

**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

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

Meeting Minutes

Rare Disease Council Members Present (attended in person=**Bold**, Attended virtually=*italicized*, * indicates ex officio member):

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| <input type="checkbox"/> <i>Lisa Kaplowitz, Chair</i> | <input type="checkbox"/> <i>Ijeoma Azubuko</i> | <input type="checkbox"/> Jennifer Macdonald, MPH, BSN, RN* |
| <input type="checkbox"/> Jana Monaco, Vice Chair | <input type="checkbox"/> <i>Holly Kearl</i> | <input type="checkbox"/> <i>Dr. John Morgan*</i> |
| <input type="checkbox"/> <i>Dr. Peter Kasson</i> | <input type="checkbox"/> Rebecca Goldbach | <input type="checkbox"/> Dr. Samantha Hollins* |
| <input type="checkbox"/> <i>Dr. Samantha Vergano</i> | <input type="checkbox"/> <i>Megan O'Boyle</i> | |
| <input type="checkbox"/> Sarah Paciulli, MS, RN, NP | <input type="checkbox"/> Dr. Richard Nicholas | |
| <input type="checkbox"/> <i>Dr. Tiffany Kimbrough</i> | <input type="checkbox"/> Susan Klees | |
| <input type="checkbox"/> <i>Dr. Stephen Green</i> | <input type="checkbox"/> <i>Dr. Maureen Dempsey</i> | |
| <input type="checkbox"/> Gregory Josephs | <input type="checkbox"/> <i>Dr. Stephen Rich</i> | |

Council Members Absent:

- Shannon McNeil

VDH Staff Present:

- Samantha Clark**
- Daphne Miller*
- Shamaree Cromartie*
- Robin Buskey*
- Mary Lowe*
- Marcus Allen**

10:00 – 10:30	Welcome, Jana Monaco, Vice-Chair A. Roll call and introductions B. Review of Agenda C. Approval of Council Bylaws D. Approval of 9/27/21 meeting minutes <i>The council did not meet the in person attendance requirement needed to hold a quorum. Council bylaws and 9/27/21 meeting minutes will be voted on at the next quarterly meeting.</i>
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10:30 – 11:10	<p>VDH Programmatic Updates</p> <p>A. Children and Youth with Special Health Care Needs, Marcus Allen, MPH Reviewed priorities and updates of the program, including: emphasis on federal requirements, managing budgets, and keeping contract current and programs running efficiently, strong partnerships in education and medical, reducing barriers in health care needs, special projects and data requests. Priority programs: Child Development Centers, providing assessments for behavioral/developmental disorders in children and connecting families to resources, decline in numbers due to COVID-19. Highlighted breadth of disorders diagnosed and highlighted challenges in finding care and treatment with limited resources and services. Speech, language, ADHD and Autism are the most common diagnoses. Care Connection for Children; largest program, provides care coordination for children with condition of physical basis that lasts, or is expected to last 1 year or more. Provides funding and connects families with resources/services to provide support.</p> <p>B. Sickle Cell and Blood Disorders Program, Shamaree Cromartie, MPH Discussed the Sickle Cell program in Virginia, including recently expanded inclusion criteria for eligibility to include adults. Program supports care coordination and services for nurses and social workers and federally funding health centers, assistance on health insurance premiums and other funding, and provides funding for therapies for patients experiencing delay in insurance coverage. Virginia Bleeding Disorders Assessment Project (VBDAP), Due to changes in the healthcare system and how funding was being utilized, VDH partners with VCU to conduct a needs assessment to guide a comprehensive evaluation of how the program serves its target population and evaluate impact of significant changes in bleeding disorders care and the funding for health care. Currently in the final evaluation stage of analysis. Virginia Sickle Cell Awareness Program (VACAP), started in the 1970s to provide funding and educate Black Richmond Residents living with Sickle Cell Anemia. Program and collaboration has expanded to open centers and offer screenings. Provided a brief overview of program data taken from centers looking at impacts and target population demographics. CDC Sickle Cell Data Collection program, received funding from CDC to create a surveillance program to identify an accurate number of patients living with sickle cell anemia and to identify gaps and needs and disseminate for other stakeholders to identify and create policy change to improve quality of life.</p> <p>C. Dried Blood Spot Newborn Screening, Mary Lowe, RN Emphasis on the benefits of the Newborn Screening and its importance in diagnosis, treatment and health outcomes. The Newborn Screen Panel is the Uniform Screening Panel. Recommendations are made to the committee for inclusion for criteria for disorders to be added to the panel which will be universally used for screening. Provided overview of newborn screenings stats. Over 5000 babies diagnosed with disorder from screening.</p>
11:10 - 11:15	<p>Public Comment</p> <p>No public comments were received.</p>

11:15 – 11:30	<p>NORD Summit Highlights:</p> <p>Samantha Clark provided a high-level overview of the October 2021 NORD Breakthrough Summit which is the largest rare disease summit bringing in leading experts and researchers in the field from all over the world. Ms. Clark covered four leading themes highlighted throughout the meeting: Lessons learned from COVID-19, rare disease as public health priority/issue, the future of genetic testing and sequencing, and building collaboration and strengthening partnerships.</p>
11:30 - 12:00	<p>Presentation, Ijeoma Azubuko, The Ruby Ball Foundation, Rare Disease Council Member</p> <p>Ms. Ijeoma Azubuko shared her personal experiences of how Sickle Cell Anemia has touched her life and those around her. Ms. Azubuko shared how she utilized these experiences to create the Ruby Ball Foundation, a non-profit focused on spreading awareness, while empowering and improving the quality of life for individuals living with sickle cell disease.</p>
12:00 - 12:30	<p>Break for Lunch</p>
12:30 - 1:00	<p>Guest speaker, Minnesota Rare Disease Advisory Council, Amy Gaviglio, MS, CGC, Executive Committee Lead</p> <p>Ms. Amy Gaviglio shared accomplishments and lessons learned over the two years since Minnesota's Rare Disease Advisory Council was established in 2019. She shared the council's vision, mission, goals/objectives and current initiatives. The foundation of Minnesota's Council centers on partnerships and collaboration, education and awareness, and policy and recommendations. This has influenced their pillars of focus on the needs of the rare disease community, increasing access to and coordination of care, modifying strategies to reduce time to diagnosis, and accelerating research.</p>
1:00 - 1:30	<p>Review Rare Disease Council Survey Results, Samantha Clark, MPH</p> <p>Ms. Clark shared the results collected from the Rare Disease Council Feedback Survey disseminated to council members for the purpose of identifying and prioritizing goals, expectations, and prioritizing for year one. These included funding needs and strategies, creating subcommittees to expand scope of work, and identifying a timeline for completing goals and action items, and creating a strategy to identify goals and needs for the next few years.</p>
1:30 - 2:00	<p>Open Discussion</p> <ul style="list-style-type: none"> ● Open discussion was held to address pending action items to determine the Rare Disease Council meeting schedule for 2022. ● Council explored strategies for identifying the main needs of the rare disease community which is imperative for guiding research and allocating funding for providing support for individuals living for rare diseases in the Commonwealth. ● Identified potential partnerships and collaborations to engage in the future.
2:00	<p>Adjournment</p>