

Rare Disease Council Subgroup Meeting
Thursday, May 5, 2022
11:00 AM – 12:30 PM

Virtual Meeting

Registration Link: https://vdh.zoom.us/webinar/register/WN_f4BOYS5cQ7CQn217tYmWpA

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

Meeting Minutes

Council Members Present: Rebecca Goldbach, Dr. Lisa Kaplowitz, Jana Monaco

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

After welcoming everyone and reviewing the agenda, Dr. Lisa Kaplowitz, Chair of the Rare Disease Council, reviewed the Purpose of the Rare Disease Council as defined in § 32.1-73.14 of the Code of Virginia to help focus the discussion. After reviewing the whiteboards from the subgroup visioning activity on 4/15/2022, Khalida Willoughby, MS, provided guidance to help Council Members refine concepts from the prior meeting into a draft vision statement. Christen Crews, MSN, RN, continued to capture key elements on a virtual whiteboard that participants in the meeting could view and request changes to in real time. The subgroup discussion led to a refined draft vision statement to present to the full Council for discussion in the next meeting on 5/17/2022.

The Chair and Ms. Willoughby then recommended that the subgroup consider omitting developing options for values at this time, and move on to options for strategic planning. The subgroup reviewed the Powers and Duties of the Council as defined in § 32.1-73.15 of the Code of Virginia and considered potential workgroup options to help the Council achieve some of its goals. Using the whiteboard to capture and consolidate feedback in real time, the subgroup was able to identify four potential workgroups to present to the full Council for discussion in the next meeting on 5/17/2022.

The subgroup then agreed to use the Purpose of the Council, as defined by the legislation, as a reference for developing a draft Mission Statement for the Council. After brief discussion, and continuing to use the whiteboard to capture content, the subgroup developed a draft mission statement to present to the full Council for discussion in the next meeting on 5/17/2022.