

Rare Disease Council Meeting
Tuesday, May 17, 2022
10:00 AM – 2:00 PM

Meeting Location: Twin Hickory Area Library, Meeting Room

Address: 5001 Twin Hickory Road, Glen Allen, VA 23059

To register to attend virtually: https://vdh.zoom.us/webinar/register/WN_HZtWC6lvQXmx30V2GaDTwQ

Meeting Minutes

Council Members Attending In Person (*ex officio members italicized*): Dr. Lisa Kaplowitz, Jana Monaco, Megan O'Boyle, Susan Klees, Rebecca Goldbach, Sarah Paciulli, Holly Kearl, Dr. Maureen Dempsey, *Dr. Samantha Hollins, Jennifer Macdonald*

Council Members Attending Virtually: Dr. Samantha Vergano, Shannon McNeil, Ijeoma Azubuko, Dr. Peter Kasson

Council Members Absent: Dr. Richard Nicholas, Gregory Josephs, Dr. Stephen Green, Dr. Stephen Rich, Dr. Tiffany Kimbrough, *Dr. John Morgan*

Virginia Department of Health Staff Present: Christen Crews, Katherine Crawford

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Welcome, Roll Call, Confirm Quorum, Review Agenda, Council Votes

Dr. Lisa Kaplowitz, Chair, welcomed attendees, and VDH staff conducted roll call and confirmed that the Council did not meet the in-person attendance requirements to meet a quorum. The Chair reviewed the agenda and noted that the Council would not be able to vote on draft bylaws or draft meeting minutes without a quorum.

Present materials from Rare Disease Council Subgroup meetings for discussion

The Chair and Vice-Chair presented materials from the April 15 visioning activity and May 5 subgroup meeting to the Council for discussion, including a draft mission statement, draft vision statement, and proposed workgroups.

- *Draft mission statement:* On behalf of those impacted by rare diseases in the Commonwealth of Virginia, the Rare Disease Council shall:
 - Advise the Governor and the General Assembly on the needs of those affected by rare diseases;
 - Identify challenges and barriers faced by those affected with rare diseases; and
 - Address funding of research and supports for persons with rare diseases.
- *Draft vision statement:* To serve as a voice for Virginia's Rare Disease Community by advising policymakers and empowering families and individuals affected by rare diseases.
- *Proposed Council workgroups:*
 - Resources/Education
 - Data Collection
 - Funding
 - Strategic Planning

The Council discussed the draft mission and vision statements and proposed workgroups, including how to share resources with individuals and families recently diagnosed with a rare disease, the importance of defining purpose and methods for data collection and potential resources to provide support, potential sources of funding for a survey, and defining short-term and long-term goals to prioritize efforts.

Public Comment Period

Two individuals provided comments during the public comment period:

Teresa expressed the importance of telehealth to her family for getting access to care for her child, and issues with receiving care due to a lack of available telehealth services prior to COVID. The requirement for an in-person visit annually in order to receive telehealth services is still a barrier. She requested that the Council include specific disorders when thinking of its survey.

Melissa, a caregiver of two children with a rare disease, asked if the Council had plans to help with legislation to get more services covered. She explained issues with getting insurance coverage for needed therapies due to how a diagnosis is defined (ex. as a symptom of a speech disorder versus a neurological condition), providers not being in-network, and certain therapies not taking insurance.

Present information on telemedicine in Virginia for discussion / Council Member Open Discussion

The Chair then presented information on telemedicine to the Council for discussion, noting that Virginia is not part of the Interstate Medical Licensure Compact, which provides a way for physicians to apply for rapid licensure in another state for telemedicine. The Chair shared that legislation passed in Virginia allows a practitioner outside of Virginia with an existing physician-client relationship, who has seen a patient at least one time a year in person, to provide follow-up care via telemedicine without requiring a Virginia license. Council members discussed challenges for families and patients with rare diseases to meet the yearly in-person visit requirement, if joining the compact would be helpful, if rapid licensure might negatively affect licensure standards, and the increasing demand for telehealth services.

Review key points for the Council's annual report to the Governor and General Assembly for discussion

After a break period, VDH staff reviewed key points for the Council's annual report to the Governor and the General Assembly, including background, status report on Council activities, findings and/or recommendations, and status of funding available to the Council. Council members provided feedback for each section of the report and reviewed member vacancies and initial term expirations.

Discuss the focus of the Council for the next two years / Council Member Open Discussion

The Council then discussed potential areas of focus for the Council for the next two years, referencing information compiled during the subgroup visioning activity, including the proposed Council workgroups. Options discussed included developing a list of publicly accessible resources on rare diseases for the Council's webpage; researching to identify and advise on policies relevant to rare disease patients and caregivers, taking the legislative process and timing into account; establishing a Rare Disease Day event; developing a communications plan; and initiating workgroups.