

**Rare Disease Council Quarterly Meeting  
Tuesday, November 29, 2022, 10:00 AM – 2:00 PM**

**Meeting Location & Address:**

Virginia Hospital & Healthcare Association  
Washington and Jefferson Meeting Rooms  
4200 Innslake Dr, Glen Allen, VA 23060

If you would like to view the meeting virtually or provide public comment, please register here:  
[https://vdh.zoom.us/webinar/register/WN\\_\\_8q5OVS6SPi43f\\_oqTVKYg](https://vdh.zoom.us/webinar/register/WN__8q5OVS6SPi43f_oqTVKYg)

**Meeting Minutes**

Council Members Present (*ex officio members italicized*): Jana Monaco (Vice Chair), Wes Fisher, Elisabeth Scott, Dr. Stephen Green, Dr. Michael Friedlander, Dr. Peter Kasson, Susan Klees, Sarah Paciulli, Dr. Richard Nicholas, Megan O'Boyle, Dr. Samantha Vergano, Elissa Pierson, Dr. Tiffany Kimbrough, *Dr. Samantha Hollins, Jennifer Macdonald, Dr. John Morgan*

Council Members Absent: Dr. Lisa Kaplowitz (Chair), Ijeoma Azubuko, Gregory Josephs, Dr. Stephen Rich

Virginia Department of Health (VDH) Staff Present: Katherine Crawford, Christen Crews, Lauren Staley, Marcus Allen

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**Call Meeting to Order, Roll Call and Introductions, Review Agenda**

Jana Monaco, Vice Chair, welcomed attendees and called the meeting to order. Introductions were conducted by Council and VDH staff, the Vice Chair reviewed the agenda and the Vice Chair and VDH staff confirmed that the Council met the in-person requirements to meet a quorum.

**Council Business**

The Vice Chair introduced the draft Electronic Meetings Policy (EMP) and VDH staff provided an overview of the EMP. The Vice Chair asked the Council to read through the EMP and pointed out the restrictions specific to the EMP. Council asked VDH staff to discuss changes to this version of the EMP compared to the prior one. VDH staff discussed changes to the EMP that included the circumstances that would allow for an all-virtual meeting. VDH staff noted that Council can review this document in another meeting but that remote meeting participation by Council members cannot occur without the EMP adopted. Council noted that it may be helpful to add "may include but are not limited to" to the last bullet in Section 3 of the EMP dealing with all-virtual meetings, but that the draft policy's phrasing was acceptable. The Vice Chair asked the Council if they had any other input related to the EMP. The Council had no additional comments. The Vice Chair made a motion to accept the EMP as stated. Council voted unanimously to adopt the EMP.

The Vice Chair then introduced the draft Bylaws and asked if any Council members had comments or wanted to make a motion. Council had no comments on the draft Bylaws, made a motion and voted unanimously to adopt the Bylaws. After voting, Council asked for clarification related to research funding and VDH staff clarified that the legislation that created the Council also established a Rare Disease Council Fund. In response to questions from Council members about the Rare Disease Council

Fund, VDH staff proposed that someone from the treasury or policy office speak to the Council about the Fund in a future quarterly meeting to help the Council better understand required processes.

The Vice Chair introduced the previous 7 draft meeting minutes and asked the Council if they had a time to review the minutes and gave the option to vote on them today. Council agreed to vote on them today, made a motion and voted to approve all 7 draft meeting minutes. One new Council member abstained from voting while all other Council members voted yes.

**Presentation: Jackie Yetka & Sandy Hermann, Hampton Roads Area Care Connection for Children**

Sandy and Jackie provided an overview of transition into adulthood for children with special health care needs and difficulties experienced in the Hampton Roads region of Virginia related to transition. Sandy stated that when a person turns 18, they, by law, transition into adulthood and that some individuals have significant needs when transitioning while others may not. Care coordinators can help families with thinking about transitioning from a legal standpoint, such as considerations about guardianship, the level of assistance needed, supportive decision making, power of attorney, advance directives, etc. Sandy shared that she is a parent of a child with a rare disease and some of her experiences going through transition with her child. Sandy also discussed that Care Connection for Children (CCC) assists with transition, until the age of 21, and works to empower the individual and parents to function without CCC. Additionally, she explained that CCC communicates with families regarding the transition from pediatric to adult providers. She noted that pediatric specialists and pediatric hospitals do not have to accept individuals after they turn 21 and that pediatric providers may not always have privileges at other hospitals. Sandy stated an issue they run into is that it is really hard to change providers, especially for a child with a rare disease or complex needs. While the pediatric providers know the child and family and their needs, transitioning to adult providers and establishing a medical home is important. The CCCs try to work with families to help them transition early while they still have access to pediatric providers and can have time to find an adult provider with whom they are comfortable. Other issues that Sandy discussed were the lack of specialists in adulthood, providers not wanting to accept individuals with complex needs, and individuals losing Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services at the age of 21, which can affect covered services, such as private duty nursing and specialty formulas. CCC staff work with parents to find a new payor or Medicaid waiver for those services, as well as helping families determine eligibility for SSI.

Council asked if the Hampton Roads area had any unique challenges as opposed to other areas of Virginia. Sandy stated that it becomes more difficult the more rural you get and noted that in Southwest Virginia the options are limited. VDH staff shared that due to limited resources, the Southwest Virginia CCC partnered with UVA to provide neurology services for people with epilepsy, and that although transitioning is an issue across the board, issues are compounded in rural areas. Two Council members shared they didn't know there was a CCC clinic in their region of the state, and asked how people find out about them. Sandy explained that it depends on how savvy and knowledgeable providers are, that the information could come from schools, but that it really depends on outreach and word of mouth. Council asked about the scope of activities for CCC. Sandy and VDH staff stated that they assist with a broad range of services from birth to 21 for individuals who meet qualifying criteria as defined by the Code of Virginia. In addition to case management, care coordination includes other services, such as assisting individuals and families with overcoming barriers. Council members shared experiences with transitioning their children and challenges they are facing, and discussed if increasing CCC services up to the age of 26 might improve the transition process for individuals with rare diseases and their families.

**Presentation: Anne Wienke, Roanoke Area Care Connection for Children**

Anne provided an overview of how transition is handled in the Roanoke region of Virginia and difficulties her region has experienced related to transition. Anne stated that expanding CCC services until age 26 would be very helpful and that it is a journey to get individuals transitioned into adult care services. Anne explained that in her region, transition planning begins at birth, formal planning begins at age 12, and transition is from 18 and beyond and that planning is critical for positive health and psychosocial outcomes. Anne went on to explain that during planning, CCC works with the family to consider questions such as ‘what does their future look like, what will the age of transition be, what will be the age of responsibility, and is guardianship necessary’. Additionally, Anne discussed that CCC services include encouraging families early on to obtain a service facilitator for funding support services, assessing an individual’s future options for educational, vocational, or rehabilitative services, and working on self-image and family planning, among other services. Anne stated that in her region Carilion partners with the CCC to help children with special needs transition to an adult care provider. Transition services include assisting families with finding providers, specialists, insurance, and community resources, applications to SSI and Medicaid, establishing power of attorney or guardianship as applicable, and setting up tours of adult inpatient units as an introduction to adult care services. Anne addressed several barriers her region is experiencing including the lack of adult providers. While medical advances are helping children with complex needs live longer, adult providers often have little understanding of what these children need, and as time is not incentivized, there can be a lack of communication, though warm handoffs are completed as often as possible. Anne noted that nurse involvement, family support, and clear medical notes are very important and that a system with a formal coordination process (ex. electronic records initiatives) can contribute to a successful transition.

Council members shared experiences with transitioning their children and brought up concerns that the medical community is missing education and training on the needs of this population.

**Presentation Nickie Brandenburger, Partnership for People with Disabilities Center for Family Involvement, Virginia Commonwealth University**

Nickie, Mauretta Copeland, and Renee Soniat provided an overview of the Center for Family Involvement (CFI) under the Partnership for People with Disabilities and shared some experiences and difficulties parents of children with rare diseases are facing. Nickie explained that under the Partnership for People with Disabilities, there are several program areas (community living, early childhood/early intervention, education, and health) and that CFI is a parent-to-parent mentoring service model, meaning that all 23 staff members and 90 volunteers throughout the state are parents or caregivers of individuals with a disability. Nickie stated that the work is split up among 6 regions across the state, and that navigators (volunteers) and a Regional Network Coordinator reside in each region who are familiar with resources in that area. Mauretta explained that Cultural Brokers are parents/caregivers/self-advocates who are spread throughout the state and represent the African American, Latino, refugee, and rural community populations and that their role is to support families in their regions and act as liaisons. Nickie went on to discuss how families are matched and how they benefit from shared experience and having someone from a similar cultural background to support them.

Nickie shared that CFI also has specialists spread across the state who are parents or caregivers with experience and knowledge of resources related to aging parents, deaf/hard of hearing, blind/visually impaired, and mental health. CFI provides one-on-one emotional support with a matched mentor to help parents navigate a diagnosis and prioritize next steps. CFI also provides a free helpline service that

families can contact to request support, and has resources to connect with parent-to-parent groups across the United States with families with rare genetic disorders or rare diseases.

A video was shared of a mother living in Southwest Virginia who discussed the difficulties and successes she was experiencing with her child, who has an IEP, and the agencies she was successfully able to get involved with, such as the Department for Aging and Rehabilitative Services. Another story was shared of a mother living in Northern Virginia and her experiences with her child who has a rare disease diagnosis and how a Medicaid waiver was very helpful for her family to provide services and supplies that other health insurance would not cover.

### **Public Comment Period**

No comments were provided during the public comment period. The Vice Chair adjourned for lunch.

### **Council Business/Updates**

Three Council members did not return after lunch. The Vice Chair introduced the draft Mission Statement and draft Vision Statement for vote. Council addressed the draft Mission Statement wording, particularly the word “Address” in the last bullet point. After discussion among the Council, “Direct” was recommended by Council to replace the word “Address”. A motion was made to change “Address” to “Direct”. Nine Council members voted yes to change the word to “Direct”. Another motion was made to vote on the draft Mission Statement. Nine Council members voted yes to approve the draft Mission Statement. No comments were made on the draft Vision Statement. A motion to vote on the draft Vision Statement was made. All Council members voted yes.

Approved Mission Statement:

*On behalf of those impacted by rare diseases in the Commonwealth of Virginia, the Rare Disease Council shall:*

- Advise the Governor and the General Assembly on the needs of those affected by rare diseases;
- Identify challenges and barriers faced by those affected with rare diseases; and
- Direct funding of research and supports for persons with rare diseases.

Approved Vision Statement:

*To serve as a voice for Virginia’s Rare Disease Community by advising policymakers and empowering families and individuals affected by rare diseases.*

VDH staff addressed the workgroups/work plan and short, intermediate, and long-term goals. Suggestions were made by Council to change the second bullet under short term goals to “individuals and their families”. Suggestions were made by Council to remove “other necessary services” and change “health care services” to “coordination of care” in the first bullet under the ‘policy recommendations address’ section under intermediate goals. The goals were not voted on today.

VDH staff discussed the draft list of publicly accessible resources to publish on the Council’s webpage. Council recommendations included adding phone numbers, listing in alphabetical order, paring down the list, and adding resources for providers. The webpage list was not voted on today.

The Vice Chair discussed an update regarding service facilitators, stating there was a push to move monthly DMAS service facilitator meetings back to in person/in home visits from those that became virtual during COVID. Council discussed the benefits of empowering caregivers to work with DMAS to choose whether to have an in person or virtual visit, and the need to balance risks and benefits of either

option. The DMAS ex officio representative offered to receive and share Council member perspectives about the challenges associated with in person versus virtual service facilitator meetings.

VDH staff discussed the upcoming calendar year meeting schedule and stated they would send out quarterly meeting date options and questions regarding Council members' availability. Council asked if they could add a link on the Council's webpage for individuals interested in joining the Council. Council members also expressed interest in breakout sessions in the next quarterly meeting to move forward with refining and addressing the Council's work plan.

**Council Member Closing Discussion, Adjourn**

The Vice Chair thanked Council members for their attendance and adjourned the meeting.

**Public Hearing at 2pm**

No attendance for the public hearing.