

Rare Disease Council Quarterly Meeting

Wednesday, February 18, 2026

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_psFt6nVuQ0iWn78fVYFWhQ#/registration

Meeting Minutes

Council Member Attendance	Voting Record Y=Yes, N=No, A=Abstain		
	11/19/25 Meeting Minutes	Updated Bylaws	Updated Presentation Policy
Bold = Present, in person Bold* = Present, remote participation (Reason*, Location) <i>Italicized</i> = Absent			
Voting Members			
Gwen Traficant (Chair)	Y	Y	Y
Hermionne Johnson (Vice Chair)	Y	Y	Y
Ijeoma Azubuko	Y	2 nd - Y	Y
<i>Wes Fisher</i>	--	--	--
Gregory Josephs* (1, home)	Y	--	--
Sharon Kopis* (1, home)	Y	Y	Y
<i>Stephen Rich</i>	--	--	--
Elisabeth Scott	A	Y	Y
Stephen Green* (4, home)	--	--	--
<i>Elissa Pierson</i>	--	--	--
Michael Friedlander	1 st - Y	Y	2 nd - Y
<i>Tiffany Kimbrough</i>	--	--	--
<i>Angela Olmsted</i>	--	--	--
Judy Stecker	A	1 st - Y	Y
<i>John Feore</i>	--	--	--
Christina Peroutka	Y	Y	1 st - Y
Paul Kruszka	2 nd - Y	Y	Y
Ex Officio Members			
Marcus Allen, VDH			
Samantha Hollins, DOE			
Rachel Cain, DMAS			
Vacant			
Representative from Health Plan Companies			

***Reasons for Remote Participation:** 1. Disability or other medical condition that prevented the member's physical attendance (*counts towards quorum*); 2. Family member's medical condition that prevented the member's physical attendance (*counts towards quorum*); 3. Distance between the member's principal residence and the meeting location > 60 miles ; 4. Personal matter
Virginia Department of Health (VDH) Staff Attending: Lauren Staley, Jennifer Macdonald, Mary Lowe, Jayla Dickens

<p>Council Business</p> <ul style="list-style-type: none"> Chair called meeting to order at 10:11 AM. Introductions and roll call by Lauren Staley (VDH). Quorum achieved. Chair reviewed agenda. No additions made. Chair introduced 11/19/2025 minutes for vote. Minutes approved. Chair suggested moving vote on Updated Bylaws and Presentation Policy to end of meeting. Council approved.
<p>Public Comment</p> <ul style="list-style-type: none"> No public comments.

Rare Disease Innovation Hub Presentation, Amy Rick, Food & Drug Administration (FDA)

- Amy Rick shared information regarding the Rare Disease Innovation Hub (RDIH).
 - FDA Structure and its three distinct centers: device, drug, and biologic. Emphasized the need for consistency across these three centers.
- FDA standard is applicable to all drugs for diseases, ranging from those that are the rarest to the least rare. Also stated that in terms of drug trials, there is a limitation to the level of testing that can be done currently, as some populations can be excluded if they were already on the drug prior to the trial.
- RDIH became part of the Federal Drug Administration as of Q4 2024, which has been impactful for them as an organization.
- RDIH has three main goals currently:
 - Aims to advance regulatory science of rare disease therapies, enhance and strengthen coordination and alignment between medical product centers, with a focus on Center for Drug Evaluation and Research (CDER) and Center for Biologics Evaluation and Research (CBER), and to create a centralized point of contact for external partners.
- RDIH's 2026 Strategic Agenda includes:
 - Further engage with the industry and patient community on innovative methods and designs, patient voice in drug development process, and RDIH as community point of contact.
- Regarding CDER and CBER, RDIH also aims to make sure that those reviewing similar diseases around the same time work together to ensure consistent reviews of drug application. Noted that it may be helpful for reviewers to know who their counterpart is in the review process.

Chair Updates, Gwen Traficant, Chair of Rare Disease Council (RDC)

- Marshall Summar, MD, is a potential speaker for a future meeting.
- RDC Council Member Survey feedback revealed interest in more action, awareness and collaboration.
- Action tasks for the Council include
 - Engaging the General Assembly, potential changes for the August meeting date, impact care for rare disease patients, supporting rare disease research, funding to support RDC goals, more working meetings with actionable outcomes, and RDC activity and communication between meetings.
- There is now an official way to receive funds and potentially fund research. The Council is fully self-funded and is not receiving any State funds at this time. Since the Rare Disease Council falls under VDH, financial transactions are to be handled through VDH and stored in the State Treasury.
- Council is aiming to create more awareness by utilizing social media, promoting resources, featuring personal stories, sharing upcoming media dates, highlighting other organizations, and highlighting patient stories. Council members were encouraged to participate in organization's social media engagement.
- Council survey results emphasized the desire for more collaboration through member introductions, inviting policy makers, gathering provider and consumer input, ensuring diverse patient representation, improving internal communications, and creating more opportunities for active participation.
- Rare Disease Day occurs on February 28th, 2026.
- A format for subcommittee meetings was proposed. A vote, by show of hands, was made to accept format. Noted that FOIA compliance is essential.
 - Occur after in-person meetings.
 - Incorporates three working groups that include a chair, bylaws, agenda, and minutes.
 - Council members would volunteer to be in a subcommittee group.

RUSP Update, Mary Lowe, Virginia Department of Health (VDH)

- Provided background of the Recommended Uniform Screening Panel (RUSP). It is currently managed by the federal Department of Health and Human Services (DHHS) and is a recommended list of disorders for states to consider for NBS programs. Disorders are chosen based on specific criteria.
- Follow-up considerations were brought to the forefront. These were noted as:
 - Availability of specialty centers for care coordination, diagnosis and treatment, communication of screen-positive results to care providers and families, and comprehensive familial support in follow-up case management.
- A flow chart was presented detailing the NBS program's New Disorder Implementation.

2026 Strategic Plan Brainstorming Groups, Rare Disease Council Members

- Chair discussed the accomplished and unaccomplished goals, actions, and impacts of the 2025 plan.
- Council broke out into two groups to brainstorm potential goals, subcommittees, and ideas for the 2026 Strategic Plan.

2026 Strategic Plan Group Discussion, Rare Disease Council Members

- Council members noted goals related to increasing resources and access to treatment, citing that military needs, geographic concerns, data or record sharing, and transportation are key factors. Members also noted the need for an increase in research, workforce education, community engagement, and funding.

Council Business

- Chair introduced Updated Bylaws for vote. Updated bylaws approved.
- Chair introduced Updated Presentation Policy. Updated Presentation Policy approved.
- Next meeting will be May 19, 2026. The location and format of this meeting is to be determined.
- Chair adjourned at 1:22 PM.