

**Rare Disease Council Meeting  
Monday, December 6, 2021  
10:00 AM –2:00 PM**

**Meeting Location**  
**Virginia Hospital & Health Care Association (VHHA)**  
**Address:** 4200 Innslake Dr, Suite 203, Glen Allen, VA 23060  
Conference Rooms: Washington and Jefferson

**To Join Virtually**  
**Meeting Link:** <https://vdh.zoom.us/j/94041758774>  
**Platform:** Zoom **Meeting ID:** 940 4175 8774

**AGENDA**

10:00 – 10:30	Welcome, Jana Monaco, Vice-Chair Introductions Review of Agenda Approval of Council Bylaws Approval of 9/27/21 meeting minutes
10:30 – 11:10	VDH Programmatic Updates <ul style="list-style-type: none"> <li>● Children and Youth with Special Health Care Needs, Marcus Allen, MPH</li> <li>● Sickle Cell and Blood Disorders Program, Shamarree Cromartie, MPH</li> <li>● Dried Blood Spot Newborn Screening, Mary Lowe, RN</li> <li>● Hearing, Birth Defects and CCHD, Christen Crews, MSN, RN</li> </ul>
11:10 – 11:15	Public Comment
11:15– 11:30	NORD Summit Highlights, Samantha Clark, MPH, VDH
11:30 – 12:00	Presentation, Ijeoma Azubuko, The Ruby Ball Foundation
12:00 – 12:30	Break for Lunch
12:30 – 1:00	Guest speaker, Minnesota Rare Disease Advisory Council, Amy Gaviglio, MS, CGC
1:00 -- 1:30	Review Survey Results, Samantha Clark, VDH <ul style="list-style-type: none"> <li>● Goals and Priorities for Year 1</li> </ul>
1:30 -- 2:00	Open Discussion, Samantha Clark, VDH  Action Items <ul style="list-style-type: none"> <li>● Determine 2022 dates, times and location</li> <li>● Alternative options - scheduling in the evening or weekends, alternating between different location site</li> </ul>
2:00	Adjournment, Jana Monaco, Vice-Chair