

Rare Disease Council Quarterly Meeting

Tuesday, November 19, 2024

10:00 AM – 1:00 PM

All-Virtual Meeting:

https://www.zoomgov.com/webinar/register/WN_Eum0gVxNTGCIZ0jVJhMkkQ

Draft Meeting Minutes

Council Member Attendance	Voting Record	
	Y=Yes, N=No, A=Abstain	
Bold = Present <i>Italicized</i> = Absent	08/15/24 Meeting Minutes	Funding Governance
Voting Members		
Gwen Traficant (Chair)	Y	Y
Hermionne Johnson (Vice Chair)	Y	Y
Ijeoma Azubuko	Y	Y
Wes Fisher	Y	Y
Gregory Josephs	Y	Y
Peter Kasson, MD, PhD	Y	Y
Sharon Kopis, EdD, MS, RN, FNP- C, CNE	Y	Y
<i>Stephen Rich, PhD</i>	-	-
Elisabeth Scott	A	Y
<i>Stephen Green, MD, FIDSA</i>	-	-
<i>Elissa Pierson</i>	-	-
Michael Friedlander, PhD	Y	Y
Tiffany Kimbrough, MD, FAAP	Y	Y
Angela Olmsted, PharmD BCPS <i>(joined after minutes vote)</i>	-	Y
Leslie Mehta, JD	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		

Virginia Department of Health (VDH) Staff Attending: Lauren Staley, Tyrique Carden, Jennifer Macdonald, Mary Lowe, Kelly Conatser, Christen Crews, Rebecca Edelstein

Council Business

- Gwen T (Chair) called meeting to order at 10:03am. Lauren S (VDH) took roll call. Quorum achieved.
- Chair reviewed agenda. No additions made.
- Chair introduced meeting minutes from August 2024. John M motioned to approve minutes. Wes F seconded motion. Minutes approved (12 – Y, 0 – N, 1 – A). One member joined after roll call and vote.

Public Comment

- Christen Matthews commented on behalf of friend with hereditary paralytic disease who is 58 and cannot function on his own. Inquired about resources for him. Stated she looked at the Rare Disease Council (RDC) website but is looking for additional information.
 - John M suggested determining what insurance he has and speaking to a case or disease manager.
 - Sharon K stated the National Institute has resources on their website.
- Christen C (VDH) asked each public attendee if they had a public comment. No additional comments.

Updates & Partner Groups Discussion, Gwen Traficant, Chair of Rare Disease Council

- Chair provided updates including:
 - Statewide visits on hold but will be readdressed after new year; getting approval for RDC social media, which will be added to the Presentation Policy; personal introductions will be removed from future agendas; attended NORD Summit and NORD's 5th Annual Rare Disease Advisory Council Stakeholder webinar; Chair, Vice Chair and Lauren S (VDH) meet monthly to collaborate.
- Chair discussed plan to implement partner groups:
 - Groups: funding, telehealth, caregiver support, research advancement, community marketing, grant applications, standards of care, health equity, insurance, Virginia support, social media.
 - Each group will have 2 members to ensure FOIA compliance.
 - Partners will establish goals. Each group will have a survey dissemination and policy component.
 - Partner group updates will be on meeting agendas moving forward. Chair discussed importance of attending in person meetings.
- Council engaged in group discussion regarding partner groups:
 - Samantha H commented that ex-officios were part of the groups, but their expertise was in the system. Might be helpful if they worked with all groups. Chair stated the groups were kept at 2 to stay FOIA compliant.
 - Leslie M asked if members could add value or ideas to other areas if they have expertise in that area or is that not the case with the new partner groups? Chair stated the intent is to continue to share amongst the whole Council during quarterly meetings.
 - Michael F commented that for research advancements, the Council needs to have a link between the funding and grant groups and a cataloguing of resources. Communication between groups is important as to not duplicate work. Chair agreed with comment.
 - Gregory J stated he is excited about community marketing and would like to link with locations on social media to connect patients to resources.
 - Chair asked if the Council was comfortable with the pairings and partner group descriptions. Stated the Council has time to think on it until the next meeting. No additional comments.
 - John F asked if there was a contact sheet for Council members. Lauren S (VDH) stated she will connect the two partners via email and that they are free to work offline together. Reminded Council to not include a third Council member on the email, to ensure FOIA compliance. Stated partner groups may include her on emails but not required.
 - Sharon K asked if the Council is working on grants other than research, as well as looking for funding? Chair stated she will not limit any funding or grants, so long as it aligns with the Council's mission and legislation. Stated they are working on finalizing funding governance, which outlines a grant application approval process, including submitting a proposal to the Chair and Vice Chair.

Action item:

- Lauren S (VDH) to send each partner group Council contact information.

Funding Governance Discussion, Lauren Staley, Virginia Department of Health

- Lauren S (VDH) discussed adding a vetting process for accepting funds. Asked how Council will decide if a funding source is reputable?
 - Council discussed liquid and unrestricted funds, funds that may yield legal risks or reputable damage to the Council, and funding sources listed under acceptable and unacceptable sections.
 - Council questioned process for accepting direct funds, if concerns are about directed funds for a particular task, and what concerns should be addressed in the document? Lauren S (VDH) stated the vetting process pertains to all funding sources and applying for grants has additional processes. Stated a vetting process was suggested by the VDH policy analyst to protect the Council, and the Council cannot use funds that do not pertain to the Council's goals and duties. Jen M (VDH) stated funds need to pertain to what is in Virginia Code and fund distribution will be handled by the State.
 - Chair discussed deal breakers for not accepting funds, such as being required to name something after the funder, breaching privacy, and funding being out of alignment with the Council's mission.

- Rebecca E (VDH policy analyst) explained that without a vetting process, the Council can receive funding from anyone and there would not be a lot the Council could do against refusing money. Stated vetting process can be broad, updated as needed, and is to protect the Council.
- Council discussed vetting process and added the following to the Funding Governance:
 - “1. VDH staff shall review for potential known financial or reputational risk to the Commonwealth and the Council relating to the contributions and share findings with Chair(s).*
 - 2. Acceptance of funding source and directed gifts shall be subject to approval of the Council or its designated proxy.*
 - 3. If necessary, the Office of Attorney General can be contacted for feedback regarding acceptance of monetary funds or donations.”*
- Council added clarifying language to the conflict of interest section.
- Council discussed and rearranged fund appropriations section for better readability.
- Peter K motioned to accept amendments to the Funding Governance and vote to approve. Michael F seconded motion. (14 – Y, 0 – N, 0 – A). Funding Governance adopted.

HCU Newborn Screening Presentation, Liz Carter, HCU Network America

- Chair introduced Liz Carter and Danae Bartke from HCU Network America (HCUNA).
- Liz C shared that her son has homocystinuria (HCU) and was missed by newborn screening.
- Danae B discussed what HCU is, why accurate newborn screening is important, and the negative health consequences if HCU is not diagnosed until later in life. Discussed how HCUNA is working to change the newborn screening methodologies for HCU, the recommended changes to the HCU newborn screening test and considerations for the RDC to collaborate with HCUNA.
 - Leslie M asked if a delay in diagnosis causes different outcomes for patients. Liz C stated that it is a serious and treatable disorder. Those who adhere to treatment have good outcomes. Shared that her son had delayed diagnosis and treatment. Danae shared that her brother missed all of his milestones and has significant cognitive issues due to delayed diagnosis.
 - John M asked if they had spoken to the American Academy of Pediatrics. Danae shared they have not and have been focusing on the metabolic side.
 - Mary L (VDH) stated the newborn blood spot program is open to working with their specialists, reviewing the cutoffs, and adding the HCU information to their website.
 - Hermionne J (Vice Chair) asked if symptoms are only in the younger population. Danae B stated they have encountered patients with a missed diagnosis from 8-58 years old and shared her personal story of getting a delayed diagnosis.
 - Peter K stated clinicians should receive additional education regarding newborn screening.
 - Emily H (DCLS) stated they are open to the recommendations with the cutoffs and are looking at historical and current data and further information.

Council Business

- Lauren S (VDH) provided updates on the RDC survey and Annual Report. Requested that Council continue to send contacts for survey dissemination list, which will be included in IRB application. Stated that Annual Report was submitted in October and is still under review.
- Chair, Vice Chair and Lauren S (VDH) provided key takeaways from the NORD Summit Conference.
- Next meeting in-person at VHHA on February 25, 2025. Quorum of 11 needed to conduct business.
- Adjourned at 12:47pm.