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# Meeting Minutes

## Chloe Barnes Advisory Council on Rare Diseases

### October 28, 2021

### 3-4:30

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#### Call to order

The quarterly meeting of the [Chloe Barnes Advisory Council on Rare Diseases](#) was called to order on Thursday, October 28th, 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, guest presentation

Dr. Tolar reviewed the agenda and called for the approval of the July meeting minutes. Sheldon Berkowitz made a motion to approve, seconded. After a call for discussion or comments from Dean Tolar the Council approved the minutes. Tom Kelly, VP of Marketing and Innovation Special Needs Initiative at United Health Group and father of a child with a rare disease, then presented on his

experience and professional work. Following the presentation, Council members asked questions and made comments related to Council work and initiatives.

### Council structure and scope presentation and discussion

Dr. Tolar asked for a motion to approve moving forward with an electronic vote that would be submitted to Amy Gaviglio as executive subcommittee chair and Erica Barnes as Council administrator **to answer the following question with answers of Yes or No: “The Council would like more autonomy to advocate and participate in policy making and would like to move out of the University of Minnesota if a suitable alternate organization can be identified.” Dr. Paul Orchard made first motion and Sheldon Berkowitz seconded.** Amy Gaviglio then conducted a presentation in which the ongoing discussion on Council structure, scope, and future organization was reviewed in preparation for discussion and vote. Ms Gaviglio instructed that a YES vote would indicate a decision to move from the University and a NO vote would indicate a decision to remain at the University. Following the presentation Amy presented the opportunity for members to ask questions or make comments and asked members to indicate if they did not receive an email prior to the meeting that would allow them to respond with their vote.

Sheldon Berkowitz asked for clarification from Ms Gaviglio on contact that was made by the University of Minnesota to Council members in reference to the upcoming vote. Ms Gaviglio responded that, given individual Council members’ affiliation with the University of Minnesota, there could be a perception of expectation to vote in favor of the University should the vote be public. Ms Gaviglio emphasized the benefit of anonymity. A discussion was engaged in relative to who on the Council has voting privileges. Dr. Orchard requested clarification on the Council’s limitations around engaging with the legislature. It was reiterated by Ms Gaviglio and Dr. Tolar that any engagement with the state legislature on policy positions must be done on an individual basis and not on behalf of either the Council itself or the University of Minnesota. While Council membership can be referenced, all testifying must be done on an individual basis. Dr. Orchard followed up that the Council is allowed to create a white paper to be provided to the legislature. Dr. Orchard also requested clarification on whether or not the Council could request additional funding for specific Council goals. Ms Gaviglio verified that this would not be within Council scope. Rep. Albright raised the issue of the Council better defining and understanding its mission and purpose. Stated his position that moving from the University of Minnesota would be premature and questioned whether or not the alternative entities would have a different structure. Rep Albright suggested that the vote be delayed due to the vagueness of who is eligible to vote. Reminded the Council that the appropriations had not been expended for the initial legislation and questioned the appropriateness of changing fiscal sponsor mid-stream. Dr. Tolar asked Ms Gaviglio if she would like to proceed with the vote or introduce an alternative motion based on Council member comments. Dr. Tilstra asked for clarity on the Council mission and stated that he wondered if advocacy needed to be fundamental to the Council’s mission. Rep Albright Ms Barnes referenced the Council work plan which contains the Council’s vision and mission as well as a list of actions and offered to provide it to anyone who wanted to review it. Dr. Tolar asked the Council to determine if they would like to vote or delay the vote. Stated his preference to keep the Council at the University. Ms Gaviglio stated her preference that the Council be in a structure that would allow the Council to influence policy as a collective body. Ms Gaviglio then asked if there was a motion to postpone the vote. Dr. Tolar made a motion to postpone the vote and asked for a first and second. Karl Nelsen made the first motion. Sheldon Berkowitz asked for clarification on

how long the delay in vote was being proposed and stated he did not want the vote to be delayed “forever”. Karl Nelsen asked how long it would take to validate the voting members and stated that this would be the length of the delay. Rep Albright stated that the non-partisan legal counsel at the legislature could provide a response back to Ms Barnes with the list of voting members. Dr. Tolar then asked for verbal vote for delaying the vote. A number of Council members responded with yes, Sheldon Berkowitz voted “no” due to lack of clarity on how long the postponement would be. Ms Gaviglio asked if a week would be sufficient time to provide the Council with clarifications. Sheldon Berkowitz asked that he be informed of the length of delay as well as clarity on the procedure around how the vote would be conducted in the future. Karl Nelsen stated he thought a week would be sufficient to allow for an electronic vote. Rep Albright stated that he thought that voting members could be clarified within a week but he suggested that the vote be conducted at the next Quarterly Council meeting as he did not see immediacy to voting before then. Dr. Tolar agreed with Rep Albright that this was reasonable and stated that clarity on who could vote could be completed within a week and the vote would be conducted at the next quarterly council meeting. Dr. Tolar then asked for a motion to adjourn and Karl Nelsen moved, seconded by Paul Orchard. Meeting was adjourned at 4:30.

### Adjournment

Next meeting to be held in Q1 of 2022. Dr. Tolar called for motion to adjourn, motion made and meeting ended at 4:30.

### Next steps: