
Meeting Minutes

Chloe Barnes Advisory Council on Rare Diseases

July 29, 2021

3-4:30

Call to order

The quarterly meeting of the [Chloe Barnes Advisory Council on Rare Diseases](#) was called to order on Thursday, April 29, 3:00 pm by Council Chair, Dean Tolar. Those present:

Member	Present	excused
Abigail Miller	x	
Rep Kelly Morrison	x	
Amy Gaviglio		x
Arthur Beisang	x	
Barbara Joers	x	
Jackie Foster	x	
Karl Nelsen	x	
Karri LaFond	x	
Kerry Hansen	x	
KrisAnn Schultz	x	
Lee Jones	x	
Lisa Schimmenti		x
Nicole Brown	x	
Paul Orchard		x
Rae Blaylark	x	
Sen Julia Coleman	x	
Sen Matt Klein		x
Sheldon Berkowitz	x	
Soraya Beiraghi	x	
David Tilstra	x	
Thomas Blissenbach	x	
Timothy Schacker		x
Rep Tony Albright	x	

Approval of minutes

Following a guest presentation by rare disease patient/caregiver Kari Olavson, Dr. Tolar called for the approval of the April meeting minutes. Karl Nelsen made a motion to approve, seconded. After a call for discussion from Dean Tolar the Council approved the minutes at 3:14pm.

Council structure and scope presentation

Rep. Albright reviewed the legislation and stated the purposes of the discussion as follows:

- Further define, examine the singular purpose of the Council
- Identify what (if any) actions by the Council are warranted for Council structure changes
- Any need for legislative amendments to align with the mission define by the Council
- Identify actions that can be taken to benefit the

Rep. Albright did request that Council members delay definitive decision making until after the University Office of General Council would have a chance to review and respond to concerns raised. Following the statement of the purpose of the discussion, a recorded presentation by executive subcommittee chair Amy Gaviglio was shown.

Council structure discussion

Following the recorded presentation, Rep. Albright requested that Erica Barnes assist in facilitating an open discussion.

Berkowitz opened the discussion with a request for clarification around specific duties and activities of the Council/request for some clarification regarding level of specificity of Council work (making general recommendations vs detailed directives). Berkowitz also commented on the requirement of the Council to obtain approval from the University's Office of General Council.

Albright responded with comments around the University's risk and liability obligations in reference to the Council taking various positions.

Berkowitz asked for clarification around the University of Minnesota's fiscal responsibility for the work of the Council.

Albright clarified that the University of Minnesota is the fiscal agent for the Council but the Council is funded by the Legislature.

Blaylark provided comments around the need to hear from the community and stakeholders affected by rare diseases and take issues to the communities to inform the work. Work from a hub and spoke model with community as the hub and the system as the spokes.

Morrison then stated that her understanding of part of the mission was to engage in policy. She further stated that in her opinion policy recommendations are critical to the work of the Council.

Albright responded that General Counsel would weigh in. "There is a difference between taking a position and actually recommending policy changes". RDAC should not take a position but can make recommendation on improving care, diagnosis. The annual report can include these recommendations that the Legislature can then take positions.

The University sees a difference between recommendations vs taking positions. The University takes exception to the RDAC taking a yes or no approach to taking a position on a procedure or research.

Information and experience is vital to collect for the Legislature to then determine positions that need to be taken.

Tolar confirmed this is his understanding.

Morrison asked for clarification on whether or not the Council would be able to comment weigh in on, or support specific legislation that would be beneficial for the rare disease community.

Albright stated he was hesitant to respond on behalf of General Counsel, then stated that at minimum, prior to support by the RDAC, General Counsel would need to be informed and the RDAC would need confirmation that the legislation would be supported by the University as well.

Berkowitz asked for clarification on the distinction between a position and a recommendation, cited a specific example related to insurance companies' need to provide coverage.

Albright stated that the RDAC could comment and observe discrepancies in coverage standards and provide a recommendation that the Legislature could then decide whether or not to pursue. RDAC should avoid mandates.

Tolar confirmed that this would be within the scope of the Council to comment on discrepancies.

Tilstra also stated interest in understanding the difference between a position and recommendation.

At the core can the RDAC speak for the University of Minnesota? Asked if this scope has been defined in the by-laws, asked if the Council is a one-off.

Tolar stated that the Council cannot speak on behalf of the University of Minnesota and verified it is a unique situation.

Albright shared that RDACs across the country have a variety of structures and missions and MN's is the most robust in scope. Some state RDACs are simply a clearing house and some are more detailed. The state of MN is looking to be a leader of all RDACs across the country. We are unique in that our residence is housed at an institution that is autonomous from the state of MN. Some housed in DHS, higher ed. Putting it in a state department does not give access to research. Other states are more subject to scrutiny of legislature when at a state department.

Joers asked that someone clarify whether or not other state RDACs are prohibited from taking policy positions.

Albright responded that, while he will defer to Office of General Counsel for definitive response, he does not see that the RDAC weighing in on policy would be prohibited in the enacting language. Will defer final say to Office of General Counsel.

Joers requested that there be continued discussion and clarification on 1.) Can the RDAC work on policy initiatives? 2.) What policy work is currently being done? 3.) What is the approval process if the Council is allowed to endorse?

Albright noted that Joers is addressing two issues. Supporting policy is supported by the legislation but endorsement of specific issues is what the University would take exception to.

Foster raised a question about the written information in the presentation stating that the Council cannot endorse but can make a policy recommendation.

Albright stated the Council must make general recommendations about better policies but avoid endorsement of specifics.

Berkowitz asked for more clarity around what the University of Minnesota is responsible for. Cited the coordination of care workgroup's initiative to create a contact registry of physicians who are willing to provide care for rare disease patients in the State. Asked if this falls within the scope of the Council.

Albright stated that he would defer to Office of General Counsel and Dr. Tolar since it relates to the practice of medicine.

Berkowitz: is it not germane since difficulty locating physicians to reach a diagnosis and receive care is a dominate theme cited in the community?

Albright stated he would defer comment on this to Office of General Counsel.

Berkowitz asked that a list of questions be kept and the Office of General Counsel attend the next meeting.

Beisang stated that every day he hears stories of the long rare disease patient journey-ability to help improve the process is why he is proud to be on the Council. Doing some good work with surveys and anticipates identifying needs and the ability to suggest policy as a very important piece of the work.

Miller commented that perhaps the physician registry could be moved to a state agency such as the Board of Medical Practice.

Albright commented that Office of General Counsel may have some clarification on this particular topic.

Legislator members are here to serve and facilitate the RDAC.

Nelsen responded that the community has needs and he hopes the Council can change things. Have to be the voice of people who don't have a voice. Stated we need definitive answers. Gathering information but it is time for action-there is urgency and we want Minnesota to be a leader.

Morrison stated that she would like to know what is happening in other states- are they engaging with policy. "This group could serve as a source of education for legislators perhaps testifying in committee hearings on behalf of RDAC". There is an opportunity here to directly engage in policy, wealth of knowledge.

Barnes stated she will reach out for clarification on other Councils work.

Nelsen asked for clarification on what will happen in the October meeting, suggested that there be a special session with Office of General Counsel prior to October meeting so that members who want to ask questions can do so.

Tolar the next meeting is October 28 but will ask Office of General Counsel if there could be a special session prior, and reminded the Council that ending of the 2-year terms are ending in October- asked members to state if they would like to continue or step away. Called for any new or old business

Adjournment

Next meeting to be held October 28. Tolar called for motion to adjourn, motion made and meeting ended at 4:29.

Next steps:

- Questions to be collected and sent to Office of General Counsel-Erica Barnes
- Clarification on the work of other state councils- Erica Barnes
- Request for a special session with General Counsel- Erica Barnes