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#### **MEMORANDUM**

TO: The Honorable Glenn Youngkin

Governor of Virginia

The Honorable L. Louise Lucas

Chair, Senate Finance and Appropriations Committee

The Honorable Luke E. Torian

Chair, House Appropriations Committee

FROM: Karen Shelton, MD

State Health Commissioner, Virginia Department of Health

SUBJECT: Henrietta Lacks Commission Annual Report

This report is submitted in compliance with the Virginia Acts of the Assembly - § 2.2-2541.2, which states:

Submit to the Governor and the General Assembly an annual report for publication as a report document as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports. The chairman of the Commission shall submit to the Governor and the General Assembly an annual executive summary of the interim activity and work of the Commission no later than the first day of each regular session of the General Assembly.

Should you have any questions or need additional information, please feel free to contact me at (804) 864-7002.

KS/AJ Enclosure

Pc: The Honorable John Littel, Secretary of Health and Human Resources

## Annual Report to the Governor and General Assembly of Virginia

Henrietta Lacks Commission

Office of Health Equity

Virginia Department of Health

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#### **Executive Summary**

This report constitutes the annual report for the Henrietta Lacks Commission for the calendar year of 2022. It is submitted to the Virginia General Assembly and the Governor in accordance with § 2.2-2541.2 of the Code of Virginia. This report provides an overview of the Commission's activities for its fourth year.

The Commission has nine appointed members as defined by current legislation and is administratively staffed by the Virginia Department of Health's Office of Health Equity. The Commission met once during the calendar year 2022, on October 14<sup>th</sup>. This initial meeting served as a Welcome Meeting to reacclimate commissioners to the work of the commission, vote on changes to the by-laws to comply with Virginia's electronic meeting policy, and to elect new officers. A second meeting was scheduled for December 1, 2022, but due to last minute conflicts, that meeting was unable to meet a quorum.

For the meeting that did meet quorum, detailed written minutes were prepared and posted in accordance with § 2.2-3707 of the Code of Virginia, and are appended to this report.

The report constitutes the annual report for the publication as required by § 2.2-2541, subsection two of the Code of Virginia.

#### Introduction

The Henrietta Lacks Commission was established in 2018 as an advisory committee to sustain the legacy of Mrs. Henrietta Lacks by laying the groundwork to develop the Henrietta Lacks Life Sciences Center. The Commission is responsible for creating a plan to establish the infrastructure required to build a life sciences facility that focuses on bioethics, cancer research, and biomedical research until its sunset July 1, 2026.

#### **Background**

#### **Creation and Charge**

On March 30, 2018, Governor Ralph Northam amended § 2.2-2101 of the Code of Virginia by adding Chapter 25 of Title 2.2 an article numbered 10 that established the Henrietta Lacks Commission pursuant to House Bill 1415, introduced by Delegate James Edmunds, II and Senate Bill 171, introduced by Senator William Stanley, Jr. The General Assembly enacted the legislation on March 9, 2018 requesting the creation of a Commission "to sustain the legacy of the life-changing contribution of Henrietta Lacks to medical science by advancing cancer research and treatment through the creation of a biomedical research and data center." From its inception, the Commission has worked diligently to develop the foundation required for the success of the tasks set before them.

The charge of the Commission, as stated in the foundational legislation, is the following: To create a biomedical research and data center in memory of Henrietta Lacks and her contributions to medical science. This research center will be a private-public partnership in Halifax County, and will focus on cancer research particularly tailored to the needs of the underserved portion of rural Southside Virginia. It also aims to bring biotech businesses to the region.

#### **Organization**

As defined by the foundational legislation §§ 2.2-2538 and 2.2-2542, the Henrietta Lacks Commission is designed to be comprised of nine members including two legislative members, three non-legislative members, and four ex officio members. The Virginia Department of Health, Office of Health Equity provides administrative staff support to the Commission.

#### **Officers**

Dr. Nettie Simon-Owens assumed the Henrietta Lacks Commission Chair position during the election held on October 14, 2022 consistent with the Henrietta Lacks Commission by-laws and § 2.2-2538-C. Ms. Kristy Johnson was elected as the Henrietta Lacks Commission Vice-Chair on October 14, 2022.

#### Members

Virginia Code § 2.2-2538 establishes the details required for membership of the Henrietta Lacks Commission. There are nine members of the Henrietta Lacks Commission. A list of the current members is provided below:

- Dr. Nettie-Owens, Chair
- Ms. Kristy Johnson, Vice-Chair
- Mrs. Jeri Lacks-Whye
- Dr. Adele Newson-Horst

- Mrs. Danyell Duncan
- Senator William "Bill" Stanley
- Delegate James Edmunds
- Dr. Betty Adams
- Honorable William "Bryant" Claiborne

#### **Commission Actions**

The Commission has reactivated pursuant of its mission by engaging with OHE staff to establish a meeting cadence that began in Fall 2022. Individual commission members were re-engaged individually by VDH staff. This engagement led to the creation of a Commission Welcome Meeting that occurred on October 14, 2022. During this special meeting led by VDH staff, Commission members were able to review past actions of the commission, update the current Commission Bylaws, and discuss plans to move forward. Full details of this meeting are provided in the meeting minutes included in the Appendix of this report. The December 1, 2022 meeting did not take place due to lack of a quorum.

Appendix: Meeting Notes from the Welcome Meeting on October 14, 2022

# Virginia Department of Health Henrietta Lacks Commission October 14, 2022 10:30AM

# Halifax County Industrial Development Authority, South Boston, Virginia MINUTES

#### **ATTENDANCE**

Sandra Serna
Janaye Oliver
Dr. Betty Adams
Dr. Adele Newson-Horst\*
Kristy Johnson
William Claiborne
Jeri Lacks-Whye\*
Dr. Nettie Simon-Owens
Danielle Dunkin

#### **AFFILIATION**

Virginia Department of Health, Office of Health Equity
Virginia Department of Health, Office of Health Equity
Southern Virginia Higher Education Center, Executive Director
Henrietta Lacks Legacy Group
Executive Director of Halifax Industrial Development Authority
Halifax County Board of Supervisors, Board Member
Henrietta Lacks Family Member
Member of Halifax County Industrial Development Authority
Clerk of the Town of South Boston, Designee of Mayor of South Boston

#### \*Participated remotely

TOPIC	DISCUSSION	ACTION
1. Call to Order,	Meeting called to order at 10:39 AM EST.	None
Introductions & Roll Call		
	Commission members introduced themselves, including what organization they represent.	
	organization they represent.	
2. Ice Breaker	What does Henrietta Lacks' legacy mean to you?	None
3. Review of Meeting	The previous meeting was conducted in Dec 2019. The commission has	VDH will identify the most recent meeting
Minutes	not convened due to the COVID-19 pandemic.	minutes in our files/archives and those notes
		will be shared for approval during the next
		meeting.
4. Old Business:	Henrietta Lacks Legislation	
	Commission Members Roles & Responsibilities	

# Henrietta Lacks Commission, 2022

TOPIC	DISCUSSION	ACTION
	<ul> <li>Annual Report</li> <li>Status of Commission Members</li> </ul>	
5. Report: Updates Virginia Department of Health, Office of Health Equity	<ul> <li>VDH Changes         <ul> <li>During the COVID-19 VDH experienced several staff changes, Sandra Serna and Janaye Oliver joined 5 months ago and are now leading the support of the Henrietta Lacks Commission.</li> <li>VDH's role and responsibilities to commission.</li> <li>Provide administrative support, assist with providing resources related to state policies and legislation, coordinating meetings and reporting to the Governor's Office. The commission's mission is to create a public private partnership that leads to a research and treatment center in Halifax County, the progress on this work will be shared in the annual report.</li> <li>Question in the chat: Who exactly are the appointed commissioners?</li> <li>Answer: Legislation appoints commissions for a 2 year term up to 4 terms. When a term expires the person serving does not have to stop their work and can serve until they are either reappointed or replaced. Roles marked by and asterisk below are allowed to have another person serve as a designee. Roles marked by bold lettering are considered ex officio, meaning they are a result of the position. These positions do not go through an appointment process. Ex officio positions with a designee may have another individual serve in their commission role for them. The appointment are as follows:</li></ul></li></ul>	Link to the legislation and the list of positions appointed: https://law.lis.virginia.gov/vacode/title2.2/chapter25/section2.2-2538/

TOPIC	DISCUSSION	ACTION
	<ul> <li>One member of Virginia Senate</li> <li>One Member of Virginia House of Delegates</li> <li>ii) As it stands all appointments have expired and must be resubmitted for appointment.         Question in Chat: Is it possible to get a copy of appointment papers?         Answer: Yes, it is, VDH will work to get a reappointment and will be send notice to each commission member         iii) Under Mr. Henry Murdaugh, the then acting director of the Office of Health Equity, a brief report was created to report the work of the commission for the last two and half years. This is not considered the annual report, but will be included in it as a status update.     </li> </ul>	VDH will submit the appointment information to the Secretary of the Commonwealth to attain appointment for the Member of the Halifax IDA, Lacks Family Member, and Board Member of Henrietta Lacks Legacy Group VDH will share the status update with the commission members
6. Sunset Date Change	In 2021, the Henrietta Lack's Commission's sunset date was amended at the behest of Senator Bill Sanely to be July 1, 2026	Legislation denoting sunset date change: <a href="https://law.lis.virginia.gov/vacode/title2.2/chapter25/section2.2-2538/">https://law.lis.virginia.gov/vacode/title2.2/chapter25/section2.2-2538/</a>
7. Commission Positions	<ul> <li>The Commission was previously led by Ms. Maddie Cowan, with her stepping down the commission needs to elect a new chair and vice chair.</li> <li>Chair Vote:         <ul> <li>Dr. Nettie Simon-Owens current Vice Chair opened the floor for nominations</li> <li>Dr. Betty Adams nominated Dr. Nettie Simon-Owens for Chair of Henrietta Lacks Commission. Kristy Johnson, seconded the nomination. Claiborne motioned to close the nominations</li> <li>No discussion</li> <li>Votes: Aye- 4, Nay-0, Abstention- 2 (Dr. Simon-Owens, Dr. Adele Newson-Horst, Jeri Lacks-Whye), No vote Cast- 2 (Senator Bill Stanley, Delegate James Edmonds)</li> </ul> </li> <li>Vice Chair Vote:         <ul> <li>Dr. Nettie Simon-Owens current Vice Chair opened the floor for nominations</li> <li>Dr. Betty Adams nominated Kristy Johnson for Vice Chair of Henrietta Lacks Commission. William Claiborne seconded the nomination. Dr. Simon-Owens moved to close nominations</li> </ul> </li> </ul>	

TOPIC	DISCUSSION	ACTION
	<ul> <li>No discussion</li> <li>Votes: Aye- 4, Nay-0, Abstention- 2 (Kristy Johnson, Dr. Adele Newson-Horst, Jeri Lacks-Whye), No vote Cast- 2 (Senator Bill Stanley, Delegate James Edmonds)</li> <li>Point of clarity: Dr. Adele Newson-Horst and Jeri Lacks-Whye are unable to vote due to their remote participation, until the bylaws are updated. A quorum is present for this vote.</li> </ul>	
8. Bylaw Review	VDH has reviewed the Henrietta Lacks Commission's Bylaws and have identified policies which it recommends be amended to address grammatical errors, changes in policies, and changes in dates. VDH recommends that the following be amended to reflect the following:      Sunset Date Change:     i) Article I Section 2 & 3; Article II Section 7,8; Article III Section 1      Grammatical errors and numbering     i) Article I; Article II Section 4, 5, 8; Article III Section 1,      Update Remote Meeting Policy and Individual Virtual Partition     i) Article II, Section 5: Remote Meetings         (1) The language to amend this section is the recommended language from the Virginia  Discussion:      Question: When amending the bylaws, will this allow for hybrid meetings, if so what are the guidelines for this?      Answer: Yes, by making these changes it would allow an individual who could not attend in person to notify the commission of this and then receive permission, VDH recommends the Chair be empowered to approve/deny individual remote participation. If approved, one individual can participate remotely up to two times or for 25% of the meetings due to personal circumstances.  Point of Clarity: We need to delineate between remote participation and virtual meetings. Remote participation is for the individuals to attend via video conferencing; virtual meetings are when all commission members and the public attend a meeting virtually.	The fully amended Bylaw document will be shared with commission members prior to the next meeting.

TOPIC	DISCUSSION	ACTION
	The commission plans to have 4 meetings in a year.	
	Question: Do the changes represent a specific enough change to the bylaws to support all of the changes? Specifically Article 2, section 5 of the bylaws, will reflect the changes of the Code of Virginia §2.2-3700.	
	Answer: Yes, the prescribed change will reflect the change. Also be careful to not be too specific to make the bylaws too narrow.	
	The commission would like to add a section to delineate between virtual and remote meetings. In the commission's bylaws, section 5's title will be changed to reflect this.	
	Question: It is difficult to hear those meetings in person, can the meeting host enable the transcription feature so remote participants can follow the discussion more closely?  Answer: The transcription feature is an individual option, attendees may choose the closed caption (CC) button at the bottom of the zoom toolbar to choose this.	
	Question: What is the language going at the end of the bylaws?  Answer: (The bylaw document is shared on the meeting screen)  VDH has added a paragraph to address the individual remote  attendance and virtual full body meetings.  The commission also amended section 5 of the bylaws to reflect that the bylaws will coincide with whatever changes occur in the Code of Virginia in relation to remote participation and virtual meetings.	
	Note: With this vote those commission members who were attending the meeting could now vote (Jeri Lacks-Whye and Dr. Adele Newson Horst) all votes in this meeting will now reflect this change.	
	<ul> <li>Bylaw Change:</li> <li>Dr. Nettie Simon-Owens current Vice Chair opened the floor for motions</li> </ul>	

# Henrietta Lacks Commission, 2022

TOPIC	DISCUSSION	ACTION
	<ul> <li>Kristy Johnson motioned to adopt the changes; Dr. Betty Adams seconded the motion.</li> <li>No Discussion</li> <li>Votes: Aye- 5, Nay-0, Abstention- 2 ( Dr. Adele Newson-Horst, Jeri Lacks-Whye), No vote Cast- 2 (Senator Bill Stanley, Delegate James Edmonds)</li> <li>Motion Carried</li> </ul>	
9. 2022/2023 Calendar	<ul> <li>2022 Annual Meeting         <ul> <li>Thursday, December 1, 2022 9AM-3PM</li> <li>i) This meeting will be a full day, in person meeting.</li> <li>ii) Agenda</li> <li>(1) Approve previous minutes, strategic plan review, discussion of latest events related to all Henrietta Lacks work, staffing for commission, website, communications review and approve annual report to submit to the Governor.</li> <li>iii)The following Commission members are unable to attend the December 2022: Betty Adams, Senator Bill Stanley</li> <li>Logistical concerns</li> <li>i) There is a hope that commission members in Maryland attend in person. With this in mind there should be a coordination of flights and travel.</li> </ul> </li> <li>2023 Calendar</li> <li>The commission will meet quarterly in 2023, with the idea to meet at the end of each quarter.</li> <li>Senator Stanley recommended during his conversation with VDH that the commission meet during the Virginia General Assembly sessions in Richmond, Virginia to allow for the commission to meet in person and to also garner support for the work of the commission. His suggestion was to have a formal reception, however commission members felt a more informal or attending other events to promote the commission may be suitable due to the financial constraints of the commission.</li> <li>During the commission outreach, VDH identified the best meeting days of the week are Thursday and Friday to</li> </ul>	VDH staff will share the meeting calendar hold via calendar invitation and email.  VDH and Commission Leadership will identify December 2022 meeting agenda  The commission will take down the website as it does not accurately reflect the work of the commission.  Kristy Johnson and the IDA oversee the commission's budget and will coordinate the flights for each commission member traveling from Maryland.

# Henrietta Lacks Commission, 2022

TOPIC	DISCUSSION	ACTION
	accommodate Jeri Lacks Whye and Dr. Adele Newson-Horst's schedules.  - The meeting schedule for 2023 is as follows:  i) Q1: January 26 <sup>th</sup> /February 2 <sup>nd</sup> – In person meeting, hold for best date to meet during the convening of the General Assembly  ii) Q2: May 18 <sup>th</sup> – Virtual Meeting  iii) Q3: August 17 <sup>th</sup> – Hybrid Meeting  iv) Q4: November 16 <sup>th</sup> – In-person Meeting	For future virtual meetings, a sound check should be conducted to ensure all participants can hear the speakers.  VDH will share the strategic plan, minutes, and any other related documents.
	Announcement: Anyone who wants to add action items to the meeting agenda, please submit to the commission chair prior to the meeting.  The commission members will review the annual report draft and strategic plan prior to the December meeting.	Dr. Simon Owens and Ms. Johnson will draft the next meeting agenda.
	<ul> <li>Calendar Dates Vote and Adjourn Meeting</li> <li>Chair Dr. Nettie Simon-Owens opened the floor to motion for a vote.</li> <li>Dr. Betty Adams motioned to adopt the changes; William Claiborne seconded the motion.</li> <li>No Discussion</li> <li>Votes: Aye- 7, Nay-0, Abstention- 0 No vote Cast- 2 (Senator Bill Stanley, Delegate James Edmonds)</li> <li>Motion Carried</li> </ul>	VDH will submit the annual report with the approval of the commission.
Next Meeting Date	The Commission is scheduled to meet Thursday, December 1, 2022 9AM-3PM.	VDH will send calendar holds for all upcoming meetings and will register the meetings as public meetings.