

Rare Disease Council Quarterly Meeting

Wednesday, May 15, 2024

10:00 AM – 1:00 PM

All-Virtual Meeting:

https://www.zoomgov.com/webinar/register/WN_ZZYUh-FWT2SAUV8Furjoyg

Draft Meeting Minutes

Council Member Attendance	Voting Record Y=Yes, N=No, A=Abstain
Bold = Present	02/23/24
<i>Italicized</i> = Absent	Meeting Minutes
Voting Members	
Gwen Traficant (Chair)	Y
Hermionne Johnson (Vice Chair)	Y
Ijeoma Azubuko	Y
Wes Fisher (joined after roll call and vote)	-
Gregory Josephs (joined after roll call)	Y
Peter Kasson, MD, PhD	Y
Sharon Kopis, EdD, MS, RN, FNP- C, CNE	Y
Stephen Rich, PhD	Y
Elisabeth Scott	Y
Stephen Green, MD, FIDSA	Y
<i>Elissa Pierson</i>	-
Michael Friedlander, PhD	Y
<i>Tiffany Kimbrough, MD, FAAP</i>	-
<i>Angela Olmsted, PharmD BCPS</i>	-
Leslie Mehta	Y
John Feore, JD	Y
John Michos, MD, FCCP (joined after roll call)	Y
Ex Officio Members	
Marcus Allen, MPH	
Samantha Hollins, PhD (joined after roll call)	
Lisa Price Stevens, MD, MPH, MBA, FACP, CHIE Proxy: Rhonda Newsome	
Vacant Seat	
Geneticist licensed and currently practicing in Virginia	

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

Council Business

- Gwen T (Chair) called meeting to order. Lauren S (VDH) took roll call. Quorum achieved for meeting to proceed (13 of 21 members present). Four members joined late and were not present for roll call.
- Chair reviewed agenda. No additions made. Two members joined meeting.
- Chair introduced minutes from February 2023 meeting. Michael F motioned to approve minutes. Ijeoma A and Gregory J both seconded motion. Meeting minutes approved (13 – Y, 0 – N, 0 – A). One voting council member joined meeting after vote concluded.

NORD Overview & Virginia Report Card Presentation, Carolyn Sheridan, NORD

- Chair introduced Carolyn S from NORD. Brief overview of NORD given. NORD focuses on all rare diseases, works on national and state levels, and publishes Report Cards for each state.
- Report cards are published annually and are based on 9 issue areas.

- Provided explanations on categories where C or fail was graded: medical nutrition, protecting patients in state regulated insurance, telehealth
 - Stated Virginia has mandate for medical nutrition, but mandate has limitations. Marcus A stated Care Connection for Children (CCC) program has limited funds to help with metabolic formula.
 - Discussed what actions Virginia has taken to mitigate the expansion of short-term, limited-duration health plans (STLDIs). Carolyn S will email code of Virginia, in regards to STLDIs, to Lauren S (VDH) to send to Council members.
 - Explained that telehealth is only evaluated on whether the state participates in the Interstate Medical Licensure Compact (IMLC) which provides access to telehealth services across states.
- Provided explanations on categories where B was graded: medical financial eligibility, newborn screening, and prescription out-of-pocket costs
 - Medicaid financial eligibility based on 4 separate categories; Virginia scored low on eligibility for children (including CHIP-funded).
 - Newborn screening (NBS) is most comprehensive program across US. Two conditions added to RUSP, which caused lower numbers in report cards for multiple states. New conditions take 2-3 years to add. Allison is resource in NORD for NBS.
 - Prescription (Rx) drug out-of-pocket costs grade based on number of protections in insurance within state code. Virginia has 2/5 protections.
- Briefly discussed categories where A was graded: protecting patients in State Medicaid programs, Rare Disease Councils (RDCs), Step Therapy
 - Protecting patients in State Medicaid programs is based on pass/fail
 - Virginia has a RDC
 - Virginia has several Step Therapy protections.
- Discussed upcoming NORD events: 30 members from 17 RDACS attended last NORD Summit
- Council member questions: How does Virginia get an A? Does NORD have resources in helping patients and providers navigate step therapy challenges? Is there any component that could help increase engagement in rare disease studies? What are the most impactful areas to focus on?
 - Carolyn S stated joining IMLC to ease access to specialists and providers and Medicaid changes to increase care for children would be impactful and helpful for Virginia.
 - Carolyn S stated there are no specific resources for Step Therapy, but patient services team may reach out to providers to provide support (case by case).
 - Carolyn S will send resources pertaining to engagement in rare disease studies.

Action Items:

- Lauren S (VDH) to provide all NORD information to Council members

Statewide Visits Discussion, Gwen Traficant, Chair of Rare Disease Council

- Gwen T (Chair) discussed proposal to conduct four statewide visits across different regions.
- Chair and Vice-Chair to use questions from survey to gather input from Virginians regarding rare disease needs. Will be reported at next RDC meeting and included in Annual Report to Governor.
- Proposed visiting Southwest Virginia first and focusing Carilion and LewisGale Health Systems.
- Chair requested resources/contacts that would aid in these visits.
 - Michael F will share resources and is well connected in the southwest area of VA
 - Greg J has a contact at Foundation of America who is an epidemiologist in charge of registry
 - Marcus A stated he has contacts at Carilion

Action Items:

- Lauren S (VDH) to gather resources/contacts and send to Chair and Vice-Chair

Future Council Initiatives & Interests Discussion, Rare Disease Council

- Lauren S (VDH) led discussion. Updated Council on status of survey. Most of survey already input into RedCap. Once complete, IRB will need to be submitted. Inquired what Council would like to focus on next while survey gets approval.

- Michael F suggested there might be opportunities to connect rare disease across the Commonwealth and NORD that relate to research and funding. Council could advocate for more inclusion of rare disease community and research trials.
- John F stated Council could look at other RDCs to compare activities to improve Virginia's RDC.
 - Hermionne J (Vice-Chair) stated she has reached out to several RDCs but has not received much feedback. Will provide updates once feedback comes in.
- Leslie M expressed comprehensive insurance and working to expand Medicaid is very important.
- John M stated VDH is working on the Health Opportunity Index which can be useful as a measuring stick and for targeting resources based on regional common issues.
- Peter K mentioned IMLC and potentially raising the discussion.
- Stephen G briefly discussed financial opportunities for the Council. Stated he would discuss more at the end of the meeting.
- Elizabeth S discussed telehealth grade from NORD. Asked what some areas are specifically that need to be addressed with telehealth and if there is anyone on the council that can speak on this.
 - Gwen T (Chair) stated accessibility is needed in rural areas.
 - Leslie M stated telehealth appointment availability has decreased since height of Covid. Council could provide potential recommendations for respite and attendant care giving services.
- Hermionne J (Vice-Chair) voiced concern that Council will not make any progress if they do not have any backers. Asked how Council can find a sponsor or specific legislators to connect with.
 - Christen C (VDH) provided guidance for expressing concerns, such as providing recommendations in the Annual Report to the Governor, speaking to the delegate or legislative representative in Council member's region and making comments at General Assembly (GA).
 - Leslie M spoke on advocacy at federal and state levels. Stated if Council is interested in unique bills, they could reach out to legislators who may be interested in sponsoring those bills.
 - Gwen T (Chair) stated desire for members from different areas of the state to help support by going before legislation.
 - Marcus A stated sickle cell community has been successful in getting resources.
 - Hermionne J (Vice-Chair) expressed need to make connections to support the RDC, getting the right language together and having ideas before the GA opens next year.
- Greg J suggested subcommittees to help support the Council.
 - Peter K stated RDC has restrictions under open meetings laws.
 - Christen C (VDH) stated subcommittees need a motion to approve and would need to follow the same rules and guidelines as larger Council.
 - Gwen T (Chair) stated that subcommittees could be considered in the future; however, the Council is not ready at this time.

Public Comment

- No members of the public pre-registered to make a public comment.
- VDH asked members of the public to use "raise hand" function if they wanted to make a public comment. No public comments made. Chair closed public comment and noted that meeting was running ahead of schedule and suggested waiting a few minutes, at which time she would re-open public comment. Council agreed.
- During this time Stephen G went into further detail regarding financial opportunities for the Council, stating his private charitable foundation, Sedona, can provide grants and emergency financial assistance to support low-income families. Suggested that the Council could potentially support a demo project for low-income families needing special diets, stating that there is no real safety net for children with rare disease.
- Chair re-opened public comment. No public comments made. Council adjourned for break.
- During break, Lauren S (VDH) received email from member of public regarding desire to make public comment, however the "raise hand" function was not working during public comment period.

- Public comment re-opened after break. Lauren S (VDH) asked each member of the public if they had a public comment. No public comments made.

Council Member Introduction Presentation, Gregory Josephs, Rare Disease Council member

- Greg J presented his experience and story as an individual living with a rare disease.
- Shared information on his background, family, and experience in setting up three support groups in Manassas, Hampton, and Richmond.
- Discussed focusing on the positive and shared that he enjoys gardening.

Council Business

- Gwen T (Chair) provided update on inquiry regarding use of social media for the RDC. Stated she will hopefully have more answers by the next meeting. Stated she is also seeking guidance related to the Funding Governance.
- Lauren S (VDH) briefly discussed survey and reminded Council to send her contacts to be added to survey dissemination list. Discussed next Annual Report timeline. Lauren S (VDH) to gather contacts and add to survey dissemination list.
- Lauren S (VDH) provided update on two GA bills that would affect Council. Both bills were approved by Governor but have not been signed yet. Governor has until May 17 to make final decision. Bills would go into effect July 1.
 - Reviewed HB1040 and highlighted added language. Discussed her interpretation of the added language based on prior conversations. Council concerned that interpretation may not be correct. Marcus A (VDH) stated VDH policy analyst may also be able to assist with interpretation. Lauren S (VDH) to follow up with FOIA and policy analyst regarding HB1040 language.
 - Reviewed HB894 and highlighted added language. No questions from Council.
- Next meeting August 15 (in-person). Quorum of 11 needed.
- Potential agenda items: Brief council member introduction presentations. Lauren S (VDH) to send out sign-up sheet.
- Adjourned at 12:57.