

Rare Disease Council Quarterly Meeting

Tuesday, November 19, 2024

10:00 AM – 1:00 PM

All-Virtual Access Link:

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

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

Council members are pre-registered.

Meeting Agenda

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| 10:00 – 10:15 | Council Business <ul style="list-style-type: none">• Call Meeting to Order (Chair)• Introductions and Roll Call (VDH)• Review Agenda (Chair)• Vote on Draft Meeting Minutes (VDH) |
| 10:15 – 10:30 | Public Comment Period
<i>(Time period may be shorter depending on the number of comments received)</i> |
| 10:30 – 11:15 | Updates & Partner Groups Discussion
Gwen Traficant, Chair of Rare Disease Council |
| 11:15 – 12:00 | Funding Governance Discussion
Lauren Staley, Virginia Department of Health |
| 12:00 – 12:15 | Break |
| 12:15 – 12:45 | HCU Newborn Screening Presentation
Liz Carter, HCU Network America |
| 12:45 – 1:00 | Council Business <ul style="list-style-type: none">• Updates <i>(Survey, Annual Report, NORD Conference)</i>• Next Meeting/Agenda items• Adjourn |

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RARE
Disease
COUNCIL

