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


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 Edmonds 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 fiend.
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 Immortal 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 among scientist and remain the most widely used cell line in biomedical research. 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 you...

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 medical 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!
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 it’s 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. Johnson’s 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
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 adendum, 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 aide 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