

Virginia Genetics Advisory Committee
Virginia Department of Health
Friday, August 16, 2019
1:00 – 4:00 p.m.
Libbie Mill Library – Large Meeting Room

Meeting Minutes

Members Present: Dr. Andrea Ferreira-Gonzalez, Dr. Raymond Lewandowski, Dr. Tom Loughran, Dr. Elvin T. Price, Dr. Stephen Rich, Dr. Luisel Ricks-Santi, Ms. Nicole Thompson, Dr. Samantha Vergano

Members Absent: Ms. Tiffany Lewis, Dr. Marshall Summar

Commissioner's Designee: Dr. Vanessa Walker Harris

VDH Staff Present: Ms. Debbie Bridwell, Ms. Robin Buskey, Dr. Laurie Forlano, Dr. Leslie Hoglund

Welcome and Introductions

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 1:05 p.m. She introduced herself and stated that she will serve as designated staff to the Virginia Genetics Advisory Committee. She introduced Dr. Laurie Forlano, VDH's Deputy Commissioner of Population Health, who provided welcoming remarks. Dr. Walker Harris then asked that all committee members and VDH staff introduce themselves by name, title and organization.

Agenda Overview and Review of the Code

Dr. Vanessa Walker Harris provided the goals of the meeting to include:

- formally establish the Virginia Genetics Advisory Committee;
- introduce committee members;
- establish committee governance;
- provide an overview of public health genomics from VDH's perspective in relation to CDC's framework of Tier 1 recommendations; and
- gain insight into current work being done in genomics/genetics by committee stakeholders.

Dr. Walker Harris shared with the group that equity is a core value of VDH. She asked that this be considered throughout advisory committee meeting discussions and the development of recommendations to ensure that all people in Virginia have a just and fair opportunity to achieve optimal health and wellness.

Dr. Walker Harris then provided some historical context for reestablishing the Virginia Genetics Advisory Committee. The impetus for doing so came after the Office of Public Health Genomics at the Centers for Disease Control and Prevention (CDC) reached out to Virginia as part of an environmental scan to assess how state agencies were addressing hereditary breast and ovarian cancer and Lynch syndrome. She then provided an overview of the meeting agenda before reviewing three sections of the Virginia Administrative Code that identify the Virginia Genetics Advisory Committee and its role.

Dr. Walker Harris read 12VAC5-71-10, Definition of Virginia Genetics Advisory Committee. This is the section of the regulation that establishes the advisory committee's mission, which is stated in the bylaws. She then read 12VAC5-71-30, subsection C and 12VAC5-71-100, subsection C. The latter is the section of the regulation that makes the distinction between the Newborn Screening Subcommittee and the Virginia Genetics Advisory Committee. Council members were advised to read along from the materials provided in the meeting packets.

Review and Discussion of Bylaws

Ms. Robin Buskey asked committee members to refer to the Draft Virginia Genetics Advisory Committee Bylaws handout that was included in the meeting packet. She asked committee members to take a few minutes to review the document and raise any points of concern. Ms. Buskey advised that she would make edits to finalize the document during the meeting. The following questions were addressed:

- Will there be a committee co-chair? Dr. Walker Harris responded that the committee is allowed to make a recommendation to establish a co-chair if desired.
- Will there be more individuals appointed to the committee? Ms. Buskey responded that the committee is intended to be a 15-member committee as stated in the bylaws. Membership is not yet complete; there are currently ten members who have agreed to serve on the advisory committee. Dr. Walker Harris encouraged committee members to provide recommendations for the remaining five slots and advised that names can be forwarded to her and Ms. Buskey for consideration.
- Can advisory committee meetings be held remotely? Dr. Walker Harris responded that members may participate remotely. Ms. Buskey provided clarification that there must be a quorum of the committee physically assembled at one meeting location in order for a member to participate from a remote location.

No edits were recommended to the bylaws. The bylaws were accepted as written.

Election of Chair

Dr. Walker Harris asked committee members to make a motion to nominate a chair. Dr. Raymond Lewandowski made a motion to serve as chair. The motion was seconded. Dr. Lewandowski was elected as chair by unanimous vote.

Presentation of Public Health Genomics

Ms. Debbie Bridwell, OFHS Comprehensive Cancer Control Coordinator, provided a presentation on the 2018-2022 Virginia Cancer Plan. She highlighted sections of the plan's strategies that aligned with align with CDC's Tier 1 recommendations for public health genomics. Dr. Leslie Hogle, OFHS Division Director of Population Health Data, presented an overview of the Virginia Cancer Registry and its current status with respect to Tier 1 public health approaches regarding bi-directional reporting, policymaking, surveillance, and designing and implementing educational outreach programs.

The committee engaged in a question and answer session following each presentation. The presentations will be provided electronically when the meeting minutes are disseminated. The third presentation was a video overview of bidirectional cancer registry reporting (<https://www.youtube.com/watch?v=CEu7kwgCTnY>).

Guided discussion – Stakeholder Synopsis of Genomics in Virginia

Dr. Walker Harris asked advisory committee members to share information regarding their organization's background, the genomics work in which the stakeholder is engaged, and opportunities for alignment with Tier 1 recommendations. Committee members described current projects that are underway and the populations served. Overall, three major themes emerged from the discussion -- 1) the need for greater access to patient level data from the Virginia Cancer Registry; 2) a population and provider level intervention to improve the accuracy of family history for cancer screening; and 3) increased access to genetic screening and meaningful results for communities of color. The themes are based on the following points noted as potential areas of opportunity and/or recommendations for genomics:

- Ensure that there is no lack of access to test results and that the results are simplistic enough for patients to understand; this may help with peer-to-peer denials
- Improve efforts to launch provider education regarding testing, treatment and resources available and used; make sure patients are not at a disadvantage
- Address the difficulty for patients and doctors with respect to specialty knowledge and access to genetic counseling in specific areas of the state
- Improve efforts to educate people about genetic data and prevent data loss
- Consider non-traditional approaches to spreading awareness (i.e. develop family health history packets and share at family reunion events)
- Determine ways for matching the best drugs to persons in the most vulnerable populations
- Make sure there is equity in the translation of genomics; build infrastructure in a way that does not result in increased disparity
- Develop the data for people of African descent in order to address the disparities in the communities most impacted
- Consider partnering with other research universities that are much further along with technologies
- Improve outreach, education and cultural competency
- Improve data collection regarding family history; more thorough and accurate reporting needed at intake
- Improve ability among staff that are non-geneticists to properly order tests and properly consent the family
- Need for better understanding of the Department of Medical Assistance Services' process for controlling medical formulary and metabolic foods

Public Comment Period

No members of the public were present.

Future Meeting Dates and Next Steps

Dr. Walker Harris shared the following suggested months for the advisory committee to meet over the next year: November 2019 and February, May and August 2020. Ms. Buskey will send out a Doodle poll with date and time options for those months.

The next step for the committee will be to develop a work plan to guide activities and recommendations moving forward based on the mission.

Adjournment

The meeting adjourned at 3:41 p.m.