

2018 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 2018 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 first 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. Since the inaugural meeting of the Commission in September, two meetings have taken place and one is scheduled before the end of the calendar year.

In this calendar year, the Commission has elected its officers, worked to develop by-laws, developed communication strategies, conducted a community health needs assessment and analysis to identify key stakeholders, and identified the proper professional organizations and persons to provide oversight 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 publically available through 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

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 Henrietta Lacks Legacy Week. 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. 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 current members is provided below.

Mattie Cowman, Chair

Dr. Nettie Simon-Owens, Vice Chair

Delegate James Edmunds, II

Senator William Stanley, Jr.

Matt Leonard

Dr. Adele Newson-Horst

Jeri Lacks-Whye

Jason Studley

Ed Owens

Committees. The Commission has assessed the work set before them by the General Assembly and developed Committees in order to expedite task completion. Commissioners Leonard & Newson-Horst oversee the Communications Committee. Commissioners Owens & Studley oversee the Legal and Funding Committee. Commissioners Cowan, Simon-Owens, and Edmunds oversee the Advisory Council Committee. Other ad hoc committees will be developed as need arises.

Findings and Recommendations

Meetings and Locations

The inaugural meeting took place on September 26, 2018 at the Halifax Industrial Development Authority. The second meeting took place on September 27, 2018 at the Southern Virginia Higher Education Center. The third meeting took place on November 9, 2018 at the

Sentara Halifax Regional Hospital. A fourth meeting took place on December 19, 2018 at the Halifax Industrial Development Authority.

Commission Actions

As of the November 9 meeting, the Commission has developed three specialized committees to conduct foundational research to ensure project success. The committees focus on communications, legal and funding issues, and the development of an advisory council. In addition, the Commission has made headway in the development of Commission By-Laws (Walker, 2018a, p. 13; Walker, 2018b, p. 10-11).

Committee Actions

The Communications Committee has begun work on the Henrietta Lacks Commission website, developing a template and securing several domain names to provide the Commission with options (Walker, 2018a, p. 14-15). The Communications Committee has also made significant headway on an elevator pitch to be used in both informational and funding pitches by Commissioners and Commission supporters (Walker, 2018b, p. 2-3).

The Legal and Funding Committee has begun to address the structural issues of the Commission as it relates to securing funding. They have advocated for the development of a separate foundation to route funding through. As of the November 9 meeting, the Committee is still researching the best structure for this foundation. The Legal and Funding Committee has also initiated a community health needs assessment and analysis in order to assist in the identification of stakeholders and potential funding sources (Walker, 2018b, p. 4).

The Advisory Committee has brainstormed the key areas of expertise that would be beneficial in providing oversight for the project progression (Walker, 2018a, p. 12) as well as

begun identifying potential organizations or individuals who might be qualified to provide oversight to the Commission's work (Walker, 2018b, p. 5-10).

Henrietta Lacks Legacy Week

On September 23, 2018, Governor Ralph S. Northam proclaimed September 23 through 29, 2018 to be Henrietta Lacks Legacy Week through the following proclamation:

The proclamation (Northam, 2018) is as follows:

WHEREAS, Henrietta Lacks was a remarkable African-American woman, a native Virginian, and a hero to us all, whose world-changing legacy has benefited untold millions around the globe; and

WHEREAS, Henrietta Lacks' cells, which were taken and used extensively without her or her family's knowledge as she battled cancer, became the first immortal cell line, allowing for the unparalleled advancement of medical and biotech research; and

WHEREAS, over the decades, her cells, shortened in name to HeLa cells, would be named in more than 11,000 patents, including the Polio vaccine, numerous therapies to fight cancer and AIDS, and mapping the human genome; and

WHEREAS, the 2018 General Assembly unanimously endorsed the Henrietta Lacks Life Science Research and Cancer Treatment Center and commission, selecting her homeplace –Halifax County – as the place to build a monument to her profoundly powerful and healing legacy; and

WHEREAS, the inaugural meeting of the Henrietta Lacks Commission and the investiture of its members is scheduled this week in Halifax, pledging to work to provide treatments

to the underserved residents of rural Southern Virginia, and develop and commercialize new therapies, which will transform the area's economy; and

WHEREAS, Henrietta Lacks' loving spirit continues through her descendants, whose mission is to extend the legacy of her miraculous gift and the unparalleled reach of her cell line;

NOW, THEREFORE, I, Ralph S. Northam, do hereby recognize September 23-29, 2018, as HENRIETTA LACKS LEGACY WEEK in our COMMONWEALTH OF VIRGINIA, and I call this observance to the attention of all our citizens.

During this seven-day period, eleven events took place (Virginia Department of Health, 2018b). The week began with a worship service at Henrietta Lacks' church home at St. Matthew Baptist Church of Clover in Clover, Virginia. That same evening, the feature film *The Immortal Life of Henrietta Lacks* (Dean & Wolfe, 2017) was simulcast at the Carpenter Theater in Richmond and The Prizery in South Boston, Virginia. The following day, Monday, September 24, the Virginia Department of Health held an internal seminar and luncheon to educate staff and honor Henrietta Lacks' contributions to public health. Tuesday evening spotlighted a public panel discussion at the Library of Virginia. This event received media coverage by The Commonwealth Times (LaBar, 2018). Wednesday, September 26, began the inaugural meeting of the Henrietta Lacks Commission, celebrated that evening by a private dinner. The following day the second session of the inaugural meeting of the Commission took place. Friday, September 28, a private closing reception took place at the Virginia Museum of History and Culture for Commissioners and community supporters. The Henrietta Lacks Legacy Week and the mission of the Henrietta Lacks Commission was covered heavily in the press throughout the Commonwealth by Virginia First (NextStar Broadcasting Inc., 2018), Virginia Commonwealth University (2018), U.S. News

(Jumaa, 2018), SoVaNow (2018), Roanoke Times (Rife, 2018), NBC12 (2018), Gazette Virginian (2018), CBS19 (2018), and the Henrietta Lacks Legacy Group (2018).

Future Steps

Looking forward, the Office of Health Equity and the Henrietta Lacks Commission have begun to understand the true staffing requirements needed to satisfy the administrative burden before the Commission. As such, the Office of Health Equity is working diligently to create an administrative support role to work within the Halifax area to provide additional, dedicated support to the Commission's efforts. A job description has been drafted and will be presented for the Commission's consideration before the end of the year. Both the Commission and the Office of Health Equity feel that a dedicated administrative support position would provide considerable assistance to the Commission in its endeavors as it moves forward through the planning phase and into the execution phase.

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Appendix A

**Henrietta Lacks Commission
Minutes
September 26, 2018 – 2 p.m.
Halifax Industrial Development Authority
1100 Confroy Dr, South Boston, Virginia 24592**

Members present: Jeri Lacks-Whye, Dr. Adele Newson-Horst, Mattie Cowan, Hon. Ed Owens, Jason Studley, Dr. Nettie Simon-Owens, Matt Leonard

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

VDH staff present: Dr. Lauren Powell, Director of the Office of Health Equity; Kira Walker, Social Epidemiology Data Analyst; Joe Hilbert, Deputy Commissioner for Governmental and Regulatory Affairs

Others present: Kristy Johnson, Deputy Director of Halifax IDA; Traci DeShazor, Deputy Secretary of the Commonwealth; Dr. Betty Adams, Executive Director of the Southern Virginia Higher Education Center; Sheila Bradley, Legislative Aide to Delegate James Edmunds; Bryan Price, UVA Cancer Center; Danville Alumnae Chapter of Delta Sigma Theta Sorority, Inc., members; Elmira Thornton, Board Member of Henrietta Lacks Legacy Group; Servant Courtney Speed, President of the Henrietta Lacks Legacy Group; Dr. Doug Corrigan; Reverend Alfred Chandler, Pastor of St. Matthew Baptist Church of Clover; Tom Whye; and Halifax County High School Leadership and Advocacy Class led by Ms. Melanie Saunders

Call to Order

Dr. Powell called the inaugural meeting of the Henrietta Lacks Commission, hereafter, “Commission”, to order at 2:00 p.m.

Welcome and Introductions

Dr. Powell welcomed and introduced all Commission members and honored guests and members of the public in attendance.

Mr. Leonard rose and requested the Commission to officially recognize honored guests in attendance, including: Dr. Betty Adams, Executive Director of the Southern Virginia Higher Education Center; Bryan Price, UVA Cancer Center; Delta Sigma Theta sorority members; Elmira Thornton, Board Member of Henrietta Lacks Legacy Group; Servant Courtney Speed, President of the Henrietta Lacks Legacy Group; Dr. Doug Corrigan, who helped draft the initial concept for the Henrietta Lacks Life Sciences Center; Reverend Alfred Chandler, Pastor - St. Matthew Baptist Church of Clover; Mr. Whye, husband to Commission member Jeri-Lacks Whye; Shelia Bradley, Legislative Aide to Delegate James Edmunds; and Halifax County High School Leadership Class led by Ms. Melanie Saunders.

Halifax High School Leadership Class member, Ashton Burton, rose on behalf of the class and thanked the Commission for inviting them to attend to learn about the Commission, and their mission to build the Henrietta Lacks Life Sciences Center.

Review of Agenda

Dr. Newson-Horst made a Point of Order, requesting review and approval of the agenda, with Mr. Leonard seconding. The motion was approved unanimously.

Ms. Cowan made a motion to move the Election of Officers agenda item to the top of the agenda with Dr. Newson-Horst seconding the motion. Dr. Powell opened the motion for discussion. Mr. Owens provided a sub-motion to continue the agenda as is to provide administrative background prior to election, with Dr. Simon-Owens seconding. The sub-motion was approved by counted vote, 4 to 3.

Dr. Powell then returned the Commission to Dr. Newson-Horst's motion to review and approve the agenda. No further discussion took place. Mr. Owens moved to approve the agenda as is, with Dr. Simon-Owens seconding. Hearing no discussion, the motion was approved by a counted vote, 5 to 2.

Presentation: History of the Initiative

Mr. Leonard advised the Commission to review the conceptual plan available in the members' binder under tab 3. Mr. Leonard provided the Commission a brief synopsis of the history behind the initial development that lead to House Bill 1415. He further explained that the concept is a product of the efforts of himself, Dr. Corrigan, and Ms. Johnson. Mr. Leonard stated that through the research done for the conceptual plan, he was connected with the Lacks family and the Henrietta Lacks Legacy Group by Dr. Simon-Owens and eventually met in Turner Station, Maryland – Mrs. Lacks' home at the time of her death. Mr. Leonard acknowledged that the legislation, House Bill 1415 and Senate Bill 171 were introduced at the General Assembly by Del. James Edmunds and Sen. William Stanley respectively, and were passed unanimously. Finally, Mr. Leonard reminded the Commission that the concept plan is an idea and not the final expected outcome. Dr. Simon-Owens thanked Mr. Leonard and chose not to expand on any points of the presentation.

Presentation from Lacks Family

The grand-daughter of Henrietta Lacks and Commission member, Jeri Lacks-Whye, addressed the Commission to state that all decisions she made will be on behalf of the family's wishes and not as an individual. Ms. Lacks-Whye then read a portion of an original poem that she authored about Henrietta Lacks' impact. Mr. Leonard made a motion to have the entire body of the poem be read in to the minutes, seconded by Dr. Newson-Horst, the motion was passed unanimously by a counted vote. This begins the original poem written and presented by Jeri Lacks-Whye:

Who Am I?

As you gain knowledge, all will become clear.
You ask Who Am I, be a daughter, wife, mother or friend.
I am just an ordinary woman, a wife to my husband, mother to my children and a friend to the world.
I became ill and departed this earth at an early age.
Through my death, I became a medical treasure.
I am the one who became immortal.
Yes, the First Imortal Human Cell.
Say the word...everlasting.
Read about me!

I am the one who helped Dr. Jonas Salk. Yes, him and I saved millions of lives by creating the polio vaccine, the disease that had killed and sickened millions of children in the 1950's. Say the word..immunization.
Read about me!

I am the one who was at the right place at the right time when a scientist accidentally poured a chemical on me. Yes, to their surprise humans have 46 chromosomes in the human body not 48. Say the words...genetic diagnosis.
Read about me!

I am growing indefinitely, frozen for decades, shared amog scientist and remain the most widely used cell line in biomedical researc. Say the words...divide and conquer.
Read about me!

I am the one who is in you and you in me.

Did you get vaccinated for polio, did you get in vitro fertilization, received radiation treatments or medication for cancer, took medicine for HIV, received the vaccine for HPV? Yes, I am responsible for helping thee...

I was snipped and placed in a petri dish, which I really did not know...

I am constantly helping mankind from the very first day I departed this earth, which I really did not know...

I became intriguing to the medial world, which I really did not know...

Even though the world LACKS the full understanding of Who I Am, time gives us opportunities to gain or lose, all that I have done and everywhere I have been, the world will gain knowledge through the telling of my story!

I am Henrietta Lacks responsible for the master piece "HeLa" cell.

Read about me!

Written by Jeri Lacks-Whye
(granddaughter of Henrietta Lacks)

Public Comment

There were no comments from any member of the public.

Board Orientation

Dr. Powell addressed the charge, scope, and structure of the Commission and advised that the charge of the Commission is to develop and create the Henrietta Lacks Life Sciences Center in Halifax, Virginia. Dr. Powell then advised the Commission that there are varying compensation expectations depending on membership type as laid out in the legislation and that HB1415 sunsets on June 30, 2021. Dr. Powell advised that the Virginia Department of Health is tasked as the administrative support to the Henrietta Lacks Commission and that this duty has been assigned by the Virginia Department of Health to the Office of Health Equity. The administrative support is at the disposal of the Commission and at its discretion. Dr. Powell overviewed Robert's Rules of Order, meeting structure, and officer elections. Dr. Powell informed the Commission that the duties of officers are to provide leadership, plan the annual cycle of meetings, monitor the implementation of decisions, and act as a spokesperson where appropriate.

Dr. Powell advised that there is required training for the Virginia Freedom of Information Act (FOIA) and that the entire FOIA statute has been provided, along with other supplementary materials. She then reminded the Commission members that they should refrain from using "reply all" when responding to emails and that any public business conducted over email becomes a public record and is subject to FOIA. Meetings per FOIA are a gathering of 3 or more members of the Commission and closed meetings are only allowed pursuant to certain permissible sections of FOIA and require a motion reading the purpose and subject as well as a citation of relevant FOIA code for a closed meeting.

Dr. Powell advised there is required training for the Conflict of Interest Act (COIA) and the link to the training is listed on page 2 of section 5 in the Commission binders. She then advised the Commission that the entirety of COIA is available on page 16 of section 5.

Mr. Leonard advised that non-legislative members of the Commission should work with Ms. Johnson of the Halifax IDA for proper compensation of Commission-based expenses.

The Commission took a five-minute break.

Election of Officers

After a brief break, Dr. Powell moved the Commission to the next order of business and proceeded with the election of officers. Dr. Powell called for any nomination for the position of Chair. Dr. Newson-Horst nominated Ms. Cowan, seconded by Mr. Owens with no discussion. Mr. Owens moved to close the nominations, and was seconded by Dr. Newson-Horst. Dr. Powell called for a vote on Ms. Cowan for the position of Chair. Ms. Cowan was elected Chair by a

counted vote with unanimous support. Dr. Powell then relinquished the floor to the Chair, Ms. Cowan.

Ms. Cowan led the Commission to nominate a Vice Chair. Ms. Lacks-Whye nominated Dr. Simon-Owens, seconded by Dr. Newson-Horst. Mr. Leonard moved to close the nomination for Vice Chair and was approved by voice vote. Dr. Simon-Owens was elected Vice Chair by a counted vote with unanimous support.

Discussion: Day 2 Agenda

Ms. Cowan directed the Commission to consider points of business for Day 2's agenda. Noting the time, Ms. Cowan advised that some points of business could be addressed immediately.

Dr. Simon-Owens asked the Commission to thank and consider allowing the Danville Alumnae Chapter of Delta Sigma Theta Sorority, Inc., to provide volunteer support for the Commission. A reference document was noted in section 3 of the Commission binder. The sorority chapter would like to support the Henrietta Lacks Commission as part of its public service initiative. Danville Alumnae Chapter would act as official volunteers for Commission events and be directed by Commission members. Dr. Simon-Owens provided background for the reasoning of Danville Alumnae Chapter of Delta Sigma Theta Sorority Inc.'s interest and acknowledged those members in attendance. Dr. Simon-Owens acknowledged that she is a member of that chapter. Ms. Cowan thanked the sorority members for their assistance. Mr. Leonard moved that the Commission vote to accept the assistance of Danville Alumnae Chapter of Delta Sigma Theta Sorority Inc., as a volunteer service and the members acts be directed through the Chair and Vice Chair, this motion was seconded by Dr. Newson-Horst. The motion carried with a voice vote, Dr. Simon-Owens abstained from voting due to conflict of interest.

Ms. Cowan called on Mr. Leonard to advise any points he deemed to be imperative for the Commission to discuss. Mr. Leonard stated the need for a technical advisory committee or panel to provide guidance to the Commission in the fields of biotechnology, medical, history, and other fields as identified. Ms. Cowan agreed that this need is valid and this item will be discussed during the second day session. Dr. Simon-Owens stated that the Commission needs to avoid bias and consider expertise over individual people. Mr. Leonard suggested that the Commission should first define the knowledge and skill set required before identifying individuals. Mr. Leonard then asked if its permissible to discuss names of potential panel members in closed session and requested Dr. Powell and the administrative team to provide a ruling and process for this. Dr. Simon-Owens stated that this Commission has a broad reach and potential panel members should be sought out globally.

Ms. Cowan addressed the next suggested item, By-Laws. Mr. Leonard stated that the Department of Health has a template for by-laws that might be of use to the Commission. Mr. Owens stated the preference for the use of state templates and requested the Commission administrator obtain those for the second session.

Ms. Cowan confirmed that meeting minutes were being transcribed for posterity.

Ms. Cowan reminded the Commission of the June 30, 2021 sunset date and requested input regarding the frequency of regular Commission meetings. She requested this item be placed on the second session agenda.

Dr. Newson-Horst asked Mr. Leonard if, in his collaboration with Ms. Johnson for the concept plan, he developed a work flow or task timeline for the development of the Henrietta Lacks Life Sciences Center. Mr. Leonard advised that they have a loose idea but nothing committed to paper. Ms. Cowan advised that a work flow should be added for the second session agenda.

Dr. Simon-Owens suggested there be a development of a committee structure and that it be incorporated at a future date into the by-laws.

Ms. Cowan asked the Commission regarding any future events. Dr. Newson-Horst advised that the 3rd Annual Henrietta Lacks Legacy Group Luncheon will take place on the first Friday in October in Turner Station, Maryland. She stated the primary objective of this luncheon is to raise funds for both the wax figure of Henrietta Lacks for the National Great Blacks in Wax Museum in Baltimore, Maryland as well as fundraising for the Henrietta Lacks Endowed Scholarship at the Community College of Baltimore in the attempts to grow the pool from \$30,000 to \$100,000. Additionally, the Henrietta Lacks Essay and Video Competition will close on December 31st for middle and high school students. Ms. Lacks-Whye stated the 9th Annual Henrietta Lacks Lecture will be held the first Saturday in October. She further stated that Morehouse School of Medicine's 23rd Annual HeLa Women's Health Symposium will take place Friday, September 28th. Ms. Lacks-Whye noted that Servant Speed and the Henrietta Lacks Legacy Group have an event the first Saturday in August annually to celebrate the life of Henrietta Lacks. Dr. Newson-Horst advised that it is important to plan for Mrs. Lacks' 100th anniversary in 2020.

Ms. Lacks-Whye and Dr. Newson-Horst provided background about Dr. Roland Pattillo, his training, and his co-authorship of the first scientific paper discussing Henrietta Lacks' cells. They continued on to state Dr. Pattillo paid for the tombstones of Henrietta Lacks and her daughter Elsie. He additionally led the team at Morehouse School of Medicine to discover the HPV vaccine. Dr. Pattillo has been a great contributor and champion of Henrietta Lacks and her legacy.

Mr. Leonard requested the Commission members express their gratitude for Dr. Powell and her staff for their efforts, including the events already completed as part of this Henrietta Lacks Legacy Week celebration. He added that Dr. Powell's passion for the project has been evident in the number and quality of events planned for the Richmond area. Dr. Newson-Horst requested a record into the minutes to state that the Henrietta Lacks Legacy Week panel discussion was an amazing and diverse group of voices that provided riveting discussion.

Ms. Cowan requested information regarding the preview of the website. Mr. Leonard reported that Ms. Johnson had worked with a web designer to prepare a template for preview for the second session of this meeting. He added that Mrs. Lacks-Whye, and David Lacks, Jr. have been involved with reviewing content thus far. Mr. Leonard stated that further discussion is required regarding the management, maintenance, oversight, policy, costs, and requirements of hosting the website.

Dr. Newson-Horst expressed her gratitude for Ms. Johnsons' planning of the Commission meeting events.

Dr. Simon-Owens requested confirmation that items pertaining to the website will be added to the second session agenda. Ms. Cowan confirmed the addition. Dr. Simon-Owens requested that Dr. Powell provide the regulatory needs that impact the development and management of the Commission website. Mr. Leonard seconded the request.

Ms. Cowan stated that the second session will also require an overview of the Commission's mission, values, and goals. Dr. Simon-Owens reiterated the request for Mr. Leonard to provide conceptual work timelines and tasks. Mr. Leonard stated that there will not be enough time between sessions to compile this information but can have it ready by the next meeting.

Ms. Cowan requested Dr. Powell or the Commission to provide any other items for discussion on the second session day. Dr. Simon-Owens suggested that the meeting schedule be addressed. Mr. Owens suggested the consideration of the fundraising process and how best to include the conceptual plan. Mr. Leonard advised that the legal and governance structures of the Commission and what is permissible for fundraising will need legal oversight and perhaps a committee should be developed to oversee that information gathering.

Dr. Simon-Owens requested the name of the Attorney General's Office contact assigned to the Henrietta Lacks Commission. Dr. Powell provided the contact at the AGO as Assistant Attorney General Amanda Lavin. Ms. Cowan asked if the AAG would be available to attend meetings. Dr. Powell stated that the designee will not come to every meeting, but at special request the AAG can be scheduled to attend Commission meetings. She stated further that AAG Amanda Lavin available by teleconference.

Ms. Cowan referred the Commission to the Halifax IDA conceptual plan that contains a mission and vision and requested the members review the content prior to the second session. Ms. Cowan thanked Mr. Leonard for his expertise and hard work on the project and stressed the importance and impact the Henrietta Lacks Life Sciences Center will have on Halifax County. Mr. Leonard stated there are no further items at this time for consideration at the second session of this meeting.

Dr. Powell requested that all Commission members sign the proclamations available as well as reminded the Commission of the closing reception on Friday.

Mr. Owens reminded the Commission that the plan developed must be both obtainable and sustainable. Mr. Leonard stated that the current concept plan may not be the final plan, and perhaps should not be the final plan. The final plan will be up to this Commission and its advisors. He agreed with Mr. Owens that the Life Sciences Center must be an ongoing enterprise, and the concept does show one possible path for sustainability simply to show it is possible, until the best final plan is crafted by the Commission.

Dr. Simon-Owens requested a review of second session items. Ms. Cowan requested a review of agenda items marked for the second session by Ms. Walker.

Ms. Cowan reminded the Commission of non-meeting Commission events scheduled for September 27th. The second session of the Commission meeting will begin September 27 at 1:00 p.m., at the Southern Virginia Higher Education Center.

Dr. Powell advised the Commission that second session items are as follows: creation of advisory panel, closed meeting process, by-laws with a template to be provided, committee structure, website preview, website management procedures, and compliance issues. Ms. Cowan asked if there any other additional items. Dr. Newson-Horst reminded the Commission to review the conceptual plan provided.

Public Comment

Servant Courtney Speed thanked the Commission for its work.

Adjourn

The meeting adjourned at approximately 3:10 p.m.

Meeting minutes recorded by Kira Walker

Henrietta Lacks Commission
Minutes
September 27, 2018 – 1 p.m.
Southern Virginia Higher Education Center
820 Bruce Street, South Boston, VA 24592

Members present: Del. James Edmunds, Dr. Adele Newson-Horst, Mattie Cowan, Hon. Ed Owens, Jason Studley, Dr. Nettie Simon-Owens, Matt Leonard

Members absent: Jeri Lacks-Whye, Sen. William Stanley

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

Others present: Kristy Johnson, Deputy Director of Halifax IDA; Danville Alumnae Chapter of Delta Sigma Theta Sorority, Inc., members; Servant Courtney Speed, President of the Henrietta Lacks Legacy Group

Call to Order

The Chair, Ms. Cowan, called the meeting to order at 1:00 p.m. The Chair requested staff to call the roll and determine quorum. A quorum was present.

Review of Agenda

Ms. Cowan requested the Commission act to Review and Approve the agenda as presented.

Dr. Newson-Horst asked that allowable Commission expenses be reviewed. Ms. Cowan requested the addition of this item behind work flow and time table. Ms. Walker is requested to resend notes to the Chair. Ms. Cowan requested that access to the gravesite be added to the end of the agenda. Additionally, the Chair requested sustainability be added to the agenda. Dr. Newson-Horst stated that sustainability be part of the mission, vision, and goals agenda item conversation. Ms. Cowan called for a motion to approve the agenda as amended. Dr. Newson-Horst moved to approve the amended agenda, seconded by Mr. Leonard, carried by a voice vote.

Mission, Vision, and Goals

Ms. Cowan requested Mr. Leonard lead this conversation and directed the Commission's attention to page 5 of the conceptual plan developed by Halifax IDA as a reference document for the Commission's mission and vision. Dr. Newson-Horst noted that this mission and vision is for the Life Sciences Center and does not reflect the scope of the Commission. Mr. Leonard agreed that adopting the mission and vision from the conceptual plan may limit the intent as needed for the Commission. Dr. Simon-Owens drew the attention of the Commission to HB1415 and the mission outlined in the foundational document. The Chair pointed out that the legislation closely mirrored the conceptual plan; Mr. Leonard supported this statement saying that the conceptual plan was reviewed during the drafting of legislation. Mr. Leonard suggested that modifications to

the mission are acceptable as long as there is no loss to the core mission set forth before the Commission. Dr. Newson-Horst stated that the mission needs to be more substantive. The Chair stated that the goals developed out of the mission will be measurable and help hone the scope further. Ms. Cowan suggested that the Commission utilize the mission as defined in the legislative document HB 1415 with no changes as proposed by Dr. Simon-Owens. The motion was made by Dr. Newson-Horst, seconded by Del. Edmunds, the motion was carried by a voice vote. The Chair stated with this motion carried, the mission may be modified at any meeting should the need arise.

House Bill 1415 § 2.2-2537.

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.

The Chair requested the Commission address the next item: vision. Mr. Leonard suggested that the Commission redirect to address the goals in order to write the vision with greater clarity and realism. The Chair accepted this suggestion and redirected the Commission to begin a brainstorming process of identifying goals.

Dr. Newson-Horst suggested a primary goal for the Commission should be identifying stakeholders. Additionally, the development of financial partnerships. The Chair stated that a committee will be developed to aide in the identification of these stakeholders and potential partners.

Mr. Owens stated that before identifying funding and building parameters, the Commission must first identify the needs of the population that will utilize the Henrietta Lacks Life Sciences Center (also referred to as the the Life Sciences Center). He further stated that the Commission must also consider proper infrastructure in place for the building of the Life Sciences Center for proper sustainment. Mr. Leonard suggested these critical components are goal and committee headers. Mr. Leonard suggested funding, facilities, and operations goals.

Mr. Owens directed the Commission to consider the development of a compelling narrative for Commission members to be able to speak to why the Commission is acting now and building in Halifax. Dr. Simon-Owens suggested supporting data to understand where the market is now, and what the opportunities for the Life Sciences Center will be. Mr. Owens suggested the development of a two minute elevator speech for the Commission members. Dr. Simon-Owens agreed that a succinct statement is required and will be included in the later developed narrative. Ms. Cowan agreed to the need for networking engagement.

Ms. Cowan directed the Commission to view the SWOT analysis in the conceptual plan to provide language to utilize in the elevator speech. Dr. Simon-Owens requested the assistance of the Virginia Department of Health's Communications Department in order to hone brainstormed language for a final elevator speech. Mr. Leonard asked Delegate Edmunds to comment on Virginia's General Assembly's core reasons for empowering this Commission and its goals to establish the Henrietta Lacks Life Science Center in Halifax County. Delegate Edmunds discussed the high rates of certain types of cancer, the relative lack of necessary treatment, and

the need to research and develop possible cures and medications where it is most needed in Henrietta Lacks' memory.

Mr. Studley commented that there is a high rate of cancer in the area as well as that Halifax is Henrietta Lacks' home and therefore is an appropriate place to build a center in her name. Dr. Powell suggested that the Office of Health Equity can provide compelling statistics to support the elevator speech. Mr. Leonard stated there is an urgent need to draft and develop this speech as well as a narrative. The Chair appointed Mr. Leonard and Dr. Newson-Horst to the Communications Committee in charge of seeing the development of the elevator speech and narrative through to completion. Mr. Owens requested a timeline for this action. The Chair requested Dr. Powell's input for turn around expectations. Dr. Powell acknowledged the need for an expedited return given the community engagement event in one weeks time and stated this may be realistic. Dr. Newson-Horst requested three key points to include in the documents to be drafted. Mr. Studley stated there is 1. A high rate of cancer, 2. Halifax is Henrietta Lacks' homeplace, and 3. It provided the opportunity to transform southern Virginia economically, socially, and in healthcare. Mr. Studley stated that for Cancer mortality, Virginia is ranked 38th in the nation, and the combined counties of Charlotte, Mecklenburg, and Halifax are in the bottom 10% of the state based on Sentara's annual report. Dr. Powell suggested that an elevator speech be drafted for both layman audience and one for high-tech and medical professions. This idea was supported by the Commission as a whole. Mr. Leonard suggested a draft be worked and developed to fruition by the Office of Health Equity, VDH Communications, and the previously appointed Communications Committee of the Henrietta Lacks Commission. The Chair requested completion of the elevator speech by Thursday for the Henrietta Lacks Legacy Group Luncheon. Mr. Leonard suggested a draft by Tuesday for a final document by Thursday. The Commission agreed to this time expectation. As an addendum, Mr. Owens suggested the addition of seeking financial support to the elevator speech.

The Chair addressed the financial constraints of the Commission and how funds can be raised. Mr. Leonard stated that the Commission must research what is the best legal structure of the Commission should be. The question posed is should the Commission take funds directly or should an independent foundation be developed as a non-profit or other organizational structure. Ms. Cowan stated that since the Commission has a sunset and a foundation continues on indefinitely, the need for a foundation is evident. Mr. Leonard suggested that further consideration is required to research how best to form and format a foundation, or whatever legal structure is best to support the work of the Commission and eventual the Henrietta Lacks Life Sciences Center. Mr. Leonard added that there are members of the current Commission with knowledge regarding such matters, indicating Mr. Studley and Mr. Owens. The Chair developed a Legal/Funding Committee and appointed Mr. Studley and Mr. Owens to lead the research initiative set forth in this discussion.

Mr. Leonard advised the Commission that there are no funds currently available for professional advice or guidance. All assistance from outside sources must be received on a charitable or in-kind basis.

Ms. Cowan directed the Commission to begin the brainstorming for proficiencies that might be required for a technical advisory panel. Dr. Simon-Owens reiterated her concern from the first

session to avoid naming persons, but instead focus on skills and areas of expertise in order to avoid bias.

The brainstorming is as follows:

- Expertise:
 - Biotech
 - Genome sequencing
 - Precision medicine
 - Fundraising
 - IT
 - Health Policy
 - Oncology
 - Geo-medicine
 - Data mining
 - Business of medicine
 - Epidemiology
 - Health equity
 - Legal
 - Legal healthcare
 - Community Engagement
 - Philanthropists
 - Patent Law/Intellectual Property
 - Facilities
- Populations
 - Nationally/internationally recognized content experts
 - Up and coming professionals

Mr. Owens suggested that the Department of Health develop a list of potential candidates that are within the Commonwealth government structure and other organizations with pre-existing relationships with the Commonwealth government. Mr. Leonard suggested the development of the Advisory Panel Committee to identify and receive personnel information for the Commission. Ms. Cowan identified Dr. Simon-Owens and herself for this Committee.

Meeting Minutes

Dr. Newson-Horst questioned the availability of meeting minutes from the previous day's meeting. The Chair advised that meeting minutes are to be posted publically as expected by the Commonwealth. The Commission discussed the differences between recess and adjournment and how that impacts the delivery of minutes. Dr. Newson-Horst clarified that she requested working documents for multi-day sessions in order to keep track of items discussed. Dr. Simon-Owens made a motion to waive the expectation that there be meeting minutes available for consecutive sessions. Mr. Leonard provided a substitute motion that the minutes be prepared and delivered within the standard time frame as expected by the Commonwealth, this was seconded by Dr. Newson-Horst. Dr. Powell advised the Commission as to the expectations for draft meeting minutes, Commission approval, and final meeting minutes. The substitute motion is carried by a voice vote.

By-Laws and Attorney General's Office Oversight

Dr. Powell provided two different examples of by-laws, one from the State Board of Health and one from the Virginia Board of Workforce Development. The Commission, preferring the brevity of the Board of Health requested to use this document as a working template.

Dr. Powell advised the Commission that all groups that meet as part of the Virginia Department of Health are under the Board of Health, and therefore would make sense to utilize the Board of Health's by-laws as a template.

Mr. Leonard moved that the Office of Health Equity utilize the Board of Health's by-laws as a template and to make modifications to suit the requested of the Commission for review via email prior to the next meeting; seconded by Mr. Owens, carried by a voice vote.

Meeting Schedule

The Chair addressed the need to determine the schedule for meetings. The Chair recognized Mr. Leonard's suggestions to hold meetings quarterly, but suggested that during the initial period to meet on a more frequent basis. Dr. Newson-Horst suggested biweekly meetings; this was deemed as logistically illogical by general consensus.

The Chair broached the topic of utilizing remote meeting options such as conference call and video conference. Clarification was provided by Ms. Walker as to FOIA's guidelines for e-meetings.

Dr. Newson-Horst clarified her suggestion for biweekly meetings that it only be for the early stages of the Commission. The Chair acknowledged this, and stated that committees may choose to meet on a more frequent basis, but the Commission cannot expect committees to have reportable intel for assigned tasks within a compressed timeframe.

Mr. Leonard expressed that the Commission should determine the minimum amount of meetings per year for the express purpose of the by-laws, with additional meetings added as needed. Dr. Simon-Owens suggested meetings of three times per year face to face, with additional meetings to be determined. The Chair suggested quarterly meetings. Mr. Owens reminded the Commission that by-laws are living documents and can be amended should the Commission determine the fixed meeting schedule to be too rigorous or too lax.

Mr. Leonard suggested that the Board of Health by-laws template for meeting schedule should be utilized as it stated quarterly meetings, with one physical meeting with all members present. He further suggested to modify the location from Richmond to Halifax County.

The Chair suggested quarterly meetings in December, March, June, and September or the last month of each quarter.

Dr. Powell advised the Commission of Commonwealth reporting expectations and how this might impact the Commission and help aid determination of meeting schedules.

Mr. Owens called the motion that the meeting schedule be listed as meeting each quarter, in the last month of each quarter (December, March, June, and September) with each third quarter meeting being the physical annual meeting, the motion was seconded by Del. Edmunds. The motion was opened for discussion. Dr. Newson-Horst advised the board that the 100 year anniversary of Henrietta Lacks will be in 2020, and perhaps a meeting scheduled close to that time in commemoration would be appropriate. The motion was carried by a voice vote.

At this time, the Chair and Commission thanked and relieved members of Danville Alumnae Chapter of Delta Sigma Theta Sorority in attendance for their volunteer duties for the day.

Expense Compensation

The Chair drew the attention of the Commission to the topic of Commission related expense compensation.

Mr. Leonard advised that there are two categories of commissioners that qualify for expense reimbursement. Legislative members will be reimbursed through the Clerks of their various legislative houses. Nonlegislative members of the commission will be reimbursed through the Halifax IDA, through Ms. Johnson. An excerpt of the legislation is included below:

House Bill 1415 § 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.

Dr. Newson-Horst requested clarification that only commission members are eligible for expense compensation. Mr. Leonard stated that the inaugural meeting is the only exception for this rule, as previously agreed to by the Halifax IDA.

Website Preview and Procedures

Mr. Leonard and Ms. Johnson discussed the website template and previewed the general layout of the proposed website. The Chair requested information about current website management, Mr. Leonard advised that there is no manager currently, but that the Commission must consider who is going to manage the website and how the cost of management will be undertaken by the Commission or foundation, should one be formed.

Ms. Johnson walked the Commission through the template website and Mr. Leonard advised they have worked with Ms. Lacks-Whye. Dr. Newson-Horst advised that the link to the Henrietta Lacks Legacy Group is incorrect and routing is to an unofficial website.

Mr. Leonard requested input on if this template is of the caliber needed for the Commission. Dr. Newson-Horst suggested that there be placement made for the uploading of Commission meeting minutes, by-laws, and other administrative documentation. Mr. Leonard stated that those items can be added as they are developed. Dr. Powell advised that the website must meet the Americans with Disabilities Act and therefore must utilize specific fonts along with other guidelines as directed by the Virginia Information Technologies Agency (VITA). Furthermore, Dr. Powell advised that from a governing standpoint it would be best for the management of the website to be conducted by a third party not associated with the Virginia Department of Health due to oversight and regulatory compliance. She stated that website include a search bar that links back to VDH, however content management is up to the Commission should they utilize a third party manager. Dr. Powell stated that in addition to this website, administrative documentation is required to be posted through Commonwealth websites and is not a compulsory requirement. Dr. Newson-Horst asked for clarification on the goals of the website; the Chair responded that the website would be of advantage for the purposes of fundraising and information gathering for potential partners. The Chair asked Dr. Simon-Owens if the Southern Virginia Higher Education Center would be able to manage. Dr. Simon-Owens stated that without funding or staffing, this would not be feasible. Mr. Leonard stated that without funding from the government or other sources the cost associated with the management of the website becomes a burden on the Commission to determine. Mr. Owens asked what the cost of management would plausibly run. The Chair suggested the Commission seek out pro-bono web management services. Mr. Leonard stated that the Halifax IDA has purchased five domain names for the Commission to choose from for the website name. Dr. Powell stated that meeting schedules and meeting minutes will be posted publically on the Commonwealth Calendar and Townhall websites. Additionally, board profiles will also be posted publically through the Commonwealth. Dr. Newson-Horst stated that there is merit to the expense of a website. The Chair requested Dr. Newson-Horst email a list of items for inclusion to the Chair, at which point she will work with Ms. Johnson of the Halifax IDA to handle initial management. Mr. Studley stated that the Commission may want to utilize student interns at some level for web management. Mr. Leonard stated that this would provide a valuable learning experience as well as practical experience for upcoming graduates. Dr. Simon-Owens requested that the website not be launched until Commission approval at the next meeting. Dr. Newson-Horst stated that the Commission should consider the management and oversight required to work with students. Dr. Newson-Horst stated that in lieu of the Chair, Commission members should send website additions to the Communications Committee.

Access to Gravesite

The Chair stated that the Commission and interested parties have been visiting the gravesite on a more frequent basis. As such, the Chair suggested that a relationship with the current property owner be cemented. Mr. Leonard stated that in addition to building a relationship with the property owner, the Commission should strive to strengthen relationships with the Lackstown community and the St. Matthew Baptist Church of Clover, Henrietta Lacks' home and

churchhome respectively. He stated that the Halifax IDA has already started engaging the Lackstown community through Rev. Chandler. Mr. Leonard stated that the real work of the Commission is the preservation and promotion of Henrietta Lacks' legacy through her homeplace. Dr. Newson-Horst that Henrietta Lacks' legacy could be a vital economic engine for tourism. The Chair asked if the Tourism Board should address this potential as the Commission may be otherwise engaged planning the Life Sciences Center. Mr. Leonard stated that the foundation, when developed, may be able to manage the tourism centered around Henrietta Lacks. Mr. Leonard stated that further work and information will need to be gathered concerning this topic and requested it be readdressed in the next meeting. The Chair agreed. Mr. Studley suggested that the Commission include a caveat in patents developed at the Life Sciences Center are required to contribute 0.001% of all patent profit to the preservation of the Henrietta Lacks homeplace to be paid to the foundation, or something to this effect. The Commission believes this is an idea worth considering.

Legal Guidance

Dr. Simon-Owens asked Dr. Powell for guidance regarding the development of a foundation. Dr. Powell advised that the Commission should contact the Attorney General's Office representative, Amanda Lavin. Dr. Powell further advised that should the Commission choose to reach out, the Commission may enter a closed session under FOIA as they would be seeking legal guidance, understanding that the Commission would cite appropriately prior to entering a closed session. The Chair stated that alternatively, she could have a one-on-one conversation prior to the next meeting with Ms. Lavin. Mr. Leonard stated that the Legal and Funding Committee, as headed by Mr. Studley and Mr. Owens, would be the group to have initial contact with the Attorney General regarding this matter.

Duties of VDH

Dr. Simon-Owens asked for reiteration of the duties of the Virginia Department of Health. Dr. Powell advised that per the legislation, the Virginia Department of Health is to provide administrative support to the Henrietta Lacks Commission. She further stated that this task has been assigned to the Office of Health Equity, which she oversees. The Office of Health Equity will develop and provide agendas, meeting minutes, commission binders, and reports as required by the Commonwealth. Additionally, the Office of Health Equity can aide in the coordination of special guests attendance or speaking at meetings. Dr. Lauren Powell also offers the Commission the full utilization of the Office of Health Equity at the Commission's discretion. Dr. Simon-Owens asked if Dr. Powell, as the Director of the Office of Health Equity, is responsible for communication with the Chair and Vice-Chair. Dr. Powell affirmed this to be accurate.

Next Meeting

The next meeting will be held November 9, 2018 from 10am to 3pm at the Sentara Halifax Regional Hospital Boardroom; 2204 Wilborn Ave, South Boston, VA 24592. The Chair advised that Dr. Newson-Horst and Ms. Lacks-Whye may remote conference in, in lieu of driving from Maryland.

The Chair requested the attendance of the Attorney General assigned to the Commission at this meeting. Dr. Powell stated that as soon as an agenda is developed, she can begin coordinating with the Attorney General's Office.

Adjourn

The meeting was adjourned at approximately 3:05 p.m.

Meeting minutes recorded by Kira Walker

Appendix B

**Henrietta Lacks Commission
DRAFT Minutes
Friday, November 9, 2018 – 11:30 a.m.
Sentara Halifax Regional Hospital
2204 Wilborn Avenue, South Boston, VA 24592**

Members present: Mattie Cowan, Dr. Nettie Simon-Owens, Jeri Lacks-Whye, Dr. Adele Newson-Horst, Jason Studley, Del. James Edmunds, Matt Leonard

Members absent: Hon. Ed Owens, Sen. William Stanley

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

Others present: Kristy Johnson, Deputy Director of Halifax IDA; Servant Courtney Speed, President of the Henrietta Lacks Legacy Group; Reverend Alfred Chandler, Pastor of St. Matthew Baptist Church of Clover; Shirley Lacks

Call to Order

Ms. Cowan, hereafter, “the Chair” called meeting of the Henrietta Lacks Commission, hereafter, “Commission”, to order at 11:30 a.m.

Determination of Quorum

Ms. Johnson called the role and determined a quorum with seven of the nine Commissioners present.

Introduction of Guests

The Chair thanked Ms. Johnson for transporting Commissioners and guests traveling from Baltimore. The Chair welcomed Reverend Chandler, Servant Speed, and Shirley Lacks for their interest and attendance.

Approval of Draft Minutes

The Chair confirmed that all Commissioners received the draft minutes of the inaugural meeting and had a chance to review them. Dr. Newson-Horst stated that while she had made suggested

edits to the Office of Health Equity, those edits were not reflected in the copy provided. She further stated that per her contact with the Office of Health Equity, edits would not be incorporated until November 13, following the feedback from the Commission. The Chair stated that the minutes could not be approved with outstanding edits required.

The Chair stated that the corrections should be sent back to the administrative support staff for editing of the minutes.

Approval of Agenda

The Chair asked if there were any agenda items that require change or addition. With no suggestions, the Chair suggested a motion be made to approve the agenda as is. The motion was made to approve the agenda as-is by Dr. Newson-Horst, seconded by Mr. Leonard. The Chair opened the motion for discussion, hearing no discussion the Chair opened the motion for a vote where it passed unanimously by a voice vote.

Committee Reports

Communications Committee: Commissioners Leonard & Newson-Horst

The Chair directed the Communications Committee to report to the Commission of their efforts. Dr. Newson-Horst stated that by agenda, order the by-laws should be discussed next. The Chair advised that due to the administrative team's tardiness, the Commission would need to push the agenda item until after their arrival. Dr. Newson-Horst requested that moving forward, all supplemental documents be provided to the Commission in advance of the meeting. The Chair advised that the suggestion will be tabled until the arrival of the administrative team and requested the Communications Committee's report on the elevator speech. Mr. Leonard advised that the Office of Health Equity drafted language for an elevator speech targeted at both a lay

audience as well as a technically skilled audience. Mr. Leonard continued to state that he and Dr. Newson-Horst used the drafted speech to build out the lay audience elevator speech. Mr. Leonard stated that he is unsure of the need for two different speeches, and then presented the document to the Commission that showed the changes made by the Communications Committee. Dr. Newson-Horst stated that changes to the elevator speech included grammatical corrections as well as modification to the language surrounding the use of the word “Virginians” as many within the Commonwealth are not or do not identify as Virginian. The following is the reading of the proposed elevator speech:

The Polio vaccine, in vitro fertilization, HIV protocols, cancer treatments—regardless of who we are or where we live, we all know someone whose life has been affected by diseases whose cures or treatments have been developed because Henrietta Lacks and her HeLa cells.

Many of us know the difficult realities of cancer only too well.

But a group of us in Virginia have been charged by the Governor and unanimous action of the legislature to transform the health, community and economy of Southern Virginia – and we’re doing it in the name of Henrietta Lacks, a Southern Virginia native and hero to the world.

I’m one of 9 members of the newly formed Commonwealth of Virginia Henrietta Lacks Commission. The Commission will create a place for cancer treatment and research in Halifax County Virginia— a place where dying from cancer is [insert statistic] more likely.

We're working to build the Henrietta Lacks Life Sciences Center (LSC), a state of the art facility that will be a cancer research and treatment center located at the home and burial site of Henrietta Lacks in Halifax County.

We know the job ahead of us as a Commission is big, and we'll need lots of help to make it happen.

I would love to speak with you further about involving you and your organization in our plans to honor Henrietta Lacks in this historic way, and to bring life-saving cancer research & treatment to her hometown.

After much discussion of the Elevator Speech, it was decided that the Communications Committee would go back and revise according to the items discussed.

The Chair announced that Del. Edmunds must leave no later than 12:15pm and so any business that requires his input should be addressed immediately. Del. Edmunds stated that he is not member of any current committees. After learning of this, the Chair suggested that Del. Edmunds assist the Vice Chair in identifying appropriate individuals for an advisory council. Del. Edmunds agreed to this posting, and will henceforth be added to the roster for the advisory council committee.

The Chair moved the Communications Committee report on to the website update. Mr. Leonard stated that the Communications Committee was waiting on what items should be included, and asked for the Chair's determination. Dr. Newson-Horst stated that at the previous meeting it was determined that the Commissioners would send in their suggestions of what they would like to see added to the website. Dr. Newson-Horst expressed that she sent her recommendations out the administrative team with the Office of Health Equity and that she would like further guidance on

who she can copy for communication. The Chair stated that upon the arrival of the administrative team, she would address this as well as formal training for FOIA. Dr. Newson-Horst stated that she took this training online and did not receive an expedient response from the administrative team despite numerous inquiries. Dr. Newson-Horst stated that the current means of communication is ineffective and unsatisfactory. The Chair stated that upon the arrival of the administrative team, she will inquire about this, but will be tabled for the time being.

Legal and Funding Committee: Commissioners Owens & Studley

Noting Commissioner Owens absence, the Chair requested the report from the Legal and Funding Committee. Mr. Studley stated that his first action was to identify the population, source of funding, and the stakeholders. Mr. Studley stated that he borrowed heavily from his resources with Sentara Halifax Regional Hospital. Mr. Studley stated that he has a nearly completed needs analysis, as well as a community health needs assessment and information from Truvent Analytics. Truvent Analytics was able to pull the population data for the surrounding areas, which limited the scope but maintain the restrictions of the hospital's service area borders. Mr. Studley stated that this methodology was utilized in order to obtain the data free of charge. He stated that he has condensed thousands of pages of information to usable maps that will be provided to the Commissioners once the final information is available to help in the needs analysis. Mr. Studley stated that once the data is obtained, the Committee can move on to identifying the stakeholders and funding sources.

Mr. Studley stated the second task requested of the Legal and Funding Committee was to investigate the process for developing a non-profit foundation. Mr. Studley stated that he is waiting for Mr. Owens direction for that task and that he is unable to obtain free legal counsel.

He suggested that Mr. Owens contacts might aid in finding a legal expert willing to provide pro-bono assistance to the Commission for this purpose.

Mr. Leonard stated that the funding aspect has a lot of pieces to consider moving forward. He stated that the operating structure of the Life Sciences Center must be determined before the constraints regarding the funding of the Life Sciences Center can be identified. Mr. Leonard stated that one way of identifying the operating structure is to identify the stakeholders and for them to identify their own operations inside the Center and the physical facility. The Center could be provided by the Commission and the stakeholders would simply lease space. Another method, as stated by Mr. Leonard, could be to stand up something along the model of the Mayo Clinic or the Cleveland Clinic that would become a life science and cancer treatment center for Virginia. The Commission would hire people who may be affiliated with or come through with funding from stakeholders, but they would be true employees of the Henrietta Lacks Life Sciences Center. He stated that the third option could be a hybrid similar to what CCAM is. This hybrid model has its pluses and minuses but allows the Life Sciences Center to be a standalone entity but maintain government funding. Mr. Leonard stated that in order to determine the best structure, the Commission must identify the potential stakeholders and their current operational structure to determine how that would best be incorporated. Mr. Leonard stated that it's also important that the Commission secure funding and the flow for funding. More precisely, the Commission should identify where the funds will be held. The Chair agreed with these points and added that should a donor offer up funds, the Commission not reject it. Mr. Leonard agreed, stating that there are entities that could fund or assist in identifying those arrangements. Specifically, Mr. Leonard mentioned the Gates Foundation and other organizations that donate for purely philanthropic reasons.

The Chair thanked Mr. Studley for his efforts completing the tasks set before the Legal and Funding Committee.

Advisory Council Committee: Commissioners Cowan, Simon-Owens, and Edmunds

The Chair requested the report of the Advisory Council Committee and the information provided the Chair and Vice Chair by Dr. Powell. The Vice Chair reminded the Commission of the brainstorming to identify areas of expertise needed that took place at the last meeting. The Vice Chair provided an internal working document to the Commissioners that detailed the potential state level sources for subject matter experts. In addition to state level sources, this document identified existing partners and community connections known to the Office of Health Equity. The Vice Chair organized this information in regards to the areas of expertise requested by the Commission. Potential names of persons meeting the expertise requirement known to the Vice Chair and Mr. Leonard were added to the table distributed, but more often than not, an entity or organization was identified rather than a person. There were gaps that require further consideration to identify appropriate sources to fill the need of expertise required. The Vice Chair requested the assistance of the Commission to continue identifying potential sources or individuals as deemed appropriate.

Dr. Newson-Horst asked for clarification that there are no funds available for compensation for advisory positions, to which the Chair confirmed. Dr. Newson-Horst then asked for confirmation that the Commission is not sourcing from the immediate region but from national and international sources as well. The Chair and Vice Chair confirmed that the names already identified are both regional, national, and international. The Vice Chair stated that the list provided is a starting point and should be used to help identify individuals to engage. The Vice

Chair suggested the engagement of Johns Hopkins, but is unsure of what role they should play as an organization.

Mr. Leonard agreed with this sentiment, and added that the number of persons on the Advisory Council may change over time. Mr. Leonard suggested that the next step is to analyze the working document and determine what skill sets are needed for the Advisory Council in a chronological order as the project progresses. The Chair suggested that the Commission identify one to two names for each category so that in the event one person is not interested in serving, there is a backup option. The Vice Chair agreed with Mr. Leonard's assessment and suggested that the first phase of the Advisory Council may help identify the next phase members. Mr. Leonard stated that while the Commission doesn't currently have the funding available for healthcare planning and design, that may change in the future, and then the Commission may require the advice of an expert in life science and cancer treatment healthcare planning and design.

Dr. Newson-Horst thanked the Vice Chair for her work. She also stated that Johns Hopkins has a lot to offer in terms of community engagement. Dr. Newson-Horst identified a Johns Hopkins employee by the name of Preston as a resident expert, and that Mrs. Lacks-Whye has had the most interaction with those at Johns Hopkins. Dr. Newson-Horst added that Dr. Pattillo has an intimate association with both the Lacks family as well as the cellular research utilizing Henrietta Lacks' cells. Dr. Pattillo is on the cutting edge of oncology and women's health, and Dr. Newson-Horst stated that he would be an asset to the Advisory Committee and could be a draw for other Advisory Council members. The Chair agreed that Dr. Pattillo is a phenomenal addition to consider. Dr. Newson-Horst again thanked the Vice Chair for her work in presenting the amount of detail in a clear and easy to follow document. Mr. Leonard and Dr. Newson-Horst

discussed Johns Hopkins history and how they have dedicated themselves to community engagement. Mr. Leonard commented that Johns Hopkins has done much of their community engagement through Kaiser Permanente, and Kaiser Permanente maybe another organization to engage for the Advisory Council. Dr. Newson-Horst stated that the best entrance point to Johns Hopkins would be Preston.

The Chair thanked all the Commissioners for their comments and asked if there were any other comments for consideration. Mr. Studley stated that he agreed with Mr. Leonard's point concerning the order of importance or need for the Advisory Council. Mr. Studley suggested that from a Legal and Funding Committee perspective that he would rank the most crucial skillsets needed as community engagement, fundraising, facilities expertise, health policy, attorneys, and finally a healthcare expert. The Chair questioned Mr. Studley's rankings if he felt that the Advisory Council only needed the top four; Mr. Studley clarified that he would prefer all six listed be in the initial wave of Advisory Council participants. Dr. Newson-Horst agreed with Mr. Studley's estimation, but stated that oncology and precision medicine had merit to be considered for top priority due to the target population's high occurrence of cancer and the suspicion surrounding precision medicine. Dr. Newson-Horst voiced her fears that while the Commission may successfully build the Life Sciences Center, the population may not support it. The Chair stated that the initial wave of members on the Advisory Council might represent a top ten of the identified skillsets, but that they must be actually critical to the work being conducted in the initial planning phase of the project. The Chair then asked to confirm that these are the skillsets being currently identified. Mr. Studley confirmed that he selected the most critical for his Committee's work. Dr. Newson-Horst stated that any other impacted Committees have yet to be developed. The Chair questioned if Del. Edmunds had any points, to which Del. Edmunds

commended Mr. Studley's efforts and stated that patent law came to mind but was of critical importance at this time.

The Vice Chair stated that the Advisory Council should be phased. Mr. Studley's rankings are important for the Legal and Funding Committee, and the Communications Committee may have other priorities. Some other priorities may be deferred or delayed based on the work flow.

The Chair questioned Del. Edmunds what protections patent law provides. Del. Edmunds stated that he was unclear as to the specific protections, but that it might help for trade secrets and knowing in the beginning will help prevent any issues in the future. The Vice Chair suggested that patent law be classified under the general need for attorneys in the Advisory Council and that she did not condense any of the brainstormed skillsets, but rather left them as is. Mr. Studley stated that depending on the organizational structure, this will impact the patent protection needed by the Life Sciences Center. The Chair added that the stakeholder group will be able to help identify the exact need and then the attorneys engaged through the Advisory Council will be able to identify the advantages and disadvantages for each issue. The Vice Chair and Mr. Leonard confirmed their understanding of this, the Chair then asked for any further comments on the matter.

Mr. Leonard suggested Dr. Conrad Tucker from Penn State, whom the Commission members met in Baltimore. Dr. Tucker works in the field of biotechnology and specifically human interface. Mr. Leonard stated he had a sincere interest to participate in the Commission's work in some way. Mr. Studley clarified that Dr. Tucker is the associate professor of the engineering design and industrial and manufacturing engineering, as well as a professor for computer science and engineering. Dr. Newson-Horst expressed her interest in his field expertise. Mr. Leonard

stated that Dr. Tucker was working on research to read an individual's blood pressure and heart rate by scanning their face.

Rev. Chandler questioned the inclusion of precision medicine. Dr. Newson-Horst suggested a keynote speaker at a previously attended event by the name of Collins. She stated that he provided the best presentation of precision medicine she had seen.

The Vice Chair then asked to further the conversation. She stated that the identification of key skillsets by Mr. Studley raised the point that some skillsets could be collapsed, and to identify which skillsets are most critical. Dr. Newson-Horst stated that Commission should focus on the message about the occurrence of cancer and the conversation around oncology and precision medicine. Mr. Leonard stated that community engagement is absolutely critical to the communication as well as fundraising, to which Dr. Newson-Horst agreed. Mr. Leonard continued to state that the Communications Committee's skillset priorities are mostly aligned with the Legal and Funding Committee's. The Vice Chair asked for the Communication Committee's top six skillsets for the Advisory Committee initial phase. Dr. Newson-Horst stated that her most critical skillsets are oncology, precision medicine, and community engagement.

Del. Edmunds excused himself from the meeting at 12 p.m. and apologized to the Chair for his early departure.

The Vice Chair stated that previous conversation regarding community engagement mentioned Preston at Johns Hopkins. The Vice Chair questioned if one other entity should be considered for community engagement. Additionally, the Vice Chair stated that the Commission should look to make contact rather than cultivate a list that will delay action. Dr. Newson-Horst stated that the other entity for consideration should be Kaiser, and that she will send the information to the Vice

Chair. The Chair requested that instead, the contact information be sent to her instead of the Vice Chair. The Vice Chair asked for the confirmation of the Commission that they are in agreement to utilize Johns Hopkins as the lead for community engagement. Mr. Leonard stated that Johns Hopkins should be involved in the Advisory Committee. The Vice Chair reminded the Commission that earlier in the day, the Chair had requested at least two contacts for each skillset needed for the Advisory Committee. The Vice Chair then requested who the second contact for community engagement should be. Dr. Newson-Horst suggested that Selwyn Ray with Johns Hopkins Bayview could be a second point for the community engagement.

The Chair questioned that both of the names are from the same entity, Johns Hopkins. Dr. Newson-Horst clarified that while Bayview falls under the Johns Hopkins umbrella name, the two have varying methodologies with community engagement and that Bayview places more of an effort in actively engaging and understanding their surrounding communities. The Chair stated that they would prefer to have two different entities represented in the potential contacts for the Advisory Committee and asked the Commissioners for other alternatives. Dr. Newson-Horst stated there is a potential to source assistance from Michigan. The Vice Chair questioned if there were any options within the Commonwealth of Virginia. Mr. Leonard suggested that community health is being actively studied within Virginia, to which Mr. Studley offered to obtain a local list. The Chair reminded the Commissioners of the desire to engage all local, regional, national, and international entities. The Vice Chair stated that Sentara network, of which Mr. Studley is a part of, encompasses a large geographic territory. Mr. Studley clarified, that beyond the internal Sentara network, he has made professional contacts who have already expressed willingness to aide in locating persons for the Advisory Committee. The Vice Chair

suggested that the second point of contact for community engagement be listed as Jason Studley, with the understanding that his professional network will be included.

The Vice Chair then requested the Commission suggest points of contact for fundraising. The Vice Chair questioned if Dr. Patrick Soon-Shiong would be a feasible candidate for this category as he is currently placing proposals for newspapers as well as funding the group Cancer Breakthroughs 2020. Mr. Leonard agreed that Dr. Soon-Shiong should be involved in some capacity. The Vice Chair stated that Dr. Soon-Shiong is making wise investments in cancer research, data mining, and analytics. Dr. Soon-Shiong is a billionaire who made his fortune in biotech genomics in Los Angeles. He has expressed an interest in certain initiatives in Virginia through the Tobacco Commission from time to time. Some members of the Commission know him pretty well, and think that for the right opportunity he would get involved in a very real way. In addition, Dr. Soon-Shiong is a partial owner of the Los Angeles Lakers. The Vice Chair stated that Dr. Soon-Shiong also developed the cancer drug Abraxane. The Chair requested a second point of contact for fundraising. Mr. Studley suggested Mark Cuban, of television's Shark Tank as well as owner of the Dallas Mavericks. The Chair agreed to this suggestion.

The Vice Chair requested the input of the Commission for identifying points of contact for facilities expertise. Mr. Leonard stated that there are a number of design and planning firms in Virginia who are highly respected for their health and biotech expertise. Mr. Leonard stated that he could reach out to these firms and identify which of these firms would be willing to give some advice in-kind for the planning phase. The Vice Chair agreed and requested Mr. Leonard report back to the Commission with the names of the firms.

Dr. Newson-Horst requested the input of the Commission for identifying points of contact for health policy. The Vice Chair stated that the entities currently identified are the University of

Virginia Center for Health Policy as well as the William & Mary Schroeder Center for Health Policy. The Chair questioned the inclusion of North Carolina A&T State University as Dr. Patrick Martin, Associate Professor of Biology has expressed interest in supporting the Commission. The Vice Chair stated that this might not be the appropriate skillset needed since Dr. Martin is not working on health policy. The Chair called for additional names for consideration. The Vice Chair added that any entities currently working in the realm, not previously identified, should also be mentioned for consideration. Mr. Studley stated, that as far as health policy champions, the Commission has to its benefit Del. Edmunds. Mr. Leonard stated that Sen. Stanley is a great advocate as well. Mr. Studley commented that in regards to engaging universities like VCU and Liberty, they would be great to bring on board, but ineffective for influencing policy at the level that the legislative members of the Commission could. The Vice Chair suggested that the Commission think further on the desire for health policy impact as a part of the Advisory Committee, if health policy means influencing policy or if it means understanding and making sure that existing policies are incorporated in the Commission's thinking and planning. Mr. Studley stated that both approaches of health policy are applicable to the Commission's work. The Vice Chair expressed concern that assigning health policy to the legislative members of the Commission may be an issue as they might not have time to dedicate unless given a specific task, given their other duties and roles. Dr. Newson-Horst agreed with the Vice Chair. Dr. Powell added that within the Virginia Department of Health, the Commission has access to Joe Hilbert, the Deputy Commissioner of Governmental and Regulatory Affairs as well as various other governmental policy appointees.

The Vice Chair requested input from the Commission for points of contact for attorneys. The Vice Chair stated that the Commission already has oversight from the Attorney General's Office

through Assistant Attorney General (AAG), Amanda Lavin. Dr. Newson-Horst suggested that the areas of patent law and non-profit development law should be considered and that the AAG could provide insight to determine the non-profit structure and process. Additionally, Dr. Newson-Horst suggested that the UVA School of Law be considered for inclusion.

Moving on to the points of contact for healthcare expert, Dr. Newson-Horst suggested Dr. Pattillo as he is an expert in both research utilizing Henrietta Lacks' cells as well as cancer treatment methods. Dr. Pamela Sutton is named as an expert in hospital operations, more specifically for oncology unit operations. Other entities for consideration are Anthem Insurance as well as the National Association of Health Careers and Education (NAHCE). Dr. Newson-Horst reminded the Commission to be inclusive in their selections and to source contacts from HBCU's, Tribal populations, and the Latinx communities. Mr. Studley supported this concern by saying that the Commission should not build the foundation on the same injustices that Henrietta Lacks faced. Dr. Powell suggested the American Hospital Association (AHA) could be a source and suggested that the Commission engage the organization and have them identify their best internal resources. Mr. Studley suggested the Commission engage the American College of Healthcare Executives (ACHE) that he is an active member of, as well as the MD Anderson Cancer Center. Dr. Newson-Horst suggested the inclusion of Dr. Luisel Ricks-Santi, the Director of the Cancer Research Center at Hampton University. Dr. Powell suggested the consideration of the Dana-Farber Cancer Institute in Boston, Massachusetts.

Approval of Draft Minutes

Returning to draft minutes, following the arrival of the administrative team and the conclusion of the Committee Reports, the Chair stated that minutes couldn't be passed unless the suggested revisions are processed. The Commission were guided through the proposed revisions by the

administrative team, and voted to approve the minutes with the suggested edits, once implemented.

By-Laws

Reviewing the working draft by-law's based of the Board of Health's by-laws, Mr. Leonard stated that the reference legislation should be included as well as specific controls for proxy voting, FOIA's remote participation guidelines, and Commission membership and terms.

Dr. Newson-Horst requested that moving forward, all supporting documents – to include agendas and other ancillary materials be provided two weeks prior to each meeting. The Chair countered and suggested that instead, the materials be provided one week prior to each meeting. The Vice Chair made a motion to have documents provided two weeks prior, which was seconded by Dr. Newson-Horst. The Chair opened the motion for discussion, to which Mr. Leonard responded that for a quarterly meeting schedule, two weeks out might make sense. However, given the current elevated meeting schedule two weeks out would be difficult administratively. Dr. Newson-Horst stated that two weeks out makes the most sense considering that all Commissioners have regular jobs and guarantees weekend time for review of documents. Mr. Leonard suggested a compromise of two weeks prior the Commission receives draft documents and final documents one week prior. Dr. Powell stated that this would create undue administrative burden with the sheer amount of correspondence required. Mr. Leonard provided a substitute motion that all support materials be provided to the Commission 10 calendar days prior to each meeting of the Commission. The motion was seconded and passed unanimously by voice vote.

Mr. Leonard stated that this decision should be added to the by-laws. The Chair stated that in regards to the previous points raised by Mr. Leonard FOIA allows for remote participation and that proxy voting is prohibited. These points are to be added to the by-laws.

In regards to the draft section stating officer roles, the Chair stated that there is no need to elect a Commissioner to the position of Treasurer without funding or a means of collecting funding. Additionally, the Chair stated that while the Office of Health Equity fulfills a secretarial role as the administrative arm, they are not to be considered an officer of the Commission. The Vice Chair stated that due to the Commissions sunset date and life span, annual elections are not needed and the elected officers will remain in office for the term of the Commission. However, the by-laws should address how to handle a resignation. Mr. Studley suggested that the Office of Health Equity act as a clerk to the Commission and that the by-laws remove the portion containing the structure and requirements of an Executive Committee. Mr. Leonard made a motion that the Commissioners can attend meetings remotely in accordance with Virginia's Freedom of Information Act, seconded by the Vice Chair and passed by a voice vote.

Other Business

The Chair questioned Dr. Powell if the Commission will be able to obtain official FOIA training. Dr. Powell stated that she has already requested formal training from Deputy Commissioner Joe Hilbert, who stated he will gladly provide the training at the Commission's next meeting. Dr. Powell clarified that Conflict of Interest (COIA) training is still a requirement and to be conducted online through the previously provided link.

Dr. Powell stated that in regards to the previously discussed elevator speech, it was supposed to be short as to invite questions. The Chair agreed that brevity is required. Mr. Leonard stated that

perhaps the elevator speech should not be included on the forthcoming website. Dr. Newson-Horst stated that she will make revisions to the document and send the revised elevator speech to the Commissioner's on Monday, November 12. In regards to the needed statistics, the Commission reviewed the mortality statistics provided by the Cancer Registry of VDH and determined to utilize other information. Mr. Studley provided information obtained through Sentara that states the cancer mortality rate per 100,000 persons in Virginia is 181.6% higher than the United States.

The Chair asked for Dr. Powell's guidance in regards to the website. Dr. Powell stated that per the Office of Communications at Virginia Department of Health, it is strongly advised that either the Commission or a third party staff and manage the website. The only strong requirement of the website is compliance with the Americans with Disabilities Act. Dr. Powell will send the compliance requirements to the Commission. Dr. Powell stated that the Virginia Department of Health cannot be responsible for the website due to oversight, posting, and encryption requirements. Ms. Johnson stated that the Halifax Industrial Development Authority has paid for the creation and hosting of the website. At this point, the website needs only edits and material additions. Eventually, the website will require maintenance which will require funding. A suggested source for website coordination was mentioned by the Vice Chair who will contact the person and inquire as to his interest and willingness. Ms. Johnson stated that Halifax IDA can provide some basic website support at no cost. The Chair stated that with an average monthly cost of \$85 per month to maintain the website, the Commission should be ready to receive donations for funding. Mr. Leonard suggested that a non-profit healthcare organization such as Sentara could function as an intermediary for holding funds until such time as an independent foundation is established.

Regarding financing, the Chair stated that if it receives donations there needs to be a foundation in order to hold the funds. The Vice Chair suggested utilizing Ryan Garrett to act as an intermediary to hold the funds. The Vice Chair stated that Del. Edmunds provided the name of Bill Thompson and his desire to be included in the Commissions efforts.

Moving on to past events and announcements, Dr. Newson-Horst provided the details regarding the recent luncheon and meeting at Johns Hopkins. Dr. Newson-Horst stated that Johns Hopkins will be breaking ground on a building to be named after Henrietta Lacks. Dr. Newson-Horst expressed that there was an opportunity to talk about the Commissions activities and put them on a national stage. The Vice Chair questioned how media releases can be packaged for dissemination to media outlets. Mrs. Lacks-Whye stated her appreciation that the Commission approached the family first and obtained their permission prior to moving forward with the legislation. The Vice Chair questioned how the Commission can best get and keep their narrative out front. Dr. Powell stated that she would need guidance on how the Department of Health handles press and if there are any restrictions, but that moving forward, the Commission should make contact with media outlets directly. The Chair questioned if the Department of Health sends out press invites for meetings. Dr. Powell informed the Chair that the Department of Health posts meeting dates, times, locations, agendas, and meeting minutes publically but does not send out press invites. The Vice Chair stated that in lieu of the Department of Health disseminating information, each Commissioner can send out information to their various contacts and relevant organizations. Dr. Newson-Horst stated that she and Mrs. Lacks-Whye will develop an initial press package. Servant Speed supplied that the Commission can reach out to Nicole Rodman, a Baltimore area journalist as she has shown great interest. Dr. Newson-Horst stated

that there has been great feedback for the Commission's development and activities in the Baltimore and Washington D.C. area.

The Chair noted that Mr. Leonard is no longer the Executive Director of the Halifax IDA. Ms. Johnson has been appointed interim Executive Director of the Halifax IDA, and has in turn appointed Mr. Leonard as her designee on the Commission.

Dr. Powell expressed her gratitude to the members of the Commission who spoke at the Office of Health Equity's plenary panel during their inaugural conference. Dr. Powell then advised the Commission of an upcoming Community Conversations event to be held at the Black History Museum & Cultural Center of Virginia on Saturday, November 17 from 2-4 p.m. Dr. Sutton as well as some of the Commissioners will attend. The Vice Chair questioned if it would be possible to organize a plenary panel in Halifax County. Dr. Powell stated that this was possible and suggested that the Commission consider organizing a state or national speaking tour, which could be funded by contributions. Dr. Newson-Horst suggested that the Commission begin reporting out after the half-year mark. The Chair stated that prior to these engagements the Commission must secure a funding source.

Dr. Powell presented the call for abstracts from the Second Conference on Bioethics Issues in Minority Health and Health Disparities Research through the Morehouse School of Medicine, Tuskegee University, and the University of Alabama at Birmingham Cancer Research Partnership. Dr. Powell stated her willingness to reach out to the event planners to see if they would be willing to accept a community based abstract and advise them of the existence of the Commission. The Commission supported Dr. Powell in making contact with the event coordinators to see if there is a place for the Commission to present. Mr. Leonard suggested that

Dr. Powell be given permission to pursue events in the interest of the Commission at her discretion, the Commission agreed.

Public Comment

The Chair opened the floor for public comment.

Shirley Lacks stated her thanks and stated that the meeting has been very informative.

Servant Courtney Speed gave blessings and thanked the Commission for its work. She reiterated her previous comment of reaching out to journalist Nicole Rodman.

Rev. Chandler stated that as there has never been a replacement found for Mrs. Lacks' cells, it is a form of divine intervention. He stated that he frequently finds that the public is either unaware of Mrs. Lacks' story or have only received half the story through reading the book. Rev. Chandler stated that the area is attracting visitors from all over the world and more information is needed to accurately answer the questions posed by visitors. Rev. Chandler further stated that attitudes are changing within the Clover-based Lacks relatives and that the Henrietta Lacks Life Sciences Center will give pride to the family and the community. The Life Sciences Center will be both a community resource as well as a continued legacy and a connection to Mrs. Lacks herself.

The Vice Chair stated that there is a need to work with the Clover area churches to spread the message. The Vice Chair stated she would work with Mrs. Lacks-Whye and Dr. Newson-Horst to develop a message specific to the churches in the region.

Servant Courtney Speed stated that Lacks family relatives are present in both Turner Station, Maryland and Clover, Virginia.

Dr. Powell thanked the Commission for their patience as the Office of Health Equity transitions into the new role and that she is quite passionate about the Commission's goals and work.

The Vice Chair thanked everyone for their efforts, time, and participation. She stated she would work with Rev. Chandler for community organization with the churches.

The Chair thanked everyone for their time. She reminded the attendants that cancer does not see color or age and that nobody should have to suffer from cancer.

Next Meeting Date

The next meeting is to be held Wednesday, December 19 starting at 12 p.m.

The meeting will be held at the Halifax IDA, located at 1100 Confroy Drive, South Boston, VA 24592.

A press invite will be sent out.

Adjournment

The meeting was adjourned at 3:18 p.m.

Meeting minutes recorded by Kira Walker