

Rare Disease Council Quarterly Meeting

Thursday, August 15, 2024

10:00 AM – 1:30 PM

Meeting Location

Virginia Hospital & Healthcare Association
Washington and Jefferson Meeting Rooms
4200 Innslake Dr, Glen Allen, VA 23060

Virtual Access Link:

https://www.zoomgov.com/webinar/register/WN_VnsSyeY4Q3KB54Rbegg3oQ.

Meeting Minutes

Council Member Attendance Bold = Present, in person * = Remote participation (Reason*, Location) <i>Italicized</i> = Absent	Voting Record Y=Yes, N=No, A=Abstain	
	05/15/24 Meeting Minutes	Amended Electronic Meetings Policy
Voting Members		
Gwen Traficant (Chair)	Y	Y
Hermionne Johnson (Vice Chair)	Y	Y
<i>Ijeoma Azubuko</i>	-	-
Wes Fisher	Y	Y
<i>Gregory Josephs</i>	-	-
Peter Kasson, MD, PhD* (4*, home)	Y	Y
Sharon Kopis, EdD, MS, RN, FNP- C, CNE	Y	Y
Stephen Rich, PhD	Y	Y
<i>Elisabeth Scott</i>	-	-
<i>Stephen Green, MD, FIDSA</i>	-	-
<i>Elissa Pierson</i>	-	-
Michael Friedlander, PhD* (4*, home)	Y	Y
Tiffany Kimbrough, MD, FAAP	Y	Y
<i>Angela Olmsted, PharmD BCPS</i>	-	-
Leslie Mehta	Y	Y
John Feore, JD	Y	Y
John Michos, MD, FCCP	Y	Y
Ex Officio Members		
Marcus Allen, MPH		
Samantha Hollins, PhD		
Lisa Price Stevens, MD, MPH, MBA, FACP, CHIE		
Proxy: Rachel Cain		
Vacant Seat		
Geneticist licensed and currently practicing in Virginia		

***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

Virginia Department of Health (VDH) Staff Attending: Lauren Staley, Christen Crews*(4*, home), Rebecca Edelstein*(4*, work office)

Council Business

- Gwen T (Chair) called meeting to order. Lauren S (VDH) took roll call. Quorum achieved for meeting to proceed (11 of 21 members physically present at time of roll call).
- Chair reviewed agenda. No additions made. One member joined meeting.

- Chair introduced minutes from May 2024 meeting. Lauren S (VDH) discussed updating the date on the minutes to reflect the year 2024 instead of 2023. John M motioned to approve minutes. Hermionne J seconded motion. Meeting minutes approved (11 – Y, 0 – N, 0 – A).

Public Comment

- Public comment was opened. No public comments made. Chair closed public comment.

Strategic Plan Discussion, Gwen Traficant, Chair of Rare Disease Council

- Gwen T (Chair) shared a strategic plan she created for the Council. Stated her goal is to visit each region in the state by the time the next Annual Report is due. Lauren S (VDH) stated that would be July 2025.
- Reviewed the plan’s vision, goals, actions, and impact. Stated she’s looking for quantitative results and wants to establish work groups around fundraising, survey analysis, funding, telehealth, support for families, access to specialists, research, etc.
- Discussed the first statewide visit taking place in Southwest Virginia and asked Marcus A if he would help with connections in that region. Stated she will send visit updates to Lauren S (VDH) and will focus on using questions from the survey at these visits.
- Stated she is looking into a social media presence for the Council and what the rules are around that.
- Discussed Virginia’s NORD grade for telehealth and how the Council can work towards a “pass”.
- Shared that the Chair and Vice Chair are considering speaking to the Generally Assembly (GA) about HB 1040. The goal may be to speak about caregiving to the GA because it is a concern of the Council.
- Marcus A stated he would share the parent survey that Care Connection for Children (CCC) did.
- Council members expressed the desire to want to do more and are looking forward to contributing.

FOIA Presentation, Alan Gernhardt, Virginia Freedom of Information Advisory Council

- Alan Gernhardt spoke with the Council about meeting requirements under the Virginia Freedom of Information Act (FOIA). Alan G stated the FOIA presentation is available online.
- Discussed FOIA’s policy for meetings, definitions of “public body” and “meeting”, open meeting requirements, meeting exceptions, Council work groups, quorum requirements, and what constitutes a public meeting.
 - Rebecca E (VDH) asked about Council members who attend presentations and if more than two people can attend. Alan G said yes, as long as they are not talking about Council business, but from the public perception viewpoint, it is better to only have two members attend.
- Discussed requirements for public meeting notices, meeting agendas, meeting minutes, Council voting, remote participation, and electronic meetings.
 - Gwen T (Chair) asked about the added language in HB 1040 regarding caregiving during the time of the public meeting. Alan G stated that one does not have to predict issues in advance regarding being a caregiver and that you would not need to specify a specific disability, just need to state it is a medical condition.
 - Rebecca E (VDH) asked if VDH can ask members if they will be a caregiver in advance of a meeting in the form of a survey the Council member would fill out. Alan G stated that is okay, but a person is not required to specify the disability or medical information. Additionally, in emergency situations, members should notify the Council as soon as reasonably possible.
 - Lauren S (VDH) asked about the added language in HB 894 regarding audio-visual technology use. Alan G stated that you cannot restrict a member from voting if they participate remotely and if Zoom is being used, the camera must be on to count towards the quorum. If the member steps away or their camera is off, they cannot be counted in the vote but you can ask them if they would like to turn on their camera and vote. Additionally, a member cannot participate if they were not approved to attend virtually. Alan G further clarified and stated that the member is considered absent if they are not on video or not available by audio, such as losing a connection; however, if a person is on Zoom and their camera goes out, they can type in the chat that they are audio only and can then participate in votes.
- Discussed FOIA requirements regarding social media

- Alan G stated that conducting Council business on social media counts as a meeting and chat features when 3 or more people are communicating would count as a public meeting. He also stated that Council member's private social media is still public record.
- Gwen T (Chair) asked if it is okay to post Council pictures and updates on personal social media accounts. Alan G stated it is not considered a FOIA violation as long as a request is submitted, and the information/post can be shared. Rebecca E (VDH) shared that Councils that want to make social media posts should be discussed and shared with the Secretary of the Commonwealth's Office prior to posting.
- Council discussed the process for sharing information with other Council members, which entails sending to Lauren S (VDH) who would then bcc to all Council members.
- Michael F asked about publishing an article on rare diseases and getting emails about it and if that is considered council business. Alan G stated it is not if other Council members were not involved in the discussion and it was not about the work of the Council.

Review and Vote on Electronic Meetings Policy

- Council reviewed Electronic Meetings Policy (EMP) and added new language from HB 1040 and HB 894.
- Leslie M motioned to approve EMP as amended. Stephen R seconded motion. EMP approved (11 – Y, 0 – N, 0 – A).
- Lauren S (VDH) reminded Council that the EMP will now need to be reviewed and approved annually.

Council Member Introduction Presentation, Gwen Traficant, Chair Rare Disease Council

- Gwen T (Chair) presented her story and background to the Council. Stated her experience as a caregiver encouraged her to serve others.
- Stated she would like to hear from other Council members about their stories as well.

Council Member Introduction Presentation, Hermionne Johnson, Vice-Chair Rare Disease Council

- Moved to next meeting due to time.

Council Business

- Lauren S (VDH) provided updates on rare disease survey, funding governance, and Annual Report. Stated she is starting the IRB process for the survey, reached out to the Department of Treasury for assistance with funding governance, and submitted the Annual Report internally for review.
- Gwen T (Chair) shared a board training that will occur in Richmond on August 26 at 2:30pm. Lauren S (VDH) will send training information to all Council members.
- Hermionne J (Vice Chair) shared that she is also trying to obtain information related to funding governance by reaching out to other Rare Disease Councils.
- Next meeting will be November 19, 2024 and is all-virtual. Quorum of 11 is needed to conduct business.
- Discussed potential agenda items for next meeting.
 - Leslie M suggested talking about action items to give to the Governor as recommendations on the next report.
 - Peter K stated he would look into the Interstate Medical Licensure Compact (IMLC) and report back at the next meeting.
- Adjourned at 1:34.