

2019 Annual Report to the Governor and General Assembly

Henrietta Lacks Commission

Office of Health Equity

Virginia Department of Health

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Executive Summary

This report for calendar year 2019 constitutes the annual report for the Henrietta Lacks Commission. 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 second year towards accomplishing its requirements.

The Commission is comprised of nine members as defined in the foundational legislation and is administratively staffed by the Virginia Department of Health, Office of Health Equity. The Commission met four times in calendar year 2019. December meeting minutes are not included in the 2019 Annual Report as they have not been approved by the Commission. December 2019 meeting minutes will be included in the 2020 calendar year annual report.

In this calendar year, the Commission completed and approved its by-laws, developed communication strategies, and identified the proper professional organizations and persons to provide advisement in the development of the Henrietta Lacks Life Sciences Center.

Following each meeting of the Commission, detailed written minutes were prepared and posted in accordance with § 2.2-3707 of the Code of Virginia. Further details beyond this report can be obtained from those minutes, made publicly available through the Commonwealth Calendar. All meetings were conducted pursuant to notice, as required by § 2.2-3707 of the Code of Virginia.

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

Introduction

As reflected in the 2018 Henrietta Lacks Commission Annual Report (Walker, 2018), the Henrietta Lacks Commission was established in 2018 as an advisory committee to sustain the legacy of Henrietta Lacks and develop the Henrietta Lacks Life Sciences Center. While still in its infancy, the Henrietta Lacks Commission has received a considerable amount of press coverage for its mission and the events held in its name during the 2018 Henrietta Lacks Legacy Week from September 23rd through 29th (Office of Health Equity, 2018). The Henrietta Lacks Commission will continue its efforts and strive to both honor the legacy of Mrs. Lacks while developing the infrastructure required to build a life sciences facility that focuses on bioethics, cancer research, and biomedical research until its sunset of July 1, 2021.

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:

§ 2.2-2537. *Henrietta Lacks Commission; purpose.*

The Henrietta Lacks Commission (the Commission) is established as an advisory commission in the executive branch of state government. The purpose of the Commission is 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.

§ 2.2-2538. *Membership; terms; vacancies; chairman and vice-chairman.*

A. The Commission shall consist of nine members that include two legislative members, three nonlegislative citizen members, and four ex officio members. Members shall be appointed as follows: (i) one member of the House of Delegates to be appointed by the Speaker of the House of Delegates in accordance with the principles of proportional representation contained in the Rules of the House of Delegates; (ii) one member of the Senate to be appointed by the Senate Committee on Rules; and (iii) one nonlegislative citizen member who is a member of the extended family of Henrietta Lacks, one nonlegislative citizen member who is a member of the Board of Directors of the Henrietta Lacks Legacy Group, and one nonlegislative citizen member who is a member of the Halifax County Industrial Development Authority to be appointed by the Governor. The mayor of the Town of South Boston, the chair of the Board of Supervisors of Halifax County, the Executive Director of the Southern Virginia Higher Education Center, and the Executive Director of the Halifax County Industrial Development Authority, or their

designees, shall serve ex officio with voting privileges. Nonlegislative citizen members of the Commission shall be citizens of the Commonwealth.

B. Legislative members and ex officio members of the Commission shall serve terms coincident with their terms of office. Nonlegislative citizen members shall be appointed for a term of two years. Appointments to fill vacancies, other than by expiration of a term, shall be for the unexpired terms. Legislative members and nonlegislative citizen members may be reappointed. However, no nonlegislative citizen member shall serve more than four consecutive two-year terms. The remainder of any term to which a member is appointed to fill a vacancy shall not constitute a term in determining the member's eligibility for reappointment. Vacancies shall be filled in the same manner as the original appointments.

C. The Commission shall elect a chairman and vice-chairman from among its membership.

§ 2.2-2539. Quorum; meetings; voting on recommendations

A majority of the members shall constitute a quorum. The meetings of the Commission shall be held at the call of the chairman or whenever a majority of the members so request.

§ 2.2-2540. Compensation; expenses.

Legislative members of the Commission shall receive such compensation as provided in § 30-19.12. Nonlegislative citizen members shall not receive compensation. All members shall be reimbursed for reasonable and necessary expenses incurred in the performance of their duties as provided in §§ 2.2-2813 and 2.2-2825. Compensation to members of the

General Assembly for attendance at official meetings of the Commission shall be paid by the offices of the Clerk of the House of Delegates or Clerk of the Senate, as applicable.

Reimbursement for the reasonable and necessary expenses of nonlegislative citizen members of the Commission shall be paid by the Halifax County Industrial Development Authority.

§ 2.2-2541. Powers and duties of the Commission.

The Commission shall have the power and duty to:

- 1. Establish a public-private partnership to create the Henrietta Lacks Life Sciences Center as a cancer research and treatment center located in Halifax County and designed to (i) transform and accelerate cancer research and treatment through the use of biodata tools, (ii) provide tailored cancer treatment medicine to an underserved portion of rural Southside Virginia, and (iii) incubate new biotech businesses across the Southside Virginia region; and*
- 2. 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. The executive summary shall be submitted 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 and shall be posted on the General Assembly's website.*

§ 2.2-2542. Staffing; cooperation of agencies of state and local governments.

The Department of Health shall provide staff support to the Commission. Every department, division, board, bureau, commission, authority, or political subdivision of the Commonwealth shall cooperate with, and provide assistance to, the Commission, upon request.

§ 2.2-2543. Sunset.

This article shall expire on July 1, 2021.

Organization

As defined in the foundational legislation referenced above, §§ 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 Commission is provided administrative staff support by the Virginia Department of Health, assigned to the Office of Health Equity.

Officers. Mattie Cowan assumed the Henrietta Lacks Commission Chair position during elections held on September 26, 2018 consistent with the Henrietta Lacks Commission by-laws and § 2.2-2538-C. Dr. Nettie Simon-Owens was elected to serve as the Henrietta Lacks Commission Vice-Chair on September 26, 2018.

Members.

A list of current members is provided below:

- Mattie Cowman, Chair
- Dr. Nettie Simon-Owens, Vice Chair

- Delegate James Edmunds, II
- Senator William Stanley, Jr.
- Brian Brown
- Dr. Adele Newson-Horst
- Jeri Lacks-Whye
- Jason Studley
- The Honorable Edward Owens

Committees. The Commission assessed the work set before them by the General Assembly and developed Committees in order to expedite task completion. Commissioner Newson-Horst oversees the Communications Committee. Commissioners Owens & Studley oversee the Legal and Funding Committee. There is no functional Henrietta Lacks Advisory Council. However, Commissioners Cowan, Simon-Owens, and Edmunds oversee the Resource Committee. Other ad hoc committees will be developed as need arises.

Findings and Recommendations

Meetings and Locations

All 2019 Henrietta Lacks Commission meetings took place at the Halifax County Industrial Development Authority. The first meeting of 2019 took place on March 19, 2019, with seven of nine Commission members present. The second meeting took place on June 26, 2019, with six of nine members present. The third meeting took place on September 23, 2019, with five of nine members present. A fourth meeting took place on December 18, 2019, with five out of nine members present.

Commission Actions

The Commission remains active in pursuit of its mission by utilizing committees to conduct foundational research to ensure project success. The committees focus on communications, legal and funding issues, and the development of a contact list of subject-matter experts. In addition, the Commission has agreed upon and created the Commission By-Laws.

Committee Actions

The Communications Committee has completed worked on the Henrietta Lacks Commission website, from domain name options agreed on by the Commission in 2018 (Walker, 2018a, p. 14-15). The Henrietta Lacks Commission website is now live and can be found at <https://henrietalackscommission.com/>. The elevator speech, agreed upon in 2018 by the Communications Committee has been in continuous use in both informational pitches by Commissioners and Commission supporters (Smith, 2019b, p. 4). They have also made significant headway on the plan development for the Henrietta Lacks 100th Birthday Celebration, expected to take place in October, 2020, in the Commonwealth of Virginia.

The Legal and Funding Committee continues to address the structural issues of the Commission as it relates to securing funding. The Resource Committee continues to brainstorm the key areas of expertise that would be beneficial in providing oversight for project progression (Walker, 2018a, p. 12). The Committee has worked on establishing a 501c3 and are continuing to looking into additional funding options (Smith, 2019c, p. 4).

Henrietta Lacks Advisory Council/Resource Committee

Due to the Code of Virginia's meeting requirements, The Henrietta Lacks Commission was unable to have an advisory council in 2019. Instead, the Commission decided to speak one-on-one with subject-matter experts for advisement on Commission matters. These alternative one-on-one interactions with subject-matter experts fulfill the purpose of the Henrietta Lacks Advisory Council as originally conceived and are facilitated by the leadership of the Resource Committee.

Henrietta Lacks Legacy Week

For the year of 2019, the Commission agreed to postpone the Henrietta Lacks Legacy Week until the year 2020. The 2020 Henrietta Lacks Legacy Week will now be combined with the Henrietta Lacks 100th Birthday Celebration. This event will remain as a seven-day period. During this seven-day period, seven (7) events are being planned to take place. The week will begin with a worship service at Henrietta Lacks' church home, St. Matthew Baptist Church of Clover in Clover, Virginia. Throughout the remainder of the week, the Commission is planning to complete a Week of Service, which will consist of regional, morning-long, volunteer service activities. Following these activities, the Commission will host luncheons, where activities of the Commission are expected to be discussed. The end of the Henrietta Lacks 100th Birthday Celebration Week will consist of a banquet, expected to be hosted at The Prizery, in South Boston, VA. Plans for the end-of-week banquet are to share the story of Henrietta Lacks, and honor three (3) local individuals who have benefited from the treatments developed from the HeLa Cells. The final plan for this seven-day period will be to host a Remote Area Medical (RAM) Clinic Day in Halifax, VA. All proposals on the Henrietta Lacks 100th Birthday Celebration Week are expected to be reviewed at the December 18, 2019 quarterly meeting.

Future Steps

The Office of Health Equity is currently working on filling the administrative support role to work within the Halifax area to provide direct support to the Commission. A job description was drafted and agreed upon by the Chair and Vice Chair. The initial contractor search did not result in a hire. However, both the Commission and the Office of Health Equity stand firm in the need to hire a dedicated administrative support person who would provide necessary assistance to the Commission in its endeavors, as it moves forward through this execution phase.

References

- Dean, K. (Producer), & Wolfe, G. (Director). (2017). *The Immortal Life of Henrietta Lacks* [Motion Picture]. USA: HBO Films.
- Lavin, A. (2019, December 5). "Re: Request for Completion: *Henrietta Lacks Commission Advisory Committee Meeting*." Email correspondence to Jasmine Smith, December 5, 2019.
- Office of Health Equity, (2018). Henrietta Lacks Legacy Week. Retrieved January 6, 2020 from <http://www.vdh.virginia.gov/health-equity/henrietta-lacks-legacy-week/>
- Smith, J. (2019b, June 10) *Henrietta Lacks Commission Minutes, June 26, 2019* [Meeting minutes]. Retrieved December 17, 2019 from <https://commonwealthcalendar.virginia.gov/Event/Details/14030>
- Smith, J. (2019c, September 07). *Henrietta Lacks Commission Minutes, September 23, 2019* [Meeting minutes]. Retrieved December 17, 2019 from <https://commonwealthcalendar.virginia.gov/Event/Details/14849>

Virginia's Legislative Information System. (2018a, March 30). 2018 Session; Chapter 705.

Retrieved November 21, 2018, from <https://lis.virginia.gov/cgi-bin/legp604.exe?181 ful CHAP0705>

Virginia's Legislative Information System. (2018b, March 30). HB 1415 Henrietta Lacks

Commission; established. Retrieved November 21, 2018, from <https://lis.virginia.gov/cgi-bin/legp604.exe?181 sum HB1415>

Virginia's Legislative Information System. (2018c, March 23). SB 171 Henrietta Lacks

Commission; established. Retrieved November 21, 2018, from <https://lis.virginia.gov/cgi-bin/legp604.exe?181 sum SB171>

Walker, K. (2018, February 20). *Henrietta Lacks Commission Annual Report*.

Walker, K. (2018, November 15). *Henrietta Lacks Commission Minutes, September 26-27,*

2018 [Meeting minutes]. Retrieved November 20, 2018, from <https://commonwealthcalendar.virginia.gov/Event/Details/11335>

Walker, K. (2019a, March 25). *Henrietta Lacks Commission Minutes, March 19, 2019* [Meeting

minutes]. Retrieved December 17, 2019 from <https://commonwealthcalendar.virginia.gov/Event/Details/13134>

Appendix A

**Henrietta Lacks Commission
Minutes
Tuesday, March 19, 2019 – 12:00 p.m.
Halifax Industrial Development Authority
1100 Confroy Dr, South Boston, Virginia 24592**

Members present: Mattie Cowan, Dr. Nettie Simon-Owens, Jeri Lacks-Whye, Jason Studley, Dr. Adele Newson-Horst, Kristy Johnson, and Ed Owens

Members absent: Del. James Edmunds, Sen. Bill Stanley

VDH staff present: Dr. Lauren Powell, Director of the Office of Health Equity; Kira Walker, Social Epidemiology Data Analyst

Others present: Servant Courtney Speed, President of the Henrietta Lacks Legacy Group; Reverend Alfred Chandler, Pastor of St. Matthew Baptist Church of Clover; Ashley Hodge, Reporter for The Gazette Virginian; Richard Crouse, and Assistant to Sen. Stanley.

Call to Order

Ms. Cowan, hereafter, “the Chair” called meeting of the Henrietta Lacks Commission, hereafter, “Commission”, to order at 12:00 p.m.

Determination of Quorum

A quorum was confirmed with seven of nine members present.

Approval of Agenda

The agenda was approved as-is unanimously by a voice vote, motioned by Dr. Newson-Horst and seconded by Dr. Simon-Owens.

New Appointments

The Chair advised that designee Matt Leonard informed the Chair of his inability to serve on the Henrietta Lacks Commission. Mr. Leonard was a designee for the Executive Director of the Halifax County Industrial Development Authority. Kristy Johnson, Interim Executive Director of the Halifax County Industrial Development Authority, will fill the open seat on the Commission until such time as a new Executive Director is named to the Halifax County Industrial Development Authority.

Action Items:

- *ACTION: Staff will update contact roster to reflect this change*

Approval of December Draft Minutes

The draft minutes from the December 19, 2018 meeting were approved as-is by a unanimous voice vote, motioned by Dr. Newson-Horst and seconded by Ed Owens.

Action Items:

- *ACTION: Staff will reformat draft minutes for final posting. Staff will post final minutes to Commonwealth Calendar and the VDH Commissioner's Meetings Calendar.*

Report Back on 2019 Second Conference on Bioethics Issues in Minority Health

Dr. Lauren Powell reported that she and Matt Leonard, attended the 2019 Second Conference on Bioethics Issues in Minority Health, hosted by Morehouse School of Medicine/Tuskegee University/University of Alabama at Birmingham Comprehensive Cancer Center Partnership. The event took place January 23-25, 2019 in Opelika, Alabama.

The conference organizers accepted an abstract put forth by the Commission and requested that Mr. Leonard present to conference attendees regarding the Commission's purpose and challenges faced. Dr. Powell was asked to facilitate a question and answer session following the attendees' tour of an exhibit showcasing both Henrietta Lacks' cells as well as the Tuskegee Syphilis experiment.

Dr. Stephen Sodeke, Bioethicist and Professor of Allied Health Sciences, Chair of Tuskegee University's Institutional Review Board, and Resource Expert for NGO Bioethics Beyond Borders has expressed his support for the Henrietta Lacks Commission and the Commission will work to foster this relationship. Dr. Powell states that connections were made with the National Institute of Health and Tuskegee University during this conference. Approximately 150 persons were in attendance at this event.

Action Items:

- *STUDY: Commission will follow up for 3rd Annual Conference on Bioethics Issues in Minority Health.*

By-Laws

Staff support, Kira Walker, advised the Commission that since quorum was lost during the last meeting, no action was taken on By-Laws. Ms. Walker advised the Commission that based on the presentation from the FOIA Council representative, Mr. Alan Gernhardt, the suggestion was to stipulate that a Committee's quorum would be all members.

The Commission discussed this potential addition and ultimately decided to leave the by-laws as is. After a brief review, a typographical error was discovered and marked for edit.

The by-laws were approved with the single edit by a unanimous voice vote, motioned by Mr. Owens and seconded by Dr. Newson-Horst.

Action Items:

- *ACTION: Staff will edit the by-laws as requested and distribute the document prior to the next meeting.*

Committee Reports

Communication Committee (Commissioners Johnson, Lacks-Whye & Newson-Horst)

With the departure of Mr. Leonard, Ms. Johnson will serve on the Communications Committee.

The Committee is working on a series of human interest pieces. The current communications plan states the first piece will discuss the Lacks Family's commitment to the work of the Commission, the second piece will report milestones achieved, and the third piece will be a call for support from the public.

The Committee provided a list of eight speaking engagements where the Commission was or will be featured between October 2018 and March 2019. Upcoming events include a NPR interview for Women's History Month on March 20 and a panel discussion on March 27.

The Committee reported that two Commissioners are requested to participate in an upcoming podcast interview. The Chair stated that the Chair, Vice Chair, Mr. Studley, and Mr. Owens are all available and Dr. Newson-Horst should reach out to schedule.

Action Items:

- *PLANNING: Dr. Newson-Horst will contact identified Commissioners for scheduling to participate in podcast.*

The Committee reported that the Halifax Strategic Initiatives presented by the Strategic Planning Steering Committee includes the support of the Henrietta Lacks Commission initiative. IT was agreed that the Commission should coordinate to present before the Strategic Planning Steering Committee.

Action Items:

- *ACTION: The Committee will develop a standard template for presentations.*
- *PLANNING: Committee will coordinate with Staff for development or transmittal of any logos/graphics.*

The Chair thanked the Committee for its efforts and requested that these efforts be mirrored in the Halifax region. Suggestions were presented to use local universities, higher education centers, and community colleges as an initial point for communications efforts in the Halifax region.

Action Items:

- *ACTION: All Commissioners are requested to send local communication opportunities, contacts, or organizations to the Communications Committee.*

The elevator speech provided by Hope Harris-Gayles, SVHEC Associate Director of Communication and Outreach was presented and discussed. One minor edit is requested. The elevator speech was approved by a unanimous voice vote, motioned by Dr. Simon-Owens and seconded by Mr. Studley. The Commission would like to extend its gratitude and appreciation to Hope Gayles for her efforts.

Action Items:

- *ACTION: Staff will make the requested edits to the elevator speech and disseminate to staff prior to the next meeting.*

Legal and Funding Committee (Commissioners Owens, Stanley & Studley)

The Committee reported they have researched potential fiduciary agents and discovered conflict of interest restrictions for those agents investigated. Further investigation for a fiduciary agent will be conducted by the Committee and Chair.

Action Items:

- *STUDY: Further investigation for fiduciary agent will be conducted by Mr. Studley and the Chair.*
- *STUDY: Mr. Owens will work with Sen. Stanley to provide advice regarding 501c3 development.*
- *STUDY: Sen. Stanley will assist in identifying potential organizations for donation of seed money.*
- *PLANNING: Committee will coordinate to develop proposal letter for seed money donations.*

Advisory Council (Commissioners Cowan, Edmunds & Simon-Owens)

The Committee reviewed the working table being utilized to identify potential members of the Advisory Council.

Action Items:

- *STUDY: Ms. Johnson will work to identify potential candidates for facilities expertise.*
- *STUDY: Mr. Owens, Mr. Studley, and Chair will work to identify a private sector attorney specializing in intellectual property/patent law.*
- *ACTION: The Chair will provide the contact information for a local attorney who might be of assistance in identifying intellectual property/patent law candidates.*

The Committee reviewed the framework document to be utilized to explain the relationship between the Commission and Advisory Committee members. The Committee discussed the addition of a statement noting that Advisory Committee members will receive no remuneration for their posting. The Chair stated that this notice should be given verbally as well.

Commissioners are asked to be aware that they will be expected to contact their assigned advisory committee candidate(s) to gauge their interest and willingness to participate. A timeline for contact will be provided by the Committee following this meeting. The suggestion was brought forth to mail a letter to candidates explaining intent and providing background of the Commission prior to calling candidates.

The suggested work flow for items surrounding the development and recruitment of the Advisory Committee is as follows:

1. Develop 501c3 or secure a fiduciary agent.
2. Publish website.

3. Develop form letter.
4. Begin seeking donations and recruitment for Advisory Committee.

Action Items:

- *ACTION: The Vice Chair will edit the framework to include no remuneration will be provided to Advisory Committee members.*
- *PLANNING: Staff and Vice Chair will meet to discuss talking points for Advisory Committee pitch, a plan of action and associated timeline, as well as a form letter for use by Commissioners to contact candidates.*
- *PLANNING: Letterhead requires development. Committee will coordinate with Staff to relay needs.*
- *ACTION: Staff will advise VDH leadership and government officials as needed about the development of an Advisory Committee.*
- *PLANNING: Ms. Johnson will send website link for Commissioner review and approval. All Commissioners will send notes no later than Friday, March 22, 2019.*

New Business

Program Director position

The Program Director position has been posted and will close on March 30, 2019. Qualified applicants are encouraged to apply through Premier Staffing Service's portal and notify staff or Commissioners of their application for internal tracking purposes. This position will provide administrative support to the Commission while acting as an ambassador for the Commission to community partners.

The job posting can be found here: <http://premierstaffingsource-careers.s3-website-us-east-1.amazonaws.com/#/jobs/9440>

Event Planning

The Commission discussed planning a 2019 Symposium in the Halifax area to celebrate the one-year anniversary of the Henrietta Lacks Commission. The focus will be to ensure the region understands what the Henrietta Lacks Life Sciences Center will be, to attract support, and to introduce the Commission to the regional population. Suggestions were brought forth to include participation from previous winners of the Henrietta Lacks Legacy Group Annual Essay and Video Competition.

Action Items:

- *PLANNING: The Chair and Vice Chair will coordinate with Commissioners individually for their assistance in planning efforts.*

The Commission discussed planning an event for August 2020 to celebrate 100 years of Henrietta Lacks. This event may compliment events from the Henrietta Lacks Legacy Group. An event to be hosted in Southern Virginia was discussed and agreed upon for September 2019, commemorating the one-year anniversary of the Commission's first meeting. The event would be multi-faceted, possibly a day event for school-aged attendees and an evening event for the adult popular, i.e., symposium or forum.

The Commission received an invitation to present to LEAD Virginia on May 18, 2019.

Rev. Chandler stated that the Atlanta Medical Association is interested in supporting the Commission. The contact information for representatives will be shared with the Chair.

Next Meeting Date

The next meeting will take place during the regularly scheduled quarterly window, in June 2019. The date is pending the response and availability of Commissioners based on a Doodle poll.

Action Items:

- *Staff will send out a Doodle Poll to determine staff availability for the meeting. Options provided will be:*
 - *Monday – Friday, 9 a.m. – 5 p.m., June 16-29.*

Adjournment

The meeting was adjourned at 2:05 p.m.

Meeting minutes recorded by Kira Walker

Appendix B



HENRIETTA LACKS COMMISSION

Chair, Mattie Cowan

Sen. William Stanley, Jr.

Dr. Adele Newson-Horst

Vice Chair, Dr. Nettie Simon-Owens

Del. James Edmunds, II

Kristy Johnson

Jeri Lacks-Whye

Hon. Ed Owens

Jason Studley

**Henrietta Lacks Commission Minutes
Wednesday, June 26, 2019 – 12:00 p.m.
Halifax Industrial Development Authority
1100 Confroy Dr, South Boston, Virginia 24592**

Members present: Mattie Cowan, Dr. Nettie Simon-Owens, Sen. Stanley, Jr., Dr. Adele Newson-Horst, Kristy Johnson, and Ed Owens

Members absent: Del. James Edmunds, Jeri Lacks-Whye, Jason Studley

VDH staff present: Dr. Lauren Powell, Director of the Office of Health Equity; Jasmine Smith, Danville YHELI Program Administrator

Others present: Servant Courtney Speed, President of the Henrietta Lacks Legacy Group; Charity Howell, Outreach Representative for U.S. Senator Mark R. Warner; Lawrence Lacks, son of Mrs. Henrietta Lacks; Veronica Lacks, granddaughter of Lawrence Lacks; Richard Crouse, Assistant to Senator Stanley.

Call to Order

Ms. Cowan, hereafter, “the Chair” called the meeting of the Henrietta Lacks Commission, hereafter, “Commission”, to order at 12:00 p.m.

Determination of Quorum

A quorum was confirmed with six of nine members present.

Approval of Agenda

After the additions of 7b; Henrietta Lacks Legacy Week, 7c; 100th Anniversary Discussion, 7d; Henrietta Lacks Documentary Discussion, and 7e; LEAD Virginia Contacts, the agenda was approved unanimously by a voice vote, motioned by Dr. Nettie Simon-Owens and seconded by Ed Owens.



Approval of March Draft Minutes

The draft minutes from the March 19, 2019 meeting were approved, with a typographical edit, by a unanimous voice vote, motioned by Dr. Adele Newson-Horst, and seconded by Kristy Johnson.

Action Items:

- *ACTION: Staff will reformat draft minutes for final posting. Staff will post final minutes to Commonwealth Calendar and the VDH Commissioner's Meetings Calendar.*

Old Business

Program Director Position

Dr. Lauren Powell reported that financial support within the agency is the current need for the Henrietta Lacks Commission new hire. The new hire would have to be exclusively dedicated to the Commission. There is currently a job description and the request has been elevated within the agency. Dr. Lauren Powell hopes to have a new hire by the next quarterly meeting.

A question was posed by the Chair, Mattie Cowan, to Senator Stanley that asked if there was anything that the Commission can do to get funding for the position. Senator Stanley noted that the Commission will need a budget amendment. The Commission can also seek out grants for funding for the new hire.

Report Back on 2019 Second Conference on Bioethics Issues in Minority Health

Dr. Lauren Powell reported that she has not heard confirmation of a third conference as of yet, however, she has been in contact with Dr. Stephen Sodeke to work with him on expanding the abstract into a short manuscript. The manuscript will not be based on scientific research, but instead on the proceedings from the conference and the discussion regarding the abstract that was submitted by the Commission.

There were some minor edits received from the Journal for Healthcare of the Poor and Underserved. The suggested edits were made and submitted. Dr. Lauren Powell will report back on this as updates are received.

By-Laws

The by-laws were approved at the March 19, 2019 meeting with the single edit by a unanimous voice vote, motioned by Mr. Owens and seconded by Dr. Newson-Horst.

Committee Reports

Communication Committee (Commissioners Johnson, Lacks-Whye & Newson-Horst)

LEAD Virginia contacted the Henrietta Lacks Commission and requested a presenter for their visit to Halifax County. A contact sheet of LEAD Virginia participants who expressed interest in volunteering their professional talents to assist with the work of the Commission. The contact sheet was provided to each Commission member.



Action Items:

- *ACTION: The Communications Committee will complete a write up on the LEAD Virginia presentation to be included on the webpage.*
- *ACTION: Following the June 26, 2019 meeting, the Commission will look over the contacts given and contact LEAD Virginia participants on any matters they can be of assistance with surrounding the Henrietta Lacks Commission*

Legal and Funding Committee (Commissioners Owens, Stanley, & Studley)

Committee member, Ed Owens made a few comments and asked Sen. Stanley to provide updates on the forms needed to establish a 501C3 foundation. Sen. Stanley gave the Chair, Mattie Cowan a paper copy of the partially completed articles of incorporation, prepared by his staff. The Henrietta Lacks Foundation Inc., was reported to be an available name and was reserved in the instance that the Commission chooses to go forth with this name. It was agreed that the preferred name of a new 501C3 entity will be The Henrietta Lacks Life Sciences Center Foundation, Inc.

Committee member, Sen. Stanley reported that the Commission and the Foundation are to be known as two separate entities.

Action Items:

- *ACTION: The Commission will need to register the Foundation with the Virginia State Incorporation Commission as soon as possible.*
- *ACTION: The Commission will need to complete the donation received form as soon as possible.*
- *ACTION: Sen. Stanley's assistant, Richard Crouse, will send example bylaws to the chair.*
- *ACTION: Sen. Stanley volunteered to be the Authorized Representative on the Application for Recognition of Exemption documents (IRS form 1023) that must be submitted for the creation of the Foundation.*
- *STUDY: The Commission will follow up on the available name options for the Foundation (i.e. the Henrietta Lacks Life Science Center Foundation, Inc.).*
- *PLANNING: 1100 Confroy Drive, South Boston, VA 24592 will be used as the physical location for the Foundation.*

A suggestion was made by Ed Owens to have a Non-Disclosure Agreement (NDA). Dr. Lauren Powell noted that being that the Commission is a public body, a Non-Disclosure Agreement may not be appropriate, however, a NDA may be appropriate for the Foundation. Dr. Simon-Owens shared that it was recommended to her that the Commission consider NDAs to protect the information Commissioners discuss with others during this planning process and in the absence of the Foundation.

Action Items:

- *ACTION: Dr. Lauren Powell will follow up with the Attorney General's Office regarding a Non-Disclosure Agreement.*



Advisory Council (Commissioners Simon-Owens, Edmunds, & Stanley)

Dr. Simon-Owens reported that the draft letter to the proposed Advisory Council members, located in the meeting documents folder, can now be updated with edits based on the information provided at this meeting. Sentiments of appreciation were given to the VDH staff for the creation of the Henrietta Lacks Commission letterhead.

Action Items:

- *ACTION: VDH staff will make the necessary edits to the draft letter and send to the Advisory Council chair.*

New Business

Building of the Henrietta Lacks Life Sciences Center

The Chair, Mattie Cowan, reported that Halifax County recently adopted a new strategic plan which includes the building of the Henrietta Lacks Life Sciences Center as one of the items listed. Halifax County is committed to this and stands behind the Commission. The elevator speech, developed by Mrs. Hope Harris-Gayles (SVHEC communications manager), was used to explain the Commission and its hard work. Positive responses were received on the elevator speech.

Action Items:

- *ACTION: There will be reports given at each quarterly meeting with updates on the building of the Henrietta Lacks Life Sciences Center.*

Henrietta Lacks Portrait and Dedications

The Ambrose Kennedy Park will be dedicated as the Henrietta Lacks Educational Park.

Henrietta Lacks Legacy Week

The Chair, Mattie Cowan, reported that the Commission wishes to have Henrietta Lacks Legacy Week in the month of October. This will be a week-long event that will work to shed light on the contributions and impact that Henrietta Lacks had in science and technology, as well as to the ongoing work of the Commission and her connection to Halifax County, VA.

A suggestion was made to have a Health Disparities Fair that consists of screenings, vital signs, community engagement, and education.

A suggestion was made to have a Henrietta Lacks Legacy Day created during the school year that is dedicated to education and essay projects surrounding Henrietta Lacks. Black History Month and Women's History month were the two suggested timeframes for this. Sen. Stanley stated that the New College University can be used to host an event in Martinsville, VA.



Action Items:

- *STUDY: VDH staff will gather information for the Henrietta Lacks Legacy Week in the month of October and will report back.*
- *ACTION: A conference call will be set up to go over this information within the coming weeks.*
- *PLANNING: The Commission agreed on the week of October 20th – 26th and planning will begin.*

100th Birthday of Henrietta Lacks

Dr. Newson-Horst reported that NPR would like to know what the Commission is planning to do for the 100th birthday. The Chair, Mattie Cowan reported the interest of completing a documentary. The documentary will consist of 25-30 minutes discussing who Henrietta Lacks is and her contributions.

Due to a documentary already being worked on by some Lacks family members, there was a discussion on collaborating on this, rather than creating a new documentary.

Action Items:

- *STUDY: Research and inquiries will be done on the potential collaboration for a documentary and information will be reported back at the next quarterly meeting.*
- *ACTION: Dr. Newson-Horst will take planning for the 100th birthday celebration to the Communications Committee and is the point person matter. Reports will be given at the conference call and the next quarterly meeting.*

Virginia State Baptist Usher's Union Advertisement

The Chair, Mattie Cowan has reported that she is a member of the Virginia State Baptists Usher's Union and plans to purchase a one-page ad for the journal being created for the 60th anniversary of the Virginia State Baptist Usher's Union that will highlight Henrietta Lacks.

Action Items:

- *ACTION: Dr. Newson-Horst and VDH staff will put together the full page ad surrounding Henrietta Lacks and the Commission.*

Next Meeting Date

The next meeting will take place during the regularly scheduled quarterly window, in September 2019. The date is pending the response and availability of Commissioners based on a Doodle poll.

Action Items:

- *ACTION: Staff will send out a Doodle Poll to determine staff availability for the meeting.*



Adjournment

The meeting was adjourned at 2:12 p.m.

Meeting minutes recorded by Jasmine Smith.



Appendix C



HENRIETTA LACKS COMMISSION

Chair, Mattie Cowan

Sen. William Stanley, Jr.

Dr. Adele Newson-Horst

Vice Chair, Dr. Nettie Simon-Owens

Del. James Edmunds, II

Brian Brown

Jeri Lacks-Whye

Hon. Ed Owens

Jason Studley

**Henrietta Lacks Commission Minutes
Monday, September 23, 2019 – 12:00 p.m.
Halifax Industrial Development Authority
1100 Confroy Dr, South Boston, Virginia 24592**

Members present: Mattie Cowan, Dr. Simon-Owens, Dr. Adele Newson-Horst, Brian Brown, and Jeri Lacks-Whye

Members absent: Del. James Edmunds, Jason Studley, Sen. Stanley, Jr., and Ed Owens

VDH staff present: Dr. Lauren Powell, Director of the Office of Health Equity; Jasmine Smith, Executive Administrator

Others present: Sable K. Nelson, Director of the Division of Multicultural Health and Community Engagement; Kristy Johnson, Deputy Director for the Halifax County Industrial Development Authority (IDA); Reverend Alfred Chandler, Pastor of St. Matthews Baptist Church (Clover, VA).

Call to Order

Ms. Cowan, hereafter, “the Chair” called the meeting of the Henrietta Lacks Commission, hereafter, “Commission”, to order at 12:00 p.m.

Determination of Quorum

A quorum was confirmed with five of nine members present.

Approval of Agenda



The agenda was approved unanimously by a voice vote, motioned by Dr. Newsonhorst and seconded by Brian Brown.

New Appointments

The Henrietta Lacks Commission welcomed, Brian Brown, recently hired as the Halifax County IDA Executive Director and will now serve as the IDA representative on the Commission, the position held by interim director Kristy Johnson.

Action Items:

- *VDH staff will include Brian Brown on the Contact Roster for the Henrietta Lacks Commission, and the Henrietta Lacks Commission Letterhead.*

Approval of June Draft Minutes

After the discussion of various points for clarification, and a motion by Dr. Simon-Owens, seconded by Jeri Lacks-Whye for a correction on page four of six, the draft minutes from the June 26, 2019 meeting were approved, by a unanimous voice vote, motioned by the Chair, and seconded by Dr. Simon Owens.

Action Items:

- *ACTION: Staff will reformat draft minutes for final posting. Staff will post final minutes to Commonwealth Calendar and the VDH Commissioner's Meetings Calendar.*

Old Business

Program Director Position

Dr. Lauren Powell reported that a budget amendment was completed for the Program Director position, for specific funding towards the line item for administrative support. This amendment will go up for review to the Secretary's office and the Governor's office. Dr. Powell made the Commission aware that funding from the budget amendment will not go into effect until July 2020.

During the waiting period for the funding to go into effect, Dr. Powell has spoken with Virginia Department of Health leadership, including the Commissioner, and received a commitment from the agency to receive funding support for this position in the interim. VDH staff has a job description, as well as a budgeted amount towards payment for this position in place.

Due to the timeline of the Commission, the Chair reported that she and Dr. Simon-Owens plan to meet with senior leadership (I prefer this to higher-ups) to express the importance and need for this position, as it pertains to the Commission's success. Dr. Powell has expressed that if the need for VDH staff presence in this meeting is present, VDH staff will plan to attend.

Action Items:



- *ACTION: VDH staff will proceed with contacting a contracting agency to fill the position.*
- *ACTION: VDH staff will have someone in place by the end of the 2019 year.*

Committee Reports

Communication Committee (Commissioners Johnson, Lacks-Whye & Newson-Horst)

Brian Brown agreed that Kristy Johnson continue to work with the Communication Committee.

Dr. Newson-Horst reported that the Henrietta Lacks Commission Mission Statement, “To plan and execute activities to promote national and regional awareness of the Commission and its activities,” has received approval by the Chair.

The Communications Committee will create three (3) human interest features, relevant to the Commission, with plans for the features to go nationally. These features are 1) the Lacks family’s commitment to the work of the Commission; 2) the milestones achieved by the Commission; 3) a general call for support of the Commission.

Action Items:

- *ACTION: The communications committee will have the three (3) features completed and given to the Chair, upon committee approval.*

The Communications Committee reported that Jeri Lacks-Whye and Dr. Newson-Horst met with Heidi from Howard University in regards to a podcast. Heidi stated that the Commission has not yet completed any tasks that can be highlighted within a podcast. At the point to which we have tasks to report, Heidi will contact the Chair and Jason Studley for completion of a podcast.

Dr. Newson-Horst reported on the production of the tri-fold brochure. The brochure shared was a draft and the floor was opened for review and edits.

Action Items:

- *The Communications Committee will place a professional, and all-inclusive, picture on the brochure. This will include either individual headshots or a full group picture.*
- *Kristy Johnson will assist the committee with acquiring the photos of the Commission.*
- *The Communications Committee will include a call for action, mission, and plan to achieve the mission within the brochure.*
- *The Communications Committee will ask Hope Harris-Gayles for design guidance on committee correspondence and within the brochure.*
- *The Communications Committee will decrease the verbiage amount and font size within the brochure.*

A suggestion was made for the Commission to have a social media platform in order to better spread the work of the Commission. The Commission has agreed that social media will be managed by VDH staff.

Action Items:



- *VDH staff will send out a poll to the Commission of options for the HLC social media handle by September 27, 2019.*
- *VDH will create and manage the Commission's social media accounts, until the Program Director position is filled.*

Legal and Funding Committee (Commissioners Owens, Sen. Stanley, Jr., & Studley)

Dr. Simon-Owens reported, on behalf of the Legal and Funding Committee, in regards to her work on the completion of the 501C3. Dr. Simon-Owens reported that the process of completing the application and information, shared with the Commission by Sen. Stanley, Jr. at the June meeting, has been started. With the assistance from Attorney James Taylor, the Chair and Dr. Simon-Owens spent time completing this and are now awaiting the review and edits from Attorney Taylor before submission. By-Laws were also required to be developed, as well as the submission of paperwork to the Commonwealth of Virginia, to which Dr. Simon-Owens and the Chair are working to complete.

Advisory Council (Commissioners Simon-Owens, Edmunds, & Sen. Stanley, Jr.)

Dr. Simon-Owens followed up on her report from the June meeting on the contact information from LEAD Virginia. Individuals from LEAD Virginia have continued to express their interest and excitement in the work on the commission and are eager to know if there are tasks that they can do to help the Commission.

Action Items:

- *ACTION: VDH staff will mail the approved advisory letter to those on the Advisory Committee list by October 15, 2019. Contact should be made by October 30, 2019.*

Dr. Simon-Owens posed the question on whether the Chair would like for Dr. Simon-Owens to reach out to the LEAD VA contacts, to see if any of the individuals are interested in the Commission presenting in their communities. The Chair agreed to this question as posed.

Action Items:

- *ACTION: Dr. Simon-Owens will reach out to the LEAD VA contacts and report back on this matter.*

New Business

Henrietta Lacks Legacy Week

Due to the short time frame for planning, the Commission has agreed to cancel the 2019 Henrietta Lacks Legacy Week in order to produce a well-planned event in the future. Discussion began for the 2020 year, with a possible combining of the 100th Birthday Celebration and the Legacy Week.

Action Items:

- *ACTION: A retraction will be made for the Henrietta Lacks Legacy Week Proclamation from the Governor's Office.*



Brian Brown made a suggestion to have a week of community service across the region, in honor of Henrietta Lacks, in collaboration with the Ministerial Alliance. The Commission agreed on this idea and the Chair has asked Brian Brown, and Reverend Chandler, to work with Dr. Newson-Horst on the planning of these events.

100th Birthday Celebration of Henrietta Lacks

Dr. Newson-Horst reported on the proposal for the Henrietta Lacks 100th Birthday Celebration. The proposal is to “Involve and enlighten the Halifax Community on the work of the Commission.” The prospective title for this will be the *Henrietta Lacks 100th Birthday Observance: A Community Celebration of Life*. The goal will be to celebrate Henrietta Lacks’ life, and those within the area that her cells have helped. A major activity for this event will be to honor three local individuals who have benefited from the treatments developed from HELA cells. Dr. Newson-Horst reported that the planned venue will be The Berry Hill Resort and Conference Center, in South Boston, VA. The Chair stated that an alternate location for the event is The Prizery, in South Boston, VA. The change in venues was agreed upon by the Chair and Dr. Newson-Horst.

Reverend Chandler stated to also highlight the community connections with Henrietta Lacks. These would include her burial, and the connection with the local church, school, and any living relatives. A suggestion was also made to create a map that can be provided to point individuals in the direction of these highlighted points of connection.

Through further discussion of the celebration, the Commission agreed on the event taking place around her birthday, during a date and time that will not conflict with other events that are being planned by Mr. David Lacks.

Action Items:

- *PLANNING: The Henrietta Lacks 100th Anniversary Planning Committee will have its first conference call on October 15th to begin strategic planning for the celebration. A date will be determined during this call.*

Dr. Newson-Horst posed the question regarding the Henrietta Lacks documentary. The Chair reiterated the discussion from the June meeting, stating that the Lacks family has discussed the possibility of a documentary. The Commission does not wish to conflict with plans that are already in place, however, the Commission would be a part of this documentary, should this be asked of them.

Action Items:

- *Jeri Lacks-Whye will reach out to the rest of the Lacks family to confirm the development or possibility of a documentary.*

Journal of Health Care for the Poor and Underserved

Dr. Powell gave an update on the publication submission, pertaining to the Bioethics Research Conference, held in January, attended by Dr. Powell and former Commissioner Matt Leonard.



After a request from the head of the Bioethics Research Conference to submit an abstract, Dr. Powell took part in co-writing the assignment. She shared versions of this abstract with the Chair and Vice Chair previously and received notification, in August, that the publication has been accepted. This publication will be in the upcoming volume that will encompass everything that took place at the conference. The submission will be published by the end of the year.

Action Items:

- *Dr. Powell will share proofs with the Chair and Vice Chair once received.*

Next Meeting Date

The next meeting has been confirmed for December 18th from 12pm – 3pm.

Action Items:

- *ACTION: Staff will send out an email notification and calendar invite, following the meeting.*

Adjournment

The meeting was adjourned at 2:06 p.m.

Meeting minutes recorded by Jasmine Smith.

