

## Rare Disease Council Quarterly Meeting

Tuesday, May 19, 2026

10:00 AM – 12:00 PM

### All-Virtual Access Link:

[https://www.zoomgov.com/webinar/register/WN\\_SXvDf\\_WWROiE-B8qw\\_ds3Q](https://www.zoomgov.com/webinar/register/WN_SXvDf_WWROiE-B8qw_ds3Q)

*Meeting attendance requires prior registration. Please register at link above.*

*Council members are pre-registered.*

### Draft Meeting Minutes

Council Member Attendance	Voting Record Y=Yes, N=No, A=Abstain		
<b>Bold = Present</b> <i>Italicized = Absent</i>	02/18/26 Meeting Minutes	Amendment of Subcommittee Bylaws	Pivot from Breakout Groups to Group Discussion
<b>Voting Members</b>			
<b>Gwen Traficant (Chair)</b>	Y	Y	Y
<b>Hermionne Johnson (Vice Chair)</b>	Y	Y	Y
<b>Ijeoma Azubuko</b>	M2 Y	Y	Y
<b>Wes Fisher</b>	Y	Y	Y
<b>Gregory Josephs</b>	M1 Y	Y	Y
<b>Sharon Kopis</b>	Y	M1 Y	Y
<i>Stephen Rich</i>	-	-	-
<i>Elisabeth Scott</i>	-	-	-
<b>Stephen Green</b>	Y	Y	Y
<i>Elissa Pierson</i>	-	-	-
<i>Michael Friedlander</i>	-	-	-
<i>Tiffany Kimbrough</i>	-	-	-
<i>Angela Olmsted</i>	-	-	-
<i>Judy Stecker</i>	-	-	-
<b>John Feore</b>	Y	Y	Y
<b>Christina Peroutka</b>	Y	Y	Y
<b>Paul Kruszka</b>	-	M2 Y	Y
<b>Ex Officio Members</b>			
<b>Marcus Allen, VDH</b>			
<b>Samantha Hollins, DOE</b>			
<b>Rachel Cain, DMAS</b>			
<b>Vacant</b>			
Representative from Health Plan Companies			

**Virginia Department of Health (VDH) Staff Attending:** Lauren Staley, Jennifer Macdonald, Jayla Dickens

<p><b>Council Business</b> The meeting was called to order at 10:05 AM. The agenda was reviewed, and quorum was achieved.</p>
<p><b>Public Comment</b> No public comments.</p>
<p><b>Chair Updates, Gwen Traficant, Chair of Rare Disease Council (RDC)</b></p> <ul style="list-style-type: none"> <li>• Gwen T reviewed the National Organization for Rare Disorders (NORD) report card. <ul style="list-style-type: none"> <li>○ Virginia received a grade of a B overall. Receiving this grade provides advocates, patients, and organizations insight into areas of success and improvement.</li> <li>○ Medicaid and financial eligibility received a B. Newborn screening received an A. Telehealth continues to be an area of failure.</li> </ul> </li> <li>• Gwen T highlighted Judy S's work regarding the Plausible Mechanism Framework.</li> </ul>

- Stecker recently spoke on the topic, emphasizing its significance for her son. She noted that there have been many improvements and advancements in the rare disease field, and that it is encouraging to see so much increased collaboration across the industry at conferences.
- Council discussed plans to move forward with subcommittees and begin developing them further.
  - Proposed subcommittees: Resources and Access subcommittee and Community Engagement subcommittee.
- It was shared that Stephen G plans to present a proposal in August focused on securing funding for one specific rare disease. Interested members were encouraged to share ideas and offer assistance. Discussion also focused on how to make ideas more actionable.
- Gwen T discussed how changes at the Federal Drug Administration (FDA) affect the rare disease community and shared the story of her husband's experience with rare disease. She noted that insight into his role at the FDA could potentially benefit the RDC and that he may participate in future meetings.
- Subcommittee Bylaws were reviewed with staff members.
  - Members voted to amend the wording of the bylaws so that subcommittee meetings would occur twice a year as part of the in-person meetings.
- Council reviewed the 2025 Strategic Plan including: goals that had been accomplished, those that remain unaccomplished, and areas with room for growth, including interstate medical licensure compact (IMLC). Discussion also focused on methods for funding research and supporting families.

**Breakout Groups (Topics: Subcommittees, Strategic Plan), Rare Disease Council Members**

Breakout groups were scheduled to discuss subcommittees and the strategic plan but due to technical issues, Council members voted to engage in these topics through a larger group discussion.

**Group Discussion, Rare Disease Council Members**

- Council discussed the need for IMLC, emphasizing that it is critical for expanding resources available to patients.
  - It was noted that some services and treatments are more accessible in Virginia than in neighboring states.
  - Discussed partnering with other rare disease associations and patients to increase awareness of available resources, as many Virginians are unaware that rare disease resources exist.
- Goal of the Council is to move strategic plan items from failing to passing status. Members were informed that once adjustments to the 2027 strategic plan are made, the revised plan will be shared with the committee for edits and additional input.
- Council discussed the importance of having formula approved by the FDA as a drug, noting that it is not only infants who rely on formula, but many individuals require it throughout their lives.
  - Council noted that certain treatments, such as B12 intramuscular injections, function as drug treatments but are not treated as such for coverage purposes, resulting in significant out-of-pocket costs for patients.
  - Discussion emphasized the importance of learning more about patient and family needs and ensuring that treatments align with patient preferences and quality of life.
- Council discussed challenges associated with partnering with other organizations and explored ways to engage the community and raise money to support research initiatives.
  - The importance of sharing personal stories to promote awareness of the Rare Disease Council was emphasized, along with the need to strengthen community partnerships.
- Council was reminded that RDC funds are housed within the state treasury and that funding documents will be redistributed to committee members. Council's role is to determine how the funding is allocated.

**Additional Council Business**

- VDH updates were provided including the Bear-y Best Start Fair taking place on May 30 at Richmond Raceway.
- Gwen T gauged Council interest in participating in the State Fair and distributing information at farmers markets.
- Next meeting will take place on August 5 at the Virginia Hospital & Healthcare Association.

**Adjournment**

Meeting adjourned at 12:00 PM.