

# MINNESOTA RARE DISEASE ADVISORY Council

## OPERATING PROCEDURES

Revised and approved January 2023

### ARTICLE I. PURPOSE, POWERS, AND DUTIES

#### SECTION 1 - STATUTORY PURPOSE

- A. This Council was created by the Minnesota Legislature in 2022. This Council and its membership and duties are described in [Minnesota Statute section 137.68 \(2020\), which was amended by 2022 Minnesota Laws Chapter 98 Article 13, Section 2, and will be renumbered as Minnesota Statutes section 256.4835](#). The Council is intended to function in an advisory capacity for the State of Minnesota.
- B. Per Statute, the Council is to provide advice on research, diagnosis, treatment, education, and policy related to rare diseases. The Council works in conjunction with the state's medical schools, the state's schools of public health, and hospitals in the state that provide care to persons diagnosed with a rare disease.

#### SECTION 2. POWERS AND DUTIES

The Minnesota Rare Disease Advisory Council shall have the duties and powers described in Minnesota Statutes section 256.4835.

### ARTICLE II. COUNCIL MEMBERSHIP

#### SECTION 1. COMPOSITION

The Council shall have the membership described in Minnesota Statutes section 256.4835 subd 2.

#### SECTION 2. MEMBER RESPONSIBILITIES

In accepting appointment to the Council, members are expected to:

- A. Attend Council meetings and other assigned meetings;
- B. Serve on work groups and other advisory groups as requested by the Chair;
- C. Prepare for active participation in discussions and decision-making by reviewing meeting materials;
- D. Act as a liaison when appropriate between constituent groups and the Council;
- E. Inform constituent groups of Council activities, actions, and issues;
- F. Recognize the importance and value of including Council members with diverse languages,

modes of communication, hearing status, ages, education, and life experiences;

G. Conduct themselves with a high standard of professional behavior by treating each other with respect throughout the process; and

H. Refrain from writing letters or engaging in other kinds of communication in the name of the Council without Council approval

I. Advise the Council staff about the implementation of Council objectives and activities and, as appropriate and feasible, participate in the implementation of such objectives and activities

If it appears there has been a violation of paragraph (F), the procedures detailed in Section 6(A) of this article shall be followed.

### SECTION 3. CONFLICT OF INTEREST

The Minnesota Rare Disease Advisory Council may make decisions that substantially affect financial or organizational interests within the disability field. The actions of the Council on Disability should be as free from conflict of interest as possible.

A conflict of interest may exist when a member of the Council participates in a Council action that directly affects that member's financial or organizational interests. A Council action that directly affects a member's organizational interests is one that will likely affect the operation, services or programs of an organization or agency when the Council member serves on the governing board of that organization or agency.

In order to avoid conflicts of interest or the appearance of conflicts of interest, Council members who have or think they may have a conflict of interest shall declare that there is, or may be, a conflict of interest. Where a conflict of interest may exist, the Council member may request a determination from the Council. Where a conflict of interest is determined to exist, Council members shall abstain from voting and shall be recorded as abstaining when votes are taken.

The following are examples of the types of "financial or organizational interest" that may exist:

1. The Council member or a member of the Council member's family is an officer of the organization, serves on a committee that governs the organization, or serves on the board of any organization of which the financial interests are directly affected by decisions of the Council.
2. The Council member or a member of the Council member's family is employed by or is a consultant paid by any organization of which the financial interests are directly affected by decisions of the Council.

If it appears there has been a violation of this section, the procedures detailed in Section 6(A) of this article shall be followed.

Council members will review and sign an Annual Conflict of Interest statement.

## SECTION 4. TERMS

The terms of the members shall be as prescribed by Minnesota Statute section 256.4835.

## SECTION 5. COMMUNICATION

- A. Council members will follow communication procedures in alignment with Open Meeting Law as specified in Minnesota Statutes, Chapter 13D
- B. Council members will communicate externally in ways that support the collective work and mission of the Council, while adhering to Open Meeting Law as specified in Minnesota Statutes, Chapter 13D.
- C. Council members will bring any issues or concerns related to the function of the Council and its mission, to the Executive Subcommittee to resolve
- D. Council members will communicate with one another during the meetings and outside the meetings related to the Advisory Council's work, in a respectful, professional manner and refrain from engaging in negative personal attacks in any verbal or written communication. All communications must align with Open Meeting Law as specified in Minnesota Statutes, Chapter 13D.
- E. Council members will refrain from reporting the opinions of other members without permission.
- F. Council members will characterize decisions accurately.
- G. Council members will share information with the organizations/constituents they represent and in turn bring the input of these groups back to the Council.

## SECTION 6. REVIEW PROCESS FOR RECOMMENDATION FOR REMOVAL FROM COUNCIL MEMBERSHIP

Pursuant of MS 15.059 Subd 4 a member may be removed by the appointing authority at any time at the pleasure of the appointing authority.

- A. When the Council Chair has reason to believe that a Council member has violated the provisions of Article II, Section 3, or Article II, Section 5, the Chair shall call a special meeting of the Executive Committee to take place in no less than 10 working days. The Chair shall then contact the member in question by registered mail, requesting the member to appear before the Committee or respond in writing, to explain the actions that it is investigating. The Chair shall also furnish the member with copies of all materials relevant to the investigation. The Committee's task shall be to determine whether a violation has occurred and, if so, to decide on appropriate disposition. Following the meeting, if it is requested by the member in question, the Committee shall provide an additional period before making a final determination in order to allow the member to respond to new information that arose at the meeting. This period of time shall not be less than 30 days. Additional meetings may be held if necessary.

At the first Council meeting following the Executive Committee's final determination, the Committee shall report its findings to the Council and recommend an appropriate disposition, which may include a request to the Governor for the member's removal from the Council. The

Council shall make its final decision on the disposition of the issue by a simple majority vote of the Council membership.

- B. Pursuant to MS 15.059 Subd. 4, (2001), when Council members miss two consecutive meetings and are therefore not in compliance with Article II, Section 5, the Council Chair shall inform them in writing and before the next meeting that they may be removed from the Council by the Governor as appointing authority if they are absent from the next meeting. If they then miss that meeting, the Chair shall notify the Governor in writing of this fact.

## SECTION 7. REIMBURSEMENT

Public members serve without compensation but may have expenses reimbursed as provided in section 15.059, subdivision 3. Legislative members may receive per diem according to the rules of their respective bodies.

## ARTICLE III. MEETINGS

This section applies to meetings of the Council, subcommittees, and work groups, unless otherwise noted.

### SECTION 1. FREQUENCY

- A. The Council shall meet as requested by the Chair or at the request of a majority of Council members as frequently as necessary and may meet at least quarterly.
- B. The number and scheduling of meetings will depend on the timing and urgency of particular issues being addressed. Any subcommittees and workgroups will meet outside of regularly scheduled meetings of the full Council.
- C. The Council, subcommittees, and workgroups can meet more frequently, as requested by the Chair or other Council or subcommittee members.

### SECTION 2. ATTENDANCE

- A. Attendance at each meeting is critical to the productivity of the Council. While it is ideal to have all members of the Advisory Council present at meetings, this is not always feasible.
- B. Members for whom travel time and distance are prohibitive may connect to meetings by teleconference or other remote means. Members who make arrangements for remote attendance are strongly encouraged to attend at least one meeting each year in person whenever in person meetings are considered appropriate.
- C. If a member cannot attend a meeting, she/he is to contact the Council Executive Director prior to the meeting.

### SECTION 3. CANCELLATIONS

- A. Meetings of the Council may be canceled and rescheduled by the Chair.
- B. Council members will be notified of cancellations in as timely a manner as possible.

## SECTION 4. VOTING

- C. Quorum: Decisions requiring a vote by the Council must be distributed to the members 1 week prior to voting.
- D. In person meetings: voting will normally be done by a show of hands and will normally be recorded as the number of ayes, number of nays, and number of abstentions. When specifically requested by a member of the Council, the Chair will take a roll call, and individual votes will be recorded.
  - 1. A majority (51%) of the membership must be available at a given meeting. Decisions can be made when a majority of voting members present reaches agreement on a given matter.
  - 2. Votes by members attending the meeting remotely are acceptable.
  - 3. When any member of the Council is attending the meeting remotely voting must be conducted via roll call.
  - 4. **Public Meetings:** All full Council meetings are open to the public per Minnesota Open Meeting Law, Minnesota Statutes, 13D.

## SECTION 5. NOTICE OF MEETING

Members shall be given notice of a meeting in compliance with Open Meeting Law, Minnesota Statutes, 13D

## SECTION 7. QUORUM

A quorum is determined in compliance with State Statute (Minnesota's Open Meeting Law, MS 13D).

## SECTION 8. DECISION MAKING

Subcommittees and workgroups will be established to assist the Council.

- A. The Chair will ask for volunteers or appoint members based on their expertise and interest to serve on a subcommittee or workgroup.
- B. Subcommittees and workgroups will be given a specified charge and period of time to fulfill that charge and will present a final report or recommendations to the Council for approval at completion of its charge.
- C. The Chair or work group leads may ask persons who are not Council members, ex-officio members, or alternates to serve on subcommittees or workgroups as necessary to fulfill a specialized or technical charge.

Each subcommittee may find it necessary to have co-chairs. These would be designated workgroup members to report to the larger Council on specific workgroup tasks and findings. Members may convene workgroups or other external experts to study complex issues with approval from the Executive Subcommittee.

- D. Other methods, such as forming short-term informational groups or appointing members to other advisory councils within Minnesota Department of Health or other state agencies, may be utilized at the discretion of the Executive Subcommittee when necessary to accomplish the work plan of the Council.

E. The Council Executive Director, workgroups, or Council members prepare background and supporting materials for Council review.

F. The Council shall collect additional topic areas for study and evaluation from the general public. In order. For the Council to study and evaluate a topic, the topic must be approved for study and evaluation by the Council. All ideas submitted for Advisory Council review should be submitted to the Executive Director and must be communicated to all members. Before an idea can be accepted or rejected it must be deliberated on by the full Council.

G. Work groups formulate proposed recommendations or projects related to their area of study and present to the full Council to be approved by majority vote. The following summarizes the key steps involved in the Council's decision-making process:

1. Council members discuss and debate matters as ideas are formulated. Discussions between the Council members provide an important opportunity to test members' reactions to ideas and, as appropriate, recommend alternative approaches.
2. The Council and the Council Executive Director develop specific recommendations based on needs identified by each group.
3. The Council formalizes its advice and recommendations. Recommendations may be recorded as a consensus opinion. Alternatively, votes may be taken, and voice reports of the majority and minority opinions may be prepared.
4. Specific consensus recommendations are developed by the Council; justification is documented.
5. Council Chair and Subcommittee/work group Chairs present the consensus recommendations via written report to relevant stakeholders. Reports include the issue, background, process, recommendations, and outcome of discussion and voting on recommendations (including other motions, as appropriate).

## SECTION 9. MEETINGS CONDUCTED ELECTRONICALLY

The Minnesota Rare Disease Advisory Council may conduct a meeting of its members by telephone or other electronic means in accordance with Minnesota Statutes section 13D.015.

## ARTICLE IV. OFFICERS

### SECTION 1. SELECTION

The Council shall elect a chairperson, vice-chairperson, and other officers as it deems necessary and in accordance with the Council's operating procedures. The Council shall be governed by an executive committee elected by members of the advisory council. One member of the executive committee must be the advisory council chairperson.

### SECTION 2. TERMS OF OFFICE

All elected officers of the Council shall serve two-year terms with an even number of appointments expiring on alternate years.

### SECTION 3. COUNCIL CHAIR

The duties of the Chair are to:

- A. call and preside at all full Council meetings
- B. call and preside at the executive committee meetings
- C. be a spokesperson and representative for the Council.
- D. meet with Executive Director to conduct interim business and plan the agenda of the Council meetings.

#### SECTION 4. COUNCIL VICE-CHAIR

At the expiration of the Chair's two-year term the Vice-chair will be appointed Chair. Vice Chair duties are to:

- A. At the request of or in the event of the disability of the Chair, the Vice-chair may perform all the duties of the Chair
- B. Assist the Chair in the discharge of any duties as the Chair may direct

#### SECTION 4. EXECUTIVE COMMITTEE

The Executive committee shall be nominated by and, when needed, voted on by members of the Council. The Executive Subcommittees consists of the following members:

1. Council Chair
2. Council Vice-chair
3. Patient Representative
4. Council member
5. Council member
6. Executive Director (ex officio)

The Executive committee has the following duties:

- A. The Executive committee provides leadership to the Council and is responsible to ensure that the necessary business of the Council is carried out efficiently, effectively, and in a manner appropriate for the proper conduct of public business.
- B. Establish work groups and subcommittees as needed to carry out the Council's work plan in consultation with the Executive director.
- C. Review applications for new council members and provide a recommendation to the governor for eventual appointment.



- D. The members of the Executive Committee shall serve for a term of two years, beginning with the member's election or appointment to the Committee, but in no case longer than the term of appointment to the Council.
- E. Attendance: Executive Committee members shall make every effort to attend Committee meetings. Members absent from two consecutive meetings shall receive a written notice from the Council Chair prior to any subsequent meeting advising them of this fact and alerting them to possible Council action if they continue to be unable to attend meetings. If they are then absent from the next Executive Committee meeting, the Chair shall recommend action to the Council.

## **ARTICLE V. VACANCIES**

If a vacancy should occur among the at-large members of the Executive Committee, the Council shall elect a replacement to serve for the remainder of the unexpired term during its next regular meeting. Nominations shall be received from the floor. The election shall be by a plurality of those Council members present and voting.

If a vacancy should occur in the office of the Vice-Chair, the Council shall elect a replacement during its next regular meeting. Election shall be as provided in Section 1 of this article.

## **ARTICLE VI. STAFF**

### SECTION 1. EXECUTIVE DIRECTOR

The advisory council shall appoint an executive director. The executive director serves as an ex officio nonvoting member of the executive committee. The advisory council may delegate to the executive director any powers and duties under this section that do not require advisory council approval. The executive director serves in the unclassified service and may be removed at any time by a majority vote of the advisory council. The executive director may employ and direct staff necessary to carry out advisory council mandates, policies, activities, and objectives.

### SECTION 2. POLICY DIRECTIVES

Staff activities generated as a result of Council policies, Council committees, or task force recommendation shall be presented through the Executive Director. The Executive Director is responsible to ensure the timely completion of staff activities.

### SECTION 3. FISCAL PROCEDURES

The Council shall conduct its fiscal activities as prescribed by the State of Minnesota.

## ARTICLE IX. Reporting

By January 1 of each year, beginning January 1, 2020, the Council shall 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 under [137.68 Subd 4](#) and other issues on which the advisory council may choose to report.

## ARTICLE X. OPERATING PROCEDURES AMENDMENT

### SECTION 1. AMENDMENTS

Amendments to these Operating Procedures may be made only after notification to the Council members at least thirty (30) days in advance of a regularly scheduled meeting. Amendment requires a vote of two-thirds of the members present. Suspension of rules or operating procedures does not constitute amendment.

### Glossary

Rare Disease: a condition that affects fewer than 200,000 people in the United States (as defined by the FDA)

Health care: any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a person's physical or mental condition.

Rural: Area with a population threshold below 50,000 (as defined by the US Census Bureau)

Rare Disease Patient Organization: nonprofit, charitable entity whose mission includes (but is not necessarily limited to) a focus on improving the health and well-being of individuals living with a rare disease