

# PATIENT ADVOCACY GROUP LISTENING SESSION: *INSIGHT REPORT*

*The need for a collective voice for the rare disease community at the state government level catalyzed the Council to host regular patient advocacy group listening sessions to better understand the community's perspective. This report summarizes the June 2023 listening session.*





## DESCRIPTION AND OBJECTIVES

The Minnesota Rare Disease Advisory Council (MNRDAC) hosted a post 2023 legislative session listening session on June 23, 2023. The objective of the listening session was to provide a debrief of the MNRDAC legislative priorities outcomes to Minnesota patient advocacy groups (PAGs) as well as gain insights on issues of concern to the rare disease community in order to incorporate these in Council priorities for the 2024 legislative session. In total, seven PAGs\* participated in the session including:

[ALS Association](#)

[Hemophilia Foundation](#)

[Krabbe Connect](#)

[Mito Action](#)

[Organic Acidemia Association](#)

[Pompe Warriors Foundation](#)

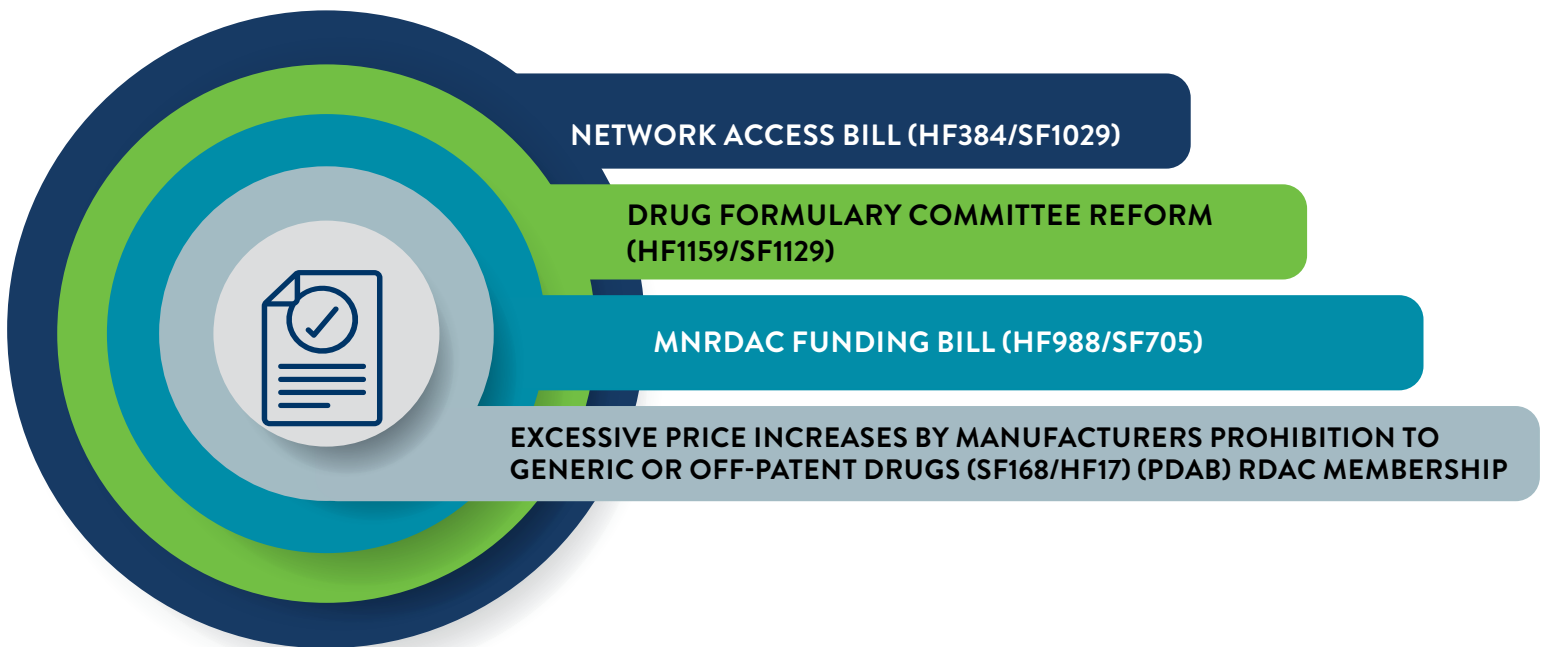
[Sickle Cell Foundation of MN, ED Foundation](#)

\*Click organization above to their visit website



## OVERVIEW OF MNRDAC LEGISLATIVE PRIORITIES AND OUTCOMES PRESENTED

The PAGs were provided an overview of the Council’s 2023 policy priorities and their outcomes. The outcomes presented and discussed are summarized as follows:



## OVERVIEW OF MNRDAC LEGISLATIVE PRIORITIES AND OUTCOMES PRESENTED

### NETWORK ACCESS BILL (HF384/SF1029)

The HHS Omnibus included this landmark legislation that allows individuals with a diagnosed rare disease (or a suspected rare disease defined by specific criteria) to receive care from a specialist with expertise in their rare disease without being assessed an out-of-network fee by health plans.

### DRUG FORMULARY COMMITTEE REFORM (HF1159/SF1129)

The HHS Omnibus contained language that makes significant positive modifications relevant for the rare disease community to the Drug Formulary Review Committee (the committee that oversees the state's preferred drug list). Reforms include the addition of the MNRDAC as a voting member, the addition of a physician with knowledge of rare diseases, and some improvements to access for specific medications.



### EXCESSIVE PRICE INCREASES BY MANUFACTURERS PROHIBITION TO GENERIC OR OFF-PATENT DRUGS (SF168/HF17) (PDAB) RDAC MEMBERSHIP

The Commerce Omnibus Bill included language to create a Prescription Drug Affordability Board (PDAB). The MN Rare Disease Advisory Council is included, serving in an advisory capacity.

### MNRDAC FUNDING BILL (HF988/SF705)

The final amount that the HHS omnibus appropriated to the MN Rare Disease Advisory Council is \$314,000 for FY23 and \$326,000 thereafter. While this is just over double the original budget, it does not include the amount requested to increase program capacity. The sunset was removed, meaning this is a base budget that does not expire in four years as did the original funding.



## OVERVIEW OF MNRDAC LEGISLATIVE PRIORITIES AND OUTCOMES PRESENTED, *continued*

To provide broader context to the discussion, policy consultant Jennifer Wirick-Breitinger, JWB Associates, provided a general summary of the legislative session. This year was fast paced with pent-up demand from last year, which had seen no state budget passed. Due to both a significant budget surplus and single party control of the legislature and executive branch, a large volume of bills relating to an array of issues passed.

Issues of potential relevance to the rare disease community and specific to health care included:

- Legalization of cannabis
- Sick and safe time
- Family medical leave
- Hospital staff plans
- The health care affordability board
- No surprises act billing changes
- Programs to monitor long Covid
- A moratorium on certain health plan conversions (excluding the Fairview/Sanford proposed merger)

Bills such as ensuring that patient assistance programs are used for patient cost sharing and do not go directly to insurance companies (similar to copay accumulator efforts in previous sessions) and obtaining additional funding for the MNRDAC are topics that are expected to continue next session. Additionally, some issues that saw legislation pass may continue in the next session in the form of clarifying legislation.

Attendees also requested an update from Jennifer on the following pieces of legislation:

- Creation of an Office of African-American Health (included in the Omnibus bill)
- Elimination of parent fees for TEFRA (passed)



## COMMUNITY FEEDBACK

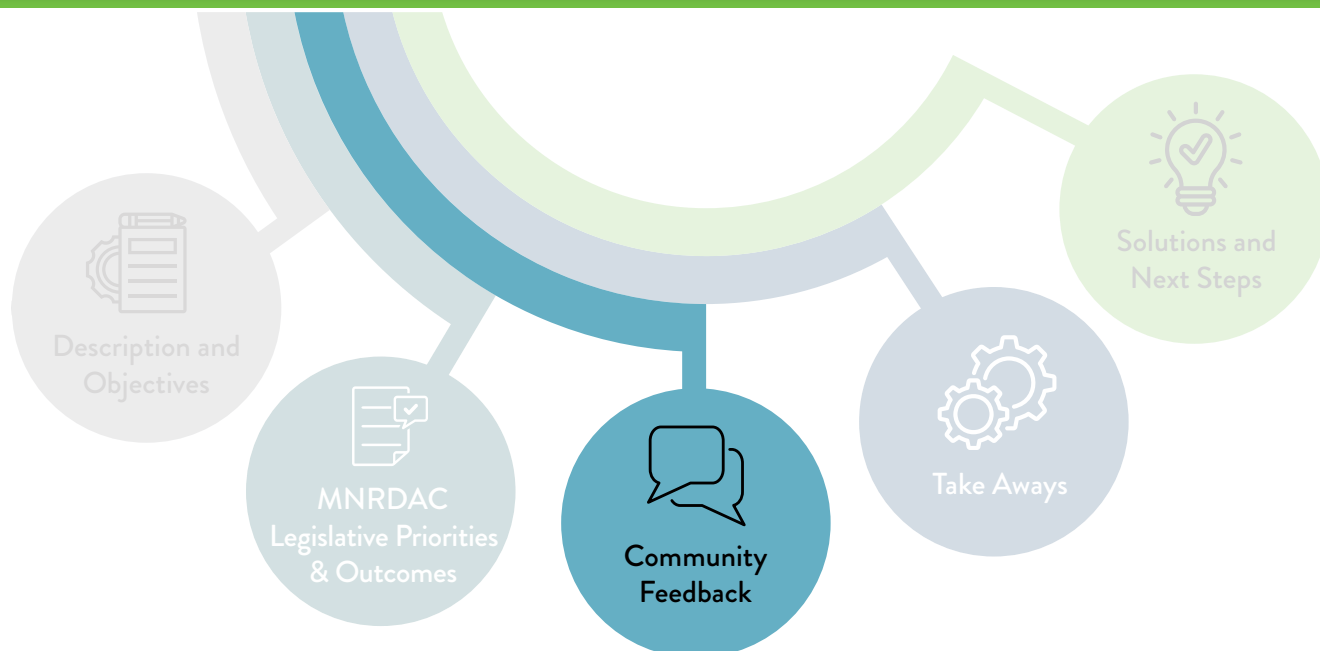
### *General challenges*

The PAGs provided feedback on some specific challenges that the rare disease community, caregivers, and advocates encounter in the medical and social services system. Various patient groups cited the lack of established standards of care for specific rare disease populations as well as difficulty accessing medically necessary services (medical foods, dental care) as common barriers encountered.

Additionally, participants raised concern that there are a limited number of doctors for many rare diseases and little information to guide clinical practice, meaning that many physicians will continue to find it challenging to care for individuals with rare diseases. While the network access bill will address this in part, the issue of no standards of care for a significant number of rare disease patient populations was raised. This could be an issue to discuss with those that regulate doctors or specialist including the county and state medical associations or those that license doctors and related health care professionals. The group suggested engaging the Minnesota Board of Medical Practice on the topic of the need for establishing standards of care for rare diseases.

Another area of concern across the patient groups was the issue of cost sharing. The group discussed the practice of health insurers disallowing patient assistance programs to be counted towards co-pays and deductibles.

Access to medical foods varied across the patient groups in attendance, with some reporting ease of access and others reporting significant challenges to what their community judges as medically necessary foods. Coverage of medical foods was identified as something that could be a common goal for the rare disease community to advocate for.



## COMMUNITY FEEDBACK, *continued*

Finally, participants discussed a need for general awareness of the rare disease community as a collective population. Lack of public awareness of the prevalence of rare diseases as well as the significant time to diagnosis were cited as particularly important facts to communicate more widely. Some periodic, public-facing planned activities were suggested such as a “Day at the Capitol.”

### *Legislation- specific feedback*

The PAGs were asked to share any specific Minnesota bills they were tracking/working on or bills they were aware of that could benefit their community. The two pieces of legislation that were identified by the participants were co-pay accumulator bills and legislation to expand dental coverage currently considered not medically necessary to a cluster of rare disease patient populations.

In general, many participants expressed their hesitancy to get involved in legislative activities, citing lack of experience and the fact that tracking/passing legislation is a time-intensive task for small organizations when other priorities such as running their organizations or caring for family members needed to be higher priorities. Levels of experience and expertise varied significantly across the organizations, but the group concluded that a legislative lobbying teach-in would be beneficial to all PAGs focused on rare diseases. The workshop could include identification of “best practices” related to how to communicate with legislators and staff as well as instruction on how to tell your story as an advocate.



## TAKE AWAYS

More public awareness of the rare disease community is needed in order to increase general understanding of the unique challenges the rare disease community encounters. The lack of a cohesive and collective voice at the state legislature is due in part to small patient groups that have limited resources and expertise. In addition, more public awareness of the rare disease community is needed to increase general understanding of the unique challenges the rare disease community encounters. The lack of a cohesive and collective voice at the state legislature is due in part to small patient groups that have limited resources and expertise in relation to legislative engagement. Clearly, there are cross-cutting issues that affect multiple rare disease communities and some of these were identified in the listening session. Further opportunities to convene the community would be beneficial. In addition, issues of concern raised by the PAGs in attendance reflected findings of [a survey](#) conducted by the Council in 2020-21 which focused on identifying common barriers to care across rare diseases. Low medical provider knowledge, inadequate insurance coverage for some aspects of care and treatment, and barriers to accessing a specialist were reported in the survey.





## SOLUTIONS AND NEXT STEPS

- “Rare at the Fair” with a focus on increasing the public’s general awareness of facts relating to the rare disease community
- Advocacy workshops and toolkits to better equip the rare disease community to engage with state legislators
- “Day at the Capitol” to unify diagnosis-specific rare disease communities and present a collective voice
- Continued forums for the rare disease community to bring priorities and legislation of interest forward with an increased number of participating PAGs



SOLUTIONS AND NEXT STEPS, *continued*



**GENERAL CHALLENGES**



General advocacy training and support needed



Limited access to medical expertise, limited access to treatments



Specific bills: copay accumulators, dental coverage

**SOLUTIONS AND NEXT STEPS**

**Training and infrastructure support needs**

- Public-facing awareness building for the rare disease community as a collective group
- Advocacy workshops and resources to increase PAGs' confidence and effectiveness in engaging on policy

**Identification of cross-cutting barriers**

- Limited medical expertise for specific rare disease communities
- Lack of access to medically necessary treatments (medical foods, dental coverage, off-label medications)

**Deliberation on specific legislative priorities**

- Copay accumulator bills
- Expanded dental coverage for treatments currently considered "not medically necessary"