

Rare Disease Council Quarterly Meeting
Friday, February 23, 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://vdhoep.webex.com/vdhoep/j.php?MTID=maa0e1feb7921ce13c8b09b5dc23ffbd4>

Meeting Minutes

| Council Member Attendance | Voting Record | | |
|--|--------------------------------|-------------------|-------------------------------|
| | Y=Yes, N=No, A=Abstain | | |
| Bold = Present, in person * = Remote participation (Reason*, Location) <i>Italicized</i> = Absent | 11/17/23 Meeting Minutes | Updated Bylaws | RDC Presentation Policy |
| Voting Members | | | |
| Gwen Traficant (Chair) | Y | Y | Y |
| Hermionne Johnson (Vice Chair) | Y | Y | Y |
| Ijeoma Azubuko (arrived at 10:50am) | - | - | - |
| <i>Wes Fisher</i> | - | - | - |
| Gregory Josephs | Y | Y | Y |
| Peter Kasson, MD, PhD*(3, home) | Y | Y | Y |
| Sharon Kopis, Ed.D. MS, RN, FNP- C, CNE | Y | Y | Y |
| Stephen Rich, PhD | Y | Y | Y |
| Elisabeth Scott | Y | Y | Y |
| <i>Samantha Vergano, MD, FAAP, FACMG</i> | - | - | - |
| Stephen Green, MD, FIDSA*(4, phone) | A | Y | Y |
| <i>Elissa Pierson</i> | - | - | - |
| Michael Friedlander, PhD*(4, home) | Y | Y | Y |
| Tiffany Kimbrough, MD, FAAP (left at noon) | Y | Y | Y |
| Angela Olmsted, PharmD BCPS | Y | Y | Y |
| Leslie Mehta | Y | Y | Y |
| John Feore | Y | Y | Y |
| Ex Officio Members | | | |
| Marcus Allen, MPH | | | |
| Samantha Hollins, PhD | | | |
| Lisa Price Stevens, MD, MPH, MBA, FACP, CHIE | | | |
| Proxy: Rhonda Newsome | | | |
| Vacant Seat | | | |
| Health Plan Companies 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

Virginia Department of Health (VDH) Staff Attending: Lauren Staley, Christen Crews

Council Business

- Gwen Traficant (Chair) called meeting to order and asked Council members to introduce themselves. VDH staff and public attendees also introduced themselves.
- Lauren Staley took roll call. Quorum achieved (13 of 21 members physically present at time of roll call).
- Review of agenda: Gwen Traficant reviewed agenda. Council approved the agenda with no additions.

- Draft meeting minutes from November 2023: Gwen Traficant introduced draft meeting minutes from previous meeting. Council made a motion to approve meeting minutes. A second motion was made. Meeting minutes approved. (12 – Y, 1 – A, 0 – N).
 - Draft updated Bylaws and draft RDC Presentation Policy: Gwen Traficant introduced draft updated Bylaws and draft RDC Presentation Policy.
 - Dr. Kasson questioned the reason for the Commissioner of Health needing to speak on behalf of the Rare Disease Council. Christen Crews explained that the Commissioner’s office requested that this be added to the Bylaws due to the Commissioner of Health potentially being involved in meetings with stakeholders without the RDC Chair.
 - Lauren Staley explained the specific updates that were made to the Bylaws (Section 3.1) and Gwen Traficant explained the reasoning behind adding Section 3.1.
 - Dr. Kasson suggested the following amendment to Section 3.1 in the draft updated Bylaws:

Original: *The Commissioner of Health, or their designee, shall be permitted to submit public comments and present to both the General Assembly and other public bodies on behalf of the Council without prior approval or vote from the Council Members.*

Amendment: *The Commissioner of Health, or their designee, shall be permitted to submit public comments and present to both the General Assembly and other public bodies on behalf of the Council without prior approval or vote from the Council Members. The Commissioner of Health, or their designee, shall provide updates at each quarterly meeting related to any public comments and/or presentations made on behalf of the Council.*
- Council made a motion to adopt the amended Bylaws and Presentation Policy. A second motion was made. Amended Bylaws and RDC Presentation Policy both approved. (13 – Y, 0 – N).

Survey Dissemination and IRB Discussion; Christen Crews, Virginia Department of Health

- Christen discussed progression and format of the survey for those new to the Council.
 - Minnesota survey used as a guideline, priorities of survey topics were identified by Council and categorized into main and extended survey groups
 - Interactive poll was conducted during last meeting to review potential questions for both survey groups; Feedback from last meeting was incorporated into the final survey questions
 - Main survey is 36 questions with option to complete expanded survey, 22 questions; both surveys include demographic information
- Asked Council if they wanted to consider adding questions related to diagnostic odyssey and including a question on misdiagnosis and #/estimated cost of diagnosis.
 - Council expressed that cost may be hard to capture. Asked what estimated cost would include, if cost could be related to out-of-pocket cost and if cost can be a ballpark. Council also mentioned caregivers stepping out of careers and how that relates to cost, as well as out of pocket cost related to gas and getting to appointments. Council suggested adding a question related to financial strain.
 - Christen stated that questions would be added related to misdiagnosis, out-of-pocket cost and financial strain and that branching logic could be used for misdiagnosis and diagnosis.
- Asked Council if they wanted to consider adding a question about known resources for the rare disease community (VDH, NORD, Everylife Foundation, Disease Advocacy Group, Facebook/social media support groups, other) to assess knowledge and rate benefits. Stated that a matrix could be used that includes a scale (ex. helpful, not helpful, never heard of it) to gain a better understanding of where individuals are going.
 - Gwen asked if these resources match what is on the Council website. Christen stated this question includes social media resources which are not on the Council website.
- Reviewed next steps for the survey. Stated that the Council has approved the questions, but it will need to go through the IRB process, since the survey data will be included in the Annual Report to the Governor.

- Explained that survey dissemination has fiscal limitations due to the Council not having funding yet and discussed approaching this survey as a pilot, sending it out electronically, and potentially partnering with NORD and other organizations to help disseminate it.
- Asked if there were any thoughts or concerns regarding the pilot approach and stated that fiscal limitations could be noted in the Annual Report. Council agreed piloting is a good approach, as well as noting limitations in the Annual Report.
- Discussed using RedCap to pilot and adding option for participants to start the survey and finish later.
- Stated that there are stakeholder groups that can be leveraged to help disseminate survey.
 - Marcus Allen discussed CCC and how it benefits individuals and families. Discussed that CCC directors would be a great resource to use to help disseminate survey since they have connections to other facilities. Christen discussed the CCC referral process and that providers, along with VDH, can refer to CCC.
 - Hermionne Johnson (Vice Chair) asked if survey can go through the school districts. Dr. Hollins stated that VDOE could share survey link to partners but cannot send to families directly.
 - Council discussed utilizing DMAS, other health districts, RDC website and social media blog posts to disseminate survey.
- Council discussed timeline of when survey will be ready and appropriate sample size and noted that data will likely not be available to include in this year's Annual Report.
- Council discussed potentially incentivizing to take survey once pilot is done and the Council has funding.

Public Comment

- No public comments were made.

Funding Discussion; Lauren Staley, Virginia Department of Health

- Discussed Funding Governance that was drafted by VDH. Stated that it was only a starting point and that funding governance needed to be established before the Council could receive funds.
- Discussed the background of the document and stated that research was conducted to look for other funding governance documents as an example, since funding governance is not established for other Councils that VDH staffs.
- Stated that draft Funding Governance had not been reviewed internally at VDH yet but wanted to get input from the Council.
- Council asked if this document had been reviewed by the legal team (OAG) yet and were informed that it has not. Council expressed that OAG may have a better idea of what should be included in Funding Governance.
- Council asked if additional elaboration is needed related to contributions and donations that are acceptable into the Fund and suggested looking at campaign finance definitions of contributions.
- Council was asked if they had any input on applying for grants. Council stated that legal would probably know more specifics but potentially certain grant categories (federal, philanthropic, non-profit, research, etc) could be included.
- Lauren stated VDH would work on having draft Funding Governance reviewed internally and by the OAG for guidance.

Council Business

- Lauren Staley provided updates on vacant Council seat and presented the Rare Disease Council logo that was drafted. Council approved logo for use on Council website, survey, etc.
- Christen Crews provided updates on HB1040 and SB85 and explained how they could potentially affect the Council's remote participation.
 - Dr. Kasson asked about updating the Electronic Meetings Policy to reflect these changes now. Christen stated it would be better to wait to see what happens with legislation.
- Gwen Traficant discussed expectations for attending meetings and the Council asked about moving one in person meeting to an alternate location. Lauren Staley discussed the results of the poll for alternate

locations that was sent out in December and stated she would send out another poll now that new appointments have been made to the Council.

- Hermionne Johnson discussed making Virginia known in the Rare Disease Community and Gwen Traficant discussed going to different areas of Virginia (hospitals, support groups, etc) to assess at a high level what the needs are, with the hope of including the results in a subsequent Annual Report. Gwen asked the Council for any contacts or connections they may have in Virginia.
- Hermionne Johnson and Marcus Allen presented the Governor's Rare Disease Day Proclamation.
- Lauren Staley discussed having NORD present the Virginia Report Card at the next meeting and asked the Council for other agenda items. The Council mentioned wanting GA updates at the next meeting.
- Action items: VDH to finalize survey and send to Council for feedback, VDH to start IRB process for survey, Council to share stakeholders with VDH who they would like to share the survey with, VDH to compile dissemination list, VDH to have Funding Governance reviewed internally/by the OAG for guidance.
- Next meeting will be all-virtual on May 15.
- Meeting adjourned at 1:21pm.