

**Virginia Genetics Advisory Committee**  
**Virginia Department of Health**  
**December 18, 2019, 1:00 – 4:00 p.m.**  
**Varina Library – Large Conference Room**

***Draft Meeting Minutes***

---

**Members Present:** Dr. Tom Loughran, Dr. Elvin T. Price, Dr. Stephen Rich, Dr. Luisel Ricks-Santi, Ms. Nicole Thompson, Dr. Samantha Vergano (via conference call)

**Members Absent:** Dr. Andrea Ferreira-Gonzalez, Dr. Raymond Lewandowski (Chair), Ms. Tiffany Lewis, Dr. Marshall Summar

**Commissioner’s Designee:** Dr. Vanessa Walker Harris

**VDH Staff Present:** Ms. Robin Buskey, Ms. Nikkia Ray

---

**Welcome and agenda overview**

Dr. Vanessa Walker Harris, Director of the Virginia Department of Health’s (VDH) Office of Family Health Services (OFHS), called the meeting to order at 1:10 p.m. She informed the committee that Dr. Raymond Lewandowski, Chair, was under the weather and would not be able to participate in the meeting discussion. She also informed the group that Dr. Samantha Vergano could not attend the meeting in person due to scheduled clinics but would call in via conference call at 2:00 p.m. Dr. Walker Harris then provide an overview of the meeting agenda.

**Discussion regarding meeting minutes and Co-Chair**

Given that there was not a quorum physically present at the meeting, the draft September meeting minutes were not approved. Dr. Luisel Ricks-Santi asked that the draft minutes be revised to note which members were absent. Ms. Robin Buskey will revise the draft meeting minutes.

Dr. Walker Harris suggested that the committee may want to revisit the discussion regarding whether to elect a Co-Chair. There was a bit of a challenge in scheduling meeting dates that worked for both the majority of the committee and the Chair. Electing a Co-Chair will allow more flexibility in scheduling meetings and also provide coverage when the Chair is absent. Committee members agreed that is a good idea, which will be put to a vote at the next meeting. Someone will need to make a nomination.

**Updates**

Dr. Walker Harris provided the following updates:

*Commissioner Oliver’s response regarding goals for the VaGAC*

Dr. Walker Harris shared that Commissioner Oliver was pleased to hear that the committee is up and running again. He stated that the most important service that the committee can provide to him is advice on genetic screenings – especially cancer. He felt that the group would have a lot to contribute about ways to increase awareness of genetic screening, genomic sciences, and the increasing applications of genomics to clinical medicine. Of note, Commissioner Oliver said that he hopes the group is able to address the issue of racial and

ethnic equity in this space. Dr. Walker Harris stated that she felt that Dr. Oliver’s guidance aligned really well with the discussion that was had at the September meeting.

#### *Virginia Cancer Registry Director*

Dr. Walker Harris shared that she was pleased to announce that VDH was able to complete the recruitment for the director of the Virginia Cancer Registry. She then provided a brief background summary and introduced committee members to Ms. Nikkia Ray, who was in attendance.

#### *VaGAC member recruitment*

Dr. Walker Harris shared that one recommendation for a potential committee member had been received and was still under consideration. Currently, there are seven members from academia. Recommendations for individuals who represent community-based and nonprofit organizations are welcome. In addition, the committee has good representation from Central, Tidewater and Northern Virginia regions. Recommendations for representation from western and southern parts of the state are also welcome. She encouraged committee members to send recommendations directly to her or Ms. Buskey.

Committee members inquired about the flexibility for members to meet remotely given the request to recruit members from far away. Members also inquired about the opportunity to meet regionally. Dr. Walker Harris stated that VDH staff would follow up to see how other similar groups meet remotely.

#### **Development of one-year workplan**

Before moving into developing the workplan, Dr. Walker Harris provided a brief recap of what the group discussed at the September meeting. VDH staff attempted to capture a synopsis of what committee members were doing in genomics and noted potential areas of opportunity and/or recommendations for genomics. Three major themes emerged from that discussion. Those three themes include:

- The need for greater access to patient level data from the Virginia Cancer Registry
- A population and provider level intervention to improve the accuracy of family history for cancer screening; and
- Increase access to genetic screening and meaningful results for communities of color.

Dr. Walker Harris noted that details regarding the potential areas of opportunity and/or recommendations were included on p.3 of the draft meeting minutes. Those points of “consideration” were incorporated in the outline of a workplan. Both the draft meeting minutes and workplan outline were included in the meeting packet. Dr. Walker Harris then shared that the goal of the day’s meeting was to develop a one-year workplan for the work of the committee.

Dr. Walker Harris shared guidance regarding committee recommendations. When making recommendations regarding funding, it is important to note that the agency must put forward a budget proposal to request funding. The timing for the committee to put such a request forth would be May 2020. Any regulator action that would need to occur happens on a rolling basis. Depending on recommendations, the committee may need to consider what other stakeholders should be included in the discussion.

Dr. Walker Harris suggested that the group consider the use of headlines to develop the workplan recommendations related to the following focus areas:

- issues pertaining to access to clinical genetic services across the Commonwealth

- provision of genetic awareness
- provision of quality services
- provision of education

In addition, the group was asked to consider:

- things that are working that Virginia should more of
- things that other states are doing that Virginia should start
- things that Virginia should stop doing

The group developed the following headlines and strategies for addressing the related objectives:

### **Access to Clinical Genetic Services**

#### Headlines

- Virginia Increases Access to Genetic Services for All Eligible Virginians
- Virginians Have Increased Access to Testing for Diseases that Run in Families
- Virginians Understand the Benefits of Genetic Screening to Know Their Risks

#### Strategies

- Quality improvement
  - Provider education
    - Use data to identify patients
    - Know when to refer
  - Community education
- Pull public health
  - Environmental scan of public health recs for cancer and compare against what Virginia is doing
- Adult cancer genetics system
  - Characterize – OHE
    - Medical geneticists
    - Genetic counselors
- Workforce development
  - Virginia’s Area Health Education Centers (AHECs)
- Funding for sequencing for x communities
- Testing germline vs. somatic

### **Provision of Genetic Awareness**

#### Headlines

- Virginians Know the Most About Genetics and Genomics
- Virginia Providers in the Know About Genetics: Confident, Competent Referrals 100% of the Time
- It’s A Family Affair: Virginians Are Genetically Aware
- It’s A Match: Virginia Families Know Their Family History and It Matches Their Genetics
- Virginia Churches and Family Reunions Preach the Genetic Gospel

#### Strategies

- Education
  - Town halls for consumers – led by genetic counselors, churches, local hospitals (i.e. Diversity and Inclusion Task Force of the National Society of Genetic Counselors)
  - Cancer center community advisory boards to assist
  - CACV sponsor workshop, CEU
  - Other professional/disease specific organizations to sponsor workshops (i.e. Virginia Geriatric Society)

- Consider health fairs
- CHWs, los promotores
- Media campaign – Thanksgiving is Family Health History Day!
  - Use social media for specific conditions
- Grand rounds on genetic testing
- Project ECHO model for genetic testing (similar to opioid, NAS)
- Target minority group associations – Asians, Pacific Islanders, Latinx
- EHR template for family history
- Medical school education on family history
- Collect family history in the Virginia Cancer Registry

## **Provision of Quality Services**

### Headlines

- Virginia Has Increased the Number of Clinical Professionals in Genetics
- One Hundred Percent of Virginias Referred for Genetic Services
- Right Genetic Test Ordered All of the Time for Cancer Patients in the Commonwealth

### Strategies

- Opportunity to centralize genetic testing
  - VDH to provide information on DCLS
- Patient navigator
- Coordinated care
  - Create an algorithm
  - Increase awareness of financial aid/benefits/programs available
- Education on genetic services
  - Nurses
- Ensure availability of interpreters
  - Training in genetics for interpreters
  - Document translation
- Funds for uninsured

## **Provision of Education**

### Headlines

- Virginians Know Their Family Health Histories (FaHx) (family, ancestry, conditions, traits, traditions)
- Commonwealth Uses Telemedicine to Educate Consumers and Providers on Genetics
- Virginia’s Bestseller Educates Kids about Cancer Disease

### Strategies

- Telemedicine
- Education
  - Kids
- Communication
  - Social media campaign; consider tying to other campaigns
  - Genetic counselor awareness day in November
  - Consider connecting to ancestry reports
    - Provide education and definitions
    - Direct to consumer
    - CLIA approved
  - NSGC
  - Access public health genomics resources (Utah, Michigan)

- Increasing higher education focus on genetics
  - Create more programs
- Catalog guidelines re:
  - Available tests to provide education to consumers and providers
- Equity focused efforts
  - Using data to target messaging and outreach to communities

**Other points noted during the discussion:**

- Look at available recommendations that are currently in existence; is there a national inventory?
- Tier 1 recommendations; look at prevalence of in communities
- Obtain list of public health recommendations to compare; perform an environmental scan of what is being done
- Is there access to adult human genetics in Virginia (i.e. Arkansas adult genetics clinic)?
- Provide sequencing for minority populations; is sequencing a barrier due to costs?
- Establish workgroups for the four buckets
- Improve VCR data collection

**Public Comment Period**

No members of the public were present.

**Future Meeting Dates and Next Steps**

Ms. Buskey reviewed the following 2020 meeting dates based on the Doodle poll:

- March 27, 2020 @ 1:00 – 4:00 p.m.
- May 20, 2020 @1:00 – 4:00 p.m.
- August 12, 2020 @1:00 – 4:00 p.m.

Dr. Walker Harris stated that the strategies developed during the meeting would be presented to the committee for feedback and a determination made regarding whether they should be packaged as recommendations. In addition, the committee should decide if any legislation or budget action would be needed through VDH.

**Adjournment**

The meeting adjourned at approximately 3:20 p.m.