be improvement in 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.

The RDAC is uniquely poised to contribute to innovation to address the challenges the rare disease community face. The Council is comprised of members who represent the top leadership and decision makers of from the private for profit, nonprofit, and public sectors. These leaders provide a cross-sector, cross institution perspective in the health care system and are intensely committed to innovation. They meet regularly and provide the only collective resource of "at the ready" decision makers in this sector.

On-boarding the RDAC as a state agency is underway with support from the Minnesota Council on Disability, the Admin SmART Team, and MMB.

To evaluate the success of this proposal the RDAC will assess:

- It's effective and compliant onboarding to the State enterprise via established processes and procedures, and ensuring the administrative foundation of the agency is developed in alignment with all regulatory requirements
- Implementation thereof
- The RDAC will evaluate whether the number of consultations and recommendations it has provided to relevant stakeholders has increased
- Evaluate the satisfaction of those stakeholders

Impact on Children and Families:

While a rare disease can affect an individual at any age, children are estimated to make up over half of the rare disease population. The disproportionate effect of rare disease on children means that not only the individual child is affected, but also their adult caregivers. A 2022 RDAC survey, which is one of the largest surveys of the rare disease population in the US, found that healthcare quality of life scores for rare disease patients fall below that of other individuals living with more common chronic illnesses. One identified reason for this in adolescents is the isolation that a lack of knowing anyone else with a rare disease can cause. By creating opportunities for peer relationships/mentorships, especially during transition of care from pediatrics to adult, the RDAC anticipates that the community's quality of life scores will improve.

Equity and Inclusion:

An axiom that is often repeated in medical school is "when you hear hoofbeats look for horses and not zebras." This phrase is used to direct medical students to look for common diseases (horses) and not rare diseases (zebras). This phrase perfectly illustrates the bias that the rare disease community, which is part of the disability community, encounters when seeking diagnosis and treatment. Unsurprisingly, the healthcare metrics for the rare disease population fall significantly outside of those for the average person seeking healthcare (see background section). This proposal will allow the Council to continue education efforts at medical conferences throughout the state addressing this bias.

In addition to general bias negatively affecting all rare disease patient communities, rare patient communities that include a high proportion of people of color face the additional barrier of systemic racism. The RDAC addresses racial and economic disparities by engaging in educational forums and discussions with students on the specific ways that patient communities such as the sickle cell community have encountered racism when seeking medical care and collaborating with the University Theater Arts Department to develop a play based in part on this aspect of rare diseases. Additionally, the RDAC actively participates in the activities of the Sickle Cell Data Collection Multidisciplinary Team at MDH, which also addresses issues of racial inequities.

The RDAC understands tribal communities are underrepresented in any health care disparity. In addition, some tribal communities have higher incidences of specific rare diseases than the general population and the agency is committed to establishing relationships with tribal communities.

Tribal Consultation:

Does this proposal have a substantial direct effect on one or more of the Minnesota Tribal governments?

☐Yes
☒No

IT Costs

Category	*FY 2024*	*FY 2025*	*FY 2026*	*FY 2027*	*FY 2028*	*FY 2029*
Payroll						
Professional/Technical Contracts	5	5	5	5	5	5
Infrastructure						
Hardware						
Software						
Training						
Enterprise Services	9	9	9	9	9	9
Staff costs (MNIT or agency)						
Total	**14**	**14**	**14**	**14**	**14**	**14**
MNIT FTEs						
Agency FTEs						

Results:

Initial data relates to activities conducted in 2021.

Type of Measure	*Name of Measure*	*Current Value*	*Date*	*Projected Value (without)*	*Projected Value (with)*	*Date*
Quantity	Consultations and collaborations with relevant stakeholders	7	2021			
Quality	Provide expert advice and letters of support for advocacy groups	5	2021			
Results	Provide policy recommendations to state agencies and legislators	3	2021			
	Presentations and trainings	17	2021			
	Listening Sessions	4	2021			

Minnesota Rare Disease Advisory Council

FY 2024-25 Biennial Budget Change Item

Change Item Title: Establishing Program Capacity

Fiscal Impact ($000s)	**FY 2024**	**FY 2025**	**FY 2026**	**FY 2027**
General Fund	340	276	276	276
Expenditures	0	0	0	0
Revenues	0	0	0	0
Other Funds				
Expenditures	0	0	0	0
Revenues	0	0	0	0
Net Fiscal Impact = (Expenditures – Revenues)	340	276	276	276
FTEs	**2**	**2**	**2**	**2**

Recommendation:

The Governor recommends appropriating $340 thousand in FY 2024 and $276 thousand in FY 2025 and ongoing to fund the expansion of the Rare Disease Advisory Council (RDAC).

This recommendation funds an expansion of the Council to build on the foundational work accomplished when it was affiliated with the University of Minnesota (U of M) Medical School related to identification of barriers to care for the rare disease community faces as well as potential solutions. To comply with the expanded duties, the RDAC will begin programming to address the identified barriers and actively seek and lead public policy solutions to those barriers.

This recommendation includes 2.0 FTE to staff public policy development and program implementation, IT professional and technical contracts to enroll in critical web-based resource tool, a clinician contract registry data base, an enterprise compliant website, and operating costs to support these activities.

Rationale/Background:

The RDAC moved from a departmental entity of the University of Minnesota (U of M) Medical School reporting to the Board of Regents to a newly established state agency during the 2022 legislative session. Further, the legislature strengthened the scope and duties of the Council in addition to establishing it as a state agency. The RDAC is advised by a diverse, cross-sector Council. Its 25 members represent leaders in non-profit, private, and public entities throughout the state of Minnesota. Previous funding sunsets at the end of FY 2023.

In recent years, interest in developing novel treatments for rare diseases has significantly increased and with it rare disease FDA approvals, many of which are cell and gene therapies. While these treatments hold potential to significantly improve care for individuals with rare diseases, they also come with a number of policy, access, and economic challenges that states will need to deliberate on and address. Since what is common sense for common diseases is not always common sense for rare diseases, it is crucial to the state of Minnesota that relevant state agencies, the legislature, and the administration have the expertise of the RDAC to advise on these complex decisions.

This recommendation establishes programmatic and public policy development activities for the only state agency tasked with addressing the rare disease community as a distinct patient population and addressing the unique barriers individuals with rare diseases face in accessing care.

Rare diseases carry a heavy economic cost to both individuals with rare diseases and the healthcare system and payers, such as Medical Assistance, which require improved policy as well as quality improvements to address.

Proposal:

This recommendation seeks to secure programmatic and public policy development funding to address the duties mandated in legislation for this newly established agency. It should be noted that the RADC does not seek to 'expand' per se, but rather fund a base to begin its programmatic and public policy work as a state agency to comply with its legislative duties. By aligning the Council's budget with the legislative mandate, the Council will have opportunities to collaborate with the private and not-for-profit sectors and develop programs to ensure that innovations and advances being are equitably shared across all patient populations. This change item allows the RDAC to shift from *identification* of barriers and solutions to *implementation* of project programs and collaborative activities with relevant stakeholders related to education and quality improvement that address the identified barriers.

Programs and projects to address the above statutorily mandated duties:

1. *Rare disease focused virtual tele-mentoring program (Project ECHO)* for general care practitioners by medical specialists with expertise in rare diseases. In a 2021 Council survey focused on front line care provider knowledge of rare diseases, the majority of clinicians reported having little knowledge of rare diseases. Over a quarter responded that their knowledge was not sufficient for their practice.
    - <u>Outcomes</u>: increased access for the primary care physician to rare disease knowledge through engagement with specialists leading to reduced time to diagnosis and improved care for individuals with rare disease
2. *Clinician Contact Registry* – Because rare diseases are not an identified population in the healthcare system and the role of "rare disease specialist" is non-existent, clinicians and families expend significant time searching for a provider with expertise in a particular rare disease or complex care specialty.
    - <u>Outcomes:</u> reduced time to diagnosis, improved coordination of care between physicians, quality improvements leading to decreased workload for clinicians
3. *Expanded educational programs*: presentations at grand rounds, 1-hour webinars designed for medical schools, monthly mentorship programs for patient advocacy leaders. In the 2022 clinician survey, 90 percent of clinician participants responded that they would benefit from more education related to rare diseases. Additionally, patient advocacy organizations are often led by family members whose loved one has been affected by a rare disease and they lack the connections to the research and medical community as well as the knowledge of what they can do to advance research.
    - <u>Outcomes</u>: Increased awareness/ identification of rare disease, reduced time to diagnosis, acceleration of research through connecting the patient and research community
4. *Centralized resource* library of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to rare diseases. Information on rare diseases is often fragmented and difficult to locate.
    - <u>Outcomes</u>: increase access to vital information for the rare disease patient, medical community and policy makers.
5. *Pilot projects* that address the critical need for early identification of many rare diseases. The significant delay in diagnosis is a cost driver for both the healthcare system and the families affected by a rare disease. The Council has identified a number of projects related to reducing the time to diagnosis, which may in turn reduce healthcare utilization and thus overall healthcare costs.
    - <u>Outcomes</u>: reduced time to diagnosis

This recommendation will establish the Minnesota Rare Disease Advisory Council as the *comprehensive policy and information resource in the state of Minnesota for all stakeholders that have engagement with the rare disease community*, enable the Council to *support and empower the rare disease patient community to advocate for* *improved quality of life*, and ensure that the Council can *equip the medical community to better address the unique needs of the rare disease community to reduce identified health disparities*.

By funding programmatic aspects of the RDAC, individuals with rare diseases will have:

- Access to more knowledgeable and competent care (due to the knowledge increase in the medical community)
- Reduced time to receiving a diagnosis (through quality improvements in healthcare systems and better application of recent advancements in diagnostic tools)
- Increased access to effective treatments (through improved policies at the state and federal level and mentorship activities)

Category	***FY 2024***	***FY 2025***	***FY 2026***	***FY 2027***
Payroll	208	213	213	213
Professional/Technical Contracts*	*96*	*36*	*36*	*36*
Outreach (marketing)	9	9	9	9
Hardware	3	0	0	0
Accreditation	2	2	2	2
Training/Prof Development, Travel	9	6	6	6
Enterprise Services*	10	7	7	7
Other MNIT Costs*	*3*	*3*	*3*	*3*
Total	**340**	**276**	**276**	**276**
Agency FTEs	2	2	2	2

Impact on Children and Families:

While a rare disease can affect an individual at any age, children are estimated to make up over half of the rare disease population. The disproportionate effect of rare disease on children means that not only the individual child is affected, but also their adult caregivers. A 2022 RDAC survey, which is one of the largest surveys of the rare disease population in the US, found that healthcare quality of life scores for rare disease patients fall below that of other individuals living with more common chronic illnesses. One identified reason for this in adolescents is the isolation that a lack of knowing anyone else with a rare disease can cause. By creating opportunities for peer relationships/mentorships, especially during transition of care from pediatrics to adult, the RDAC anticipates that the community's quality of life scores will improve.

Equity and Inclusion:

An axiom that is often repeated in medical school is "when you hear hoofbeats look for horses and not zebras". This phrase is used to direct medical students to look for common diseases (horses) and not rare diseases (zebras). This phrase perfectly illustrates the bias that the rare disease community, which is part of the disability community, encounters when seeking diagnosis and treatment. Unsurprisingly, the healthcare metrics for the rare disease population fall significantly outside of those for the average person seeking healthcare (see background section). This proposal will allow Council to continue education efforts at medical conferences throughout the state addressing this bias.

In addition to general bias negatively affecting all rare disease patient communities, rare patient communities that include a high proportion of people of color face the additional barrier of systemic racism. The RDAC addresses racial and economic disparities by engaging in educational forums and discussions with students on the specific ways that patient communities such as the sickle cell community have encountered racism when seeking medical care and collaborating with the University Theater Arts Department to develop a play based in part on this aspect of rare diseases. Additionally, the RDAC actively participates in the activities of the Sickle Cell Data Collection Multidisciplinary Team at MDH, which also addresses issues of racial inequities.

The RDAC understands tribal communities are underrepresented in any health care disparity. In addition, some tribal communities have higher incidences of specific rare diseases than the general population and the agency is committed to establishing relationships with tribal communities.

Tribal Consultation:

Does this proposal have a substantial direct effect on one or more of the Minnesota Tribal governments?

☐Yes
☒No

Results:

The work and success of the Council will be evaluated using the following **Performance measures:**

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 to reduce the identified disparities in healthcare experienced by the rare disease community	Newly established agency-no historic data			
Quantity	The Council will engage in **educational and knowledge dissemination activities** to medical associations, advocacy organizations, the 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	Newly established agency-no historic data			
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	Newly established agency-no historic data			

Type of Measure	***Name of Measure***	***Previous Value***	***Date***	***Current Value***	***Date***
	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 to support patients and clinicians seeking information about rare diseases	Newly established agency-no historic data			

The RDAC will begin implementation of the scientific approaches that have been identified to remove barriers for the rare disease patient and provider community. The previous partnership with the U of M centered the RDAC in evidence-based approaches and strategies, identified by the medical provider, patient, and health care systems communities. The intention of the agency capacity building proposal will the to implement and measure those strategies.

To evaluate the success of this proposal, the RDAC will assess whether or not processes and procedures in alignment with all regulatory requirements have been established and implemented and whether or not the number of consultations and recommendations we have provided to relevant stakeholders has increased. Additionally, the RDAC will assess the percentage of increase across the identified performance measures.

By January 1 of each year, the advisory council is required to report to the chairs and ranking minority members of the legislative committees with jurisdiction over higher education and health care policy on the advisory council's activities. Performance data will be collected and recorded by council staff and included in the annual report.