
Meeting Minutes

Chloe Barnes Advisory Council on Rare Diseases, non-mandatory meeting

December 2, 2020

1:30-2:30

Due to the continued pandemic and surge in the state of Minnesota, it was determined that the previously scheduled quarterly Council meeting would be modified to a non-mandatory, shortened meeting with approvals of the 2020 Annual Report, Operating Procedures, and April/July meeting minutes conducted via email. Council meeting frequency is not specified and decisions about meeting frequency is at the discretion of the Chair. Attendance was not recorded due to the non-mandatory meeting status.

Approval of minutes, Operating Procedures/Review of annual report

In order to accommodate the schedule members who have been impacted by the pandemic, all documents for approval and review (April and July meeting minutes, operating procedures document, annual report for 2020) was sent via email 11-25-20. Council members were requested to review all documents and provide a response.

Introduction

Trevor Turner, patient advocate with Usher Syndrome addressed the meeting. He discussed barriers and challenges he faced as he sought a treatment, care, and support. Council members asked follow up questions.

Council logistics and communications

Ms Barnes presented on a finalized system for communication and document sharing to the Council using Box. Dr. Berkowitz raised some concern about the accessibility and usability of Box for those Council members outside the University of Minnesota. Dr. Orchard commented on the benefit of added privacy features of Box. Ms Barnes will provide a communication and document sharing option in google docs for any content that does not require the added privacy features of Box.

Work group updates:

Dr. Berkowitz presented on care coordination work group. Summarized the work group's activities, opened up for questions. Dr. Berkowitz reported on continued efforts to create a clinician contact registry as well as increase education on transition of care for patients with rare and complex needs. Dr. Beisang offered his expertise in g-tube management should there be any continuing education opportunities.

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. He informed the Council of the delay in launching the provider survey due to the pandemic surge.

Dr. Miller presented on the activities of the cost work group. She reported on future opportunities to host a presentation by Global Genes on their cost burden survey. Amy Gaviglio suggested we ask Global Genes to do an even more comprehensive presentation on all the ways they engage with rare diseases. Dr. Schultz introduced the newly formed acceleration of research work group. She laid out work group priorities. Lee Jones asked questions around clinical trial design issues and Dr. Beisang spoke to the importance of the goal of supporting the organizational maturity of nascent patient communities, used the example of natural history studies in the Rhett Syndrome community.

Forward thinking discussion

Dr. Berkowitz raised the question of telehealth expansion in the state of Minnesota and if the Council will engage on this issue. He stated that the issue has been discussed in his role as President of the America Academy of Pediatrics. Ms Barnes informed the Council that Dr. Jim Cloyd, director of the Center for Orphan Drug Research is organizing his Rare Disease Day event around this topic.

Adjournment

Meeting was adjourned at 2:38.

Next steps:

- 2021 Quarterly meetings to be determined
- Box and google docs link to be sent to Council members