
Meeting Minutes

Rare Disease Advisory Council

January 31, 2020

Call to order

The quarterly meeting of the Minnesota Rare Disease Advisory Council called to order on January 31, 2020 at 9:31am. Those present:

- Dean Jakub Tolar
- Erica Barnes
- Paul Orchard
- Art Beisang
- Abigail Miller
- Barbara Joers
- Karl Nelsen
- Soraya Beiraghi
- Janet Zielgler
- Sheldon Berkowitz
- Tom Blissenbach
- Sen Klein
- KrisAnn Schultz
- Kerry Hansen
- Nicole Brown
- Rae Blaylark
- Amy Gaviglio
- Rep. Tony Albright
- Jackie Foster
- Lee Jones

Members excused:

- Rep. Alice Mann
- Sen. Scott Jensen
- Timothy Schacker
- Karri LaFond
- Srijoy Mahapatra
- Lisa Shimmmenti

Approval of minutes

Minutes approved at 9:45. Motion made by Lee Jones, second by Dr. Beisang. Minutes approved by Council

Call to Order

The meeting was called to order at 9:31am by the Chair (Dr. Tolar). Overview of the Council and duties of the Council were discussed by Dr. Tolar and Council members

Review of procedures

Procedures and operation of Council was reviewed. The following guidelines were reviewed:

- Council is disease agnostic

- Will follow modified Robert's Rules of Order
- Obligated to produce an annual report (see packet)
- Work plan (see packet)

New Business

Presentations to Council by work groups for larger consideration and feedback.

Presentation 1: Rare Disease Advisory Councils around the country overview presented by council administrator. Council members gave feedback that it would be beneficial to work with NORD (National Organization for Rare Disorders) as well as other state councils to ensure that there is no replication of efforts.

Presentation 2: Cost work group (Dr. Miller presenter Members: Barbara Joers, Dr. Mahapatra, Dr. Orchard). Discussed the difficulty narrowing scope of the issue as well as determining which lens to use (cost to patient, cost to health system/state, etc). Next steps: reach out to health economist and possibly epidemiologist. Amy Gaviglio

Presentation 3: Transition of care/coordination of care work group (Dr. Berkowitz presenter Members: Karri LaFond, Janet Ziegler, Nicole Brown). Discussed the complexity of the issue and the desire to avoid replication of efforts (gather current resources vs create new resources). Next steps: participate in the patient survey to get information from MN community, identify larger initiatives to ask for funding from state, compile a list of adult specialists to make available to pediatric specialists and families. Lee Jones asked for clarification around which specialties would be included in coordination of care discussion (pharmacies?). Dr. Berkowitz stated he would limit it to primary care and rehab but is open to Council feedback.

Presentation 4: Barriers to care work group (Tom Blissenbach and Karl Nelsen presenters Member: Dr. Beiraghi, Dr. Beisang). Both patient and physician survey was presented to the Council. Dr. Amanda Hemmesch from St Cloud State was introduced and on hand for questions as she is the survey design lead. Lee Jones recommended collaborating with payers potentially in order to get survey out to patients more comprehensively. Barbara Joers made recommendations to ensure reduced response bias of patients. Jackie Foster recommended the group include undiagnosed population. Rae Blaylark commented that she would like to ensure that populations that have not historically been heard, included be able to give their input.

At the end of presentations Dr. Berkowitz asked for clarifications around time frames and an end point for the Council. Rep. Albright stated that from a State perspective the Council does not have a sunset (although funding is secured for only 4 years). Sen Klein stated that the Council should be action focused to justify its existence and funding.

The chair called for a motion to approve the work plan. Motion made by Lee Jones, seconded by Barbara Joers with the caveat that discussion should continue in relation to role of Council Administrator.

Rep Albright provided the Council with the State perspective on the role of the Council and what the State hopes to see accomplished.

- Repository for data/portal that allows access to information and resources
- Access to everyone, especially vulnerable populations that may not have easy entry into health care (ie address the racial disparities)
- Outreach to communities
- Research
- Be a national leader and solicit partnerships both in and out of the state

Adjournment

Dr. Orchard made motion to adjourn at 11am, Dr. Beisang seconded motion to adjourn.