
Meeting Minutes

Chloe Barnes Advisory Council on Rare Diseases

January 28, 2021

Call to order

The quarterly meeting of the Chloe Barnes Advisory Council on Rare Diseases was called to order on January 28, 2021, 3:00-4:30.

Council Members Present:

Amy Gaviglio
Art Beisang
Abigail Miller
Soraya Beiraghi
Barbara Joers
Janet Ziegler
Karl Nelsen
Kerry Hansen
Krisann Schultz
Lee Jones
Nicole Brown
Rae Bylark
Rep. Tony Albright
Sheldon Berkowitz
Jackie Foster
Lisa Schimmenti
Tom Blissenbach

Members of the public present:

Trevor Turner
Amanda Hemmesch
Dee George
Jim Cloyd

Approval of Minutes

Previous minutes approved via email

Mission Moment

Mission moment focused on the typical journey of rare disease families by review of a website (<https://www.curegpx4.org/>) of a family seeking to raise money for their son with a rare disease.

Agenda Item: “Rare Disease Community” Operational Definition

Discussed the meaning and utility of the phrase “rare disease community” to ensure collective agreement on definition, guide us on the scope of the Council, and identify work activities. Erica Barnes gave a presentation entitled “The Rare Disease Community: What’s in a name?” Themes were history of the term, characteristics of the community, difficulty with using the label.

Following the presentation the Council engaged in discussion around how to scope:

- Raised the issue of genetic mutations vs a rare disease diagnosis, diseases without medical consensus, very small patient populations.
- Setting up a framework for addressing rare diseases and identifying what is common across diseases.
- How do we identify areas of care that the rare population needs.
- Dr. Schimmenti- biggest barrier for rare disease community is getting to diagnosis. Access is very limited (referrals from primary care provider, parents' socioeconomic status, language). Real problem for populations of color.
- Dr. Miller- growth of telehealth is a positive. Barriers across state lines is a barrier that should be addressed. Must ensure that telehealth is reimbursed adequately. Focus should be on common barriers across communities.
- Stay focused on the mandate of the statute.
- Dr. Beisang mentioned the 3 buckets: diagnosis, care management, treatments. What do we consider rare diseases?
- Is there a difference between disorder/disease/condition? The terms are often used interchangeably and each term is reacted to differently by different communities. One not considered better than the other.
- Trevor Turner raised the issue of the importance of a clear definition so that when the state is doing analysis on the community the information is accurate.
- Kerry Hansen raised the issue of umbrella groupings of rare diseases. Mutations are not necessarily considered a separate disease. Genome sequencing has made categorization of rare diseases difficult.
- Erica Barnes-stay focused on the frameworks/population health lens. Can we help guide rare patient populations to maturity?

Next step for determining the definition and scope- executive subcommittee will address in next meeting (2-10-21)

Agenda Item: Work Groups Updates

Barriers to Care provided updates on patient survey. 180 (148 from Minnesota) participants, balance of adults and children, 120 different rare diseases. Need to increase people of color. Discussion around increasing participation around people of color (better outreach, translation of survey to other languages). Problems of access to survey likely will reflect the problems of access in future initiatives. May be able to fund translation of survey. Barriers work group will discuss at the next meeting or executive subcommittee. Patient survey results can be available to work groups no later than May. Provider survey will launch March 1st.

Executive subcommittee to provide clarity on the process of communication with the University of Minnesota around Council activities.

Coordination of Care is expanding the clinician contact registry. Acceleration of Research group is engaging with Sanford to host meetings and collaborate.

Cost work group to host presentation from Global Genes to learn about the results of their nationwide cost burden survey and discuss any implications for Minnesota.

Next steps

Erica Barnes to request feedback via email on Council preferences for communication of activities to Council members.

Adjournment

Abbie Miller made motion to adjourn. Karl Nelsen seconded. Meeting adjourned at 4:30 pm