

**Henrietta Lacks Commission  
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 required change or addition. With no suggestions, the Chair suggested a motion be made to approve the agenda as presented. 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 is identifying appropriate individuals for an advisory council. Del. Edmunds agreed to this assignment, 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 pulling 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. 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 Commission's 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 a Commission narrative. 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.

These minutes were approved by unanimous vote of the Henrietta Lacks Commission on December 19, 2018.