

**Rare Disease Council Quarterly Meeting**  
 Tuesday, May 16, 2023, 10:00 AM – 2:00 PM

**Meeting Location:**

Virginia Hospital & Healthcare Association  
 Washington and Jefferson Meeting Rooms, 4200 Innslake Dr, Glen Allen, VA 23060  
[https://www.zoomgov.com/meeting/register/vJltd-GtrT4vHDYvN\\_Dzps1DxKqdKTrW0f8](https://www.zoomgov.com/meeting/register/vJltd-GtrT4vHDYvN_Dzps1DxKqdKTrW0f8)

**Draft Meeting Minutes**

Council Member Attendance	Breakout Sessions	Voting Record		
		Y=Yes, N=No, A=Abstain		
<b>Bold</b> = Present, In Person * = Remote Participation (Reason*, Location) <i>Italicized</i> = Absent	Attended Session**	2/15/23 Meeting Minutes	Amendment to Electronic Meetings Policy	Amended Electronic Meetings Policy
<b>Voting Members</b>				
<b>Lisa Kaplowitz, MD, MSHA (Chair)</b>	C	Y	Y	Y
<b>Jana Monaco (Vice Chair)</b>	B	Y	Y	Y
<b>Ijeoma Azubuko</b>	C	Y	Y	Y
<b>Wes Fisher</b>	A	Y	Y	Y
<b>Gregory Josephs</b>	A	Y	Y	Y
<b>Peter Kasson, MD, PhD</b>	A	Y	Y	Y
<b>Sarah C Paciulli, MS, RN, NP</b> [present until noon]		Y	Y	Y
<b>Stephen Rich, PhD</b>	B	Y	Y	Y
<b>Elisabeth Scott</b>	A	Y	Y	Y
<b>Samantha Vergano, MD, FAAP, FACMG</b>	B	Y	Y	Y
Stephen Green, MD, FIDSA* (4, out of town)	B	Y	Y	Y
Elissa Pierson* (4, home)	B	Y	Y	Y
<i>Michael Friedlander, PhD</i>				
<i>Tiffany Kimbrough, MD, FAAP</i>				
<i>Richard S. Nicholas, PharmD, ND</i>				
<i>Megan O'Boyle</i>				
<b>Ex Officio Members</b>				
<b>Jennifer Macdonald, MPH, BSN, RN</b>				
Samantha Hollins, PhD* (4, out of town) [present until noon]				
John Morgan, MD* (4, home)	C			
<b>Vacant Seats</b>				
Health Plan Companies Representative				
Biopharmaceutical Industry Representative				

\*Reasons for Remote Participation: 1. Disability or other medical condition that prevented the member's physical attendance; 2. Family member's medical condition that prevented the member's physical attendance; 3. Distance between the member's principal residence and the meeting location; 4. Personal matter  
 \*\*Breakout Session Topics: A. Survey Development, B. Survey Dissemination, C. Survey Assistance

Virginia Department of Health Staff Attending: Lauren Staley\*, Katherine Crawford, Christen Crews

**Council Business**

- The Chair called the meeting to order at 10:10 am, conducted roll call, and confirmed a quorum of members assembled at the physical meeting location.
- The Chair reviewed the draft meeting agenda and proposed moving times on the agenda to accommodate a later time for lunch.
- The Council then voted to approve the draft meeting minutes from the 2/15/2023 meeting.

**FOIA Requirements**

Alan Gernhardt, Executive Director, Virginia Freedom of Information Advisory Council, spoke with the Council about the history of the Freedom of Information Act (FOIA) and the role of the FOIA Advisory Council. He described how guidelines and requirements have changed over time, especially with consideration for electronic meetings and remote participation. He also explained that meeting requirements may vary between FOIA, the budget language, the executive branch, and the legislation that established the Council. He provided examples of how FOIA requirements have been applied to other public bodies and answered Council member questions.

**Comprehensive Care Centers**

Dr. Andrew Campbell, Director, Comprehensive Sickle Cell Disease (SCD) Program, Children's National Hospital, presented to the Council about Comprehensive Care Centers for SCD. He provided background about SCD, including challenges with access to comprehensive care, appropriate treatments, and expenses; and provided an overview of the HRSA SCD Treatment Demonstration Program and the CDC Sickle Cell Data Collection Program. He stressed the importance of improving the transition from pediatric to adult care, and of having a better understanding of how many individuals are living with SCD in the United States. He reviewed the history of newborn screening for SCD in the United States and the associated improved survival of children, noting increased hospitalization, emergency department usage, and death rates as individuals move into adulthood. Dr. Campbell shared statistics about SCD from the Centers for Medicare and Medicaid Services, and some limitations of currently available drugs and therapies, noting that gene therapies could be a game changer. He also reviewed the Sickle Cell Expansion Act of 2022 (to increase the SCD workforce, awareness, and resources/services for patients) and the SCD Treatment Centers Act (to establish hub-and-spoke networks of specialty, community health, and outpatient medical centers to partner with community-based organizations to provide comprehensive and integrated care management for SCD). Council members discussed questions with Dr. Campbell after his presentation.

**Public Comment**

- Heidi Dix from the Virginia Association of Health Plans shared that Sickle Cell Disease and new therapies are an important topic for the Virginia Medicaid Program, and that the state will have to make a decision on how to pay for them when they are associated with in-patient stays. She noted that Managed Care Programs can provide access to insurance, and there are models in other states.
- No other individuals responded to the invitation to provide public comment.

**Council Business**

- The Chair invited Council members to comment on the updated electronic meetings policy, and the Council elected to adopt an amendment to the policy, adding the following language: *The Council strongly supports public access to its meetings and deliberations and has adopted a policy to comply with existing Virginia Code. Should Virginia Code be amended in the future to be more permissive of electronic communications or telepresence in lieu of having a quorum physically gathered in one place, the Council's electronic meeting policy will default to the more permissive Virginia Code.*
- Council members voted to approve the electronic meetings policy as amended.

### **Survey Breakout Sessions**

Council members next chose to attend one of the following breakout sessions to plan for a survey to learn more about the needs and challenges faced by individuals with rare diseases, and the scope and impact of rare diseases in Virginia:

- The *Survey Development* group discussed how to determine what questions need to be asked and who they should be addressed to; and aimed to create a list of survey questions.
- The *Survey Dissemination* group discussed how to raise awareness about the survey, target the intended audience to respond, and ensure participation is inclusive and representative of the rare disease community; and aimed to create a plan for dissemination.
- The *Survey Assistance* group discussed how to identify and engage with experts on developing, disseminating, collecting, and analyzing survey results; and aimed to identify and reach out to institutions.

### **Survey Breakout Session Group Discussion and Action Plans**

After a break for lunch, Council members shared key points of discussion from each of the breakout groups:

- The *Survey Development* group discussed using the Minnesota Rare Disease Advisory Council's published survey as a reference point for developing questions, focusing first on a patient/caregiver survey, and then considering a provider survey. The group came up with ideas for how to design the survey and potential core questions, with additional optional questions for individuals interested in providing more in-depth responses.
- The *Survey Dissemination* group discussed a variety of ideas of places to send the survey to, such as hospital systems, genetic counselors, medical societies, regional groups, patient advocacy organizations, etc. The recommended format would be an electronic survey, with flexibility to complete it in different ways and at different times, if needed. The group also shared that the IRB process through the Virginia Department of Health would be highly recommended.
- The *Survey Assistance* group discussed working with academic centers and noted that funding resources would be required for some options. The group also suggested that the Virginia Department of Health might be able to assist with analyzing survey results and with drafting governance for the Rare Disease Council Fund.

### **Council Business**

- The Council discussed updates since the last Council meeting, including updates to the Council's webpage, proposed legislation related to the Interstate Medical Licensure Compact, and changes associated with Medicaid and the end of the Public Health Emergency declaration.
- The Council also reviewed proposed topics to include in the Council's annual report to the Governor and the General Assembly and requested increased opportunities to provide feedback on the next meeting's agenda.
- Council members discussed challenges with varying timeframes for appointments, and vacant, expired, and expiring seats.
- The Chair adjourned the meeting at 2:00 pm.