
Meeting Minutes

Chloe Barnes Advisory Council on Rare Diseases

July 31, 2020

9:30-11

Call to order

The quarterly meeting of the **Chloe Barnes Advisory Council on Rare Diseases** was called to order on Friday July 31, 2020 at 9:42 by Amy Gaviglio following a testimonial by Jessica Wieche, the caregiver of a child living with a rare disease. Those present:

Member	Present	excused
Abigail Miller	x	
Rep Alice Mann		
Amy Gaviglio	x	
Arthur Beisang	x	
Barbara Joers	x	
Jackie Foster	x	
Janet Ziegler	x	
Karl Nelsen	x	
Karri LaFond	x	
Kerry Hansen	x	
KrisAnn Schultz	x	
Lee Jones	x	
Lisa Schimmenti	x	
Nicole Brown		
Paul Orchard	x	
Rae Blaylark	x	
Sen. Scott Jensen	x	
Sen. Matt klein		
Sheldon Berkowitz	x	
Soraya Beiraghi	x	
Srijoy Mahapatra		
Thomas Blissenbach	x	
Timothy Schacker		
Rep Tony Albright	x	

Approval of minutes

Amy Gaviglio called for approval of minutes. Barbara Joers noted that the 4-24-20 meeting minutes did not reflect meeting content related to governance discussions, asked that meeting minutes be updated with specific questions raised (land grant, Rep Mann statement that she can provide clarifying language

for the legislation). Erica Barnes, administrator, agreed to review the minutes and ensure that the governance questions raised are reflected in the minutes. Motion made by Karl Nelsen to approve minutes, seconded by Paul Orchard, approved by Council by oral vote.

Agenda- Work group updates:

9:50- barriers to care work group presentation.

Tom Blissenbach provided updates on the patient barriers to care survey, requested involvement of full Council in recruiting participants. Paul Orchard and Jackie Foster provided feedback (clarifications on in state/out of state participation) via chat

Dr. Berkowitz presented on care coordination work group. Summarized the work group's activities, opened up for questions. Dr. Berkowitz reported reaching out to University of Minnesota and Mayo to provide further education on transition of care for rare and complex patients moving from pediatrics to adult care as well as hearing from some subject matter experts.

Dr. Miller presented on the activities of the cost work group. She reported on presentations provided by subject matter experts as well as the findings of a recent focus group centered on cost barriers in the research space. Amy Gaviglio provided a link related to the work of the work group

(<https://hpo.jax.org/app/>)

Amy Gaviglio presented two draft documents related to Council governance. The Operational Procedures document was displayed and Council member feedback solicited. Term limits and whether or not Council members could reapply was discussed. Dr. Berkowitz stated support for term limits to ensure new ideas being generated. Christine Kiel stated that the Council is only funded for 4 years. Paul Orchard supported operating on the assumption that the Council may continue after 4 years.

Discussion was raised over how new members will be appointed, application process. This was not resolved, but various Council members indicated preference for application process. Rep. Albright then raised the issue of all members disclosing any conflicts of interest, economic interests that might arise for individual members as initiatives are pursued (this extends to any new affiliations a current Council member may engage in while on the Council). This could be done in the on boarding process.

Rep Albright also raised concerns with the necessity of Council members to solicit permission from the Chair to communicate on behalf of the Council. Sheldon Berkowitz also raised concerns and cited his outreach to University of Minnesota and Mayo medical personnel as an example of how this procedure could be too constraining. Rep. Albright suggested that the wording could read "do not engage in communication that is not in keeping with the Council's vision and mission". Amy Gaviglio stated that this is a document borrowed from other state committees and can be modified prior to formal approval. Ms Gaviglio then moved to the approval process flowchart. In reference to the autonomy of the Council, Ms Gaviglio informed the Council that Ms Barnes will be scheduling a conversation with Office of General Council at the University of Minnesota to ensure alignment on approval processes. Rae Baylark commented that the Council should instate a transparent process by which requests from the public as well as Council actions and responses are tracked to allow for examination of implicit bias and to ensure transparency. Paul Orchard also stated the need to determine what the Council administrator can do unilaterally without going through a formal approval process. Amy Gaviglio stated that the executive subcommittee would continue to develop these processes

Council logistics and communications

Ms Barnes presented on the need for a more systematic communication process for the Council. She is developing Box folders and a Council calendar to allow for 1.) sharing of essential readings and documents 2.) member to member sharing 3.) upcoming events and meetings of interest. When Box set up is finalized Ms Barnes will provide instructions to work groups as well as individuals.

Forward thinking discussion

Karl Nelsen facilitated a discussion around addressing Pillar 4 of the work plan “Accelerating Research”. Mr. Nelsen provided updates on some current activities that could be more formalized to address this pillar such as the development of a resource that articulates characteristics of a mature rare patient community to be used to foster the growth of less mature patient communities. He also discussed the utilization of patient registries to accelerate research. Dr. Schultz summarized a recent meeting with Sanford Health’s CoRDS program as a possible way to collaborate in the future.

Adjournment

Next meeting to be held October 30, 2020. Council packet has materials from the meeting that members can review and called for adjournment at 11:04. Motion made to adjourn by Karl Nelsen, seconded by Paul Orchard.

Next steps:

Box to be shared with Council members in work groups and individually. Executive subcommittee to continue to refine Operating Procedures document and Approval flow chart. April meeting minutes to be revised to reflect more fully the governance discussion.