

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.

DRAFT – NOT APPROVED
Henrietta Lacks Commission
Minutes

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.*

DRAFT – NOT APPROVED
Henrietta Lacks Commission
Minutes

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.

DRAFT – NOT APPROVED
**Henrietta Lacks Commission
Minutes**

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

DRAFT