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# Meeting Minutes

## Chloe Barnes Advisory Council on Rare Diseases

### January 27, 2022

### 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 subcommittee Chair Amy Gaviglio. 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       |         |
| Kerry Hansen       | x       |         |
| KrisAnn Schultz    | 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

Amy Gaviglio reviewed the agenda and called for the approval of the October meeting minutes. Tom Blissenbach made a motion to approve, seconded by Karl Nelsen. After a call for discussion or comments from Am the Coy Gaviglio Council approved the minutes. Sophia Denis, a University of Minnesota student then presented on her experience living with a rare disease.

### Council strategic planning and public discussion on surveys

Council workgroups went to breakout rooms to discuss each group's 2022 strategic goals and identified activities for 2022. Erica Barnes facilitated a presentation and discussion of the Council patient access survey results infographic. Various members of the public asked for clarifications on some of the findings and provided their perspectives (how well it reflected their experience, how the information could be extended in the future). After 20 minutes workgroups returned and each workgroup lead provided a summary of goals for 2022, including development of marketing materials for surveys and better understanding barriers to dental care (barriers to care), completion of academic papers for possible publication (cost, acceleration of research), further extending a data capture project to identify rare disease research (acceleration of research), connect with other state Councils to learn from their work, and hosting a roundtable to identify solutions to transition of care (coordination of care workgroup). Following the workgroup updates Barbara Joers brought federal legislation entitled Accelerating Kids Access to Care to the attention of the Council and requested that the Council review it and take steps to assist Minnesota in having a larger part in this legislation.

### Newborn Screening Presentation and Discussion

Amy Gaviglio reported to the Council on recent requests from patient advocacy groups to endorse their efforts to add their disease to the newborn screening panel in Minnesota. Following a review of the Council legislation that specifies that the Council provide advice, Ms Gaviglio gave an overview of the newborn screening process. Following the presentation she laid out the need for the Council to identify a process by which the Council can then make determinations on whether or not to support additions to the newborn screening. Proposed creating an ad hoc taskforce then opened it up to questions and discussion. Sheldon Berkowitz stated that the text of the legislation seems vague, proposed that the Council consider getting clarifying language. Erica Barnes responded that this would be added to the questions before the task force. He further stated some concerns that patient groups may want to ask the Council to be a work around to the newborn screening process. Paul Orchard asked for more information about how closely the state of Minnesota aligns with the RUSP, Amy gave feedback.

### Voting on structure changes

Amy Gaviglio provided instructions to the Council on Council wide vote to stay at the University of Minnesota or move to the Minnesota Council on Disability. Vote to be held electronically, deadline Friday January 28<sup>th</sup> at noon.

### Adjournment

Ms Gaviglio called for motion to adjourn, meeting ended at 4:30.

### Next steps:

Council vote on structure change, Ms Barnes will follow up with individual Council members on any follow up items.