

Rare Disease Council Subgroup Meeting  
Friday, April 15, 2022  
2:00 PM – 3:00 PM

Virtual Meeting

Registration Link: [https://vdh.zoom.us/webinar/register/WN\\_uCLMRXk0T7SZVwBfzxOWg](https://vdh.zoom.us/webinar/register/WN_uCLMRXk0T7SZVwBfzxOWg)

*Note: Council Members participating in this subgroup meeting have been pre-registered and should not register again.*

Meeting Minutes

Council Members Present: Ijeoma Azubuko, Susan Klees, Rebecca Goldbach, Dr. Lisa Kaplowitz, Jana Monaco

Virginia Department of Health (VDH) Staff Present: Khalida Willoughby, Christen Crews, Katherine Crawford

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Council Members and VDH staff members introduced themselves and started with an ice-breaking activity. Khalida Willoughby, MS, then proceeded to facilitate the visioning activity. She defined key characteristics and the purpose of a vision statement, and provided examples of vision statements for the Council to reference.

Ms. Willoughby then led Council Members through a series of questions to discuss as a group, and Christen Crews, MSN, RN, captured key elements on a virtual whiteboard that participants in the meeting could view and request changes to in real time. Questions discussed included the following:

- What does a well functioning Rare Disease Council mean to you?
- What are important characteristics for members of the Rare Disease Council, stakeholders and the general public?
- Where are we going moving forward? How do we envision the Rare Disease Council in the next 3-5 years? What do we want to achieve in the future?

The subgroup generated multiple ideas for each question above that were captured on the whiteboard. By the end of the meeting, the subgroup had created rough concepts for a draft vision statement. Ms. Willoughby recommended a second subgroup meeting to refine the draft vision statement.