

Location: Virtual Meeting via GoToWebinar
Meeting Registration (Public):
<https://register.gotowebinar.com/register/8002855173961619470>
 (Note: Council Members have been pre-registered)
Platform: GoToWebinar **Meeting ID:** *see registration email*

Meeting Minutes

Rare Disease Council Members Present (* indicates ex officio member):

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| <input type="checkbox"/> Lisa Kaplowitz, Chair | <input type="checkbox"/> Ijeoma Azubuko | <input type="checkbox"/> Jennifer Macdonald, MPH, BSN, RN* |
| <input type="checkbox"/> Jana Monaco, Vice Chair | <input type="checkbox"/> Holly Kearl | <input type="checkbox"/> Dr. John Morgan* |
| <input type="checkbox"/> Dr. Peter Kasson | <input type="checkbox"/> Rebecca Goldbach | <input type="checkbox"/> Dr. Samantha Hollins* |
| <input type="checkbox"/> Sarah Paciulli, MS, RN, NP | <input type="checkbox"/> Megan O'Boyle | |
| <input type="checkbox"/> Dr. Tiffany Kimbrough | <input type="checkbox"/> Dr. Richard Nicholas | |
| <input type="checkbox"/> Dr. Stephen Green | <input type="checkbox"/> Susan Klees | |
| <input type="checkbox"/> Shannon McNeil | <input type="checkbox"/> Dr. Maureen Dempsey | |
| <input type="checkbox"/> Gregory Josephs | <input type="checkbox"/> Dr. Stephen Rich | |

Council Members Absent:

- Dr. Samantha Vergano

VDH Staff Present:

- Christen Crews
- Samantha Clark

10:00 – 10:15	Welcome: Jennifer Macdonald, VDH ex-officio A. Roll Call and Introductions B. Review of Agenda
10:15 – 10:30	Overview of HB1995: Christen Crews A. 2021 General Assembly Session, Delegate Kathleen Murphy presented HB 1995 proposing Rare Disease Council in Virginia. Passed in 2021 Special Session 1 establishing Rare Disease Council. B. Discrepancy noted in the section describing membership terms. Review Draft of Council Bylaws: Christen Crews A. Section on Council Meetings: Council to meet quarterly, chair/vice chair establish schedule on annual basis, majority of members shall constitute quorum. Council members may participate in meetings from a remote location pending a quorum of the taskforce is physically assembled in the central

	<p>meeting location. Voting and recommendations must occur in-person with a quorum in place.</p> <p>B. Vote to approve and adopt draft bylaws to place at the next meeting. Proposed amendments or items requiring discussion can be addressed during the next quarterly meeting or emailed to Samantha Clark, Rare Disease Council Coordinator.</p>
10:30 – 10:50	<p>Public Comment Period</p> <p>Michelle Nester: Parent of child with a rare disease. In addition to the daily challenges of navigating and managing her disease, she addressed three main concerns: access to care, specifically in rural communities; insurance coverage; and out-of-pocket costs (deductibles, loss of work, travel).</p>
10:50 – 11:10	<p>Parent perspective: Jana Monaco, Virginia State Ambassador, Virginia Rare Action Network, National Organization for Rare Disorders</p> <p>Vice-chair, Jana Monaco shared her story of caring for two children diagnosed with a rare disease and the impact early testing and intervention had in the trajectory of their health and quality of life. She highlighted her advocacy work and priority policy issues that directly impact those with rare diseases.</p>
11:10 – 11:30	<p>Open Discussion, Christen Crews</p> <p>A. Current year: 2021 Annual Report focused on activities leading up to establishing council and recruitment of Rare Disease Council (RDC) coordinator and will be coordinating council activities/items, research, circulating articles and publications, etc.</p> <p>B. As the council moves forward, the chair/vice-chair will work with VDH support staff to determine RDC priorities, plan meeting location and duration, and draft meeting agendas.</p> <ol style="list-style-type: none"> a. Agenda Items: speakers; Invite states with established Rare Disease Councils to share their work and processes; Hear from council members who are directly impacted and what their expectations are and how we can approach a rare disease practical standpoint to make an impact. b. Send out surveys to collect baseline data to determine member expectations, caregiver/patient perspective, what each organization /stakeholder group representative can contribute to council, prioritize what is most important for quality life, prioritize what is financially attainable by the Council at this time. <p>C. Acting Director, Office of Family Health Services, Heather Funkhouser Board, MPH. Requirements to meet in-person ties into the Freedom of Information Laws that ensures meetings and discussion are available for public viewing and participation.</p> <p>D. Rare Disease Council Members have the option to swear in virtually.</p> <p>Adjournment and Action Items</p>

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| | <ul style="list-style-type: none">a. Review draft of Council Bylawsb. Meeting Dates: polls will be sent out to council members to determine next meeting dates and times and a physical location will be identified. Second quarterly meeting must be held before the end of December.c. Google Form will be sent to council members asking to confirm contact information and credentials. A membership roster will be shared for internal purposes among council members and program staff. |
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