

**Community Advisory Board Meeting**  
**January 26, 2021**  
**9:00am - 11:00am**  
**Zoom Conference Call**

**Participants**

Name	Affiliation	CAB Role	Email Address
James Jackson	Western & Southern Life	CAB Chair	<a href="mailto:jjackson2@hotmail.com">jjackson2@hotmail.com</a>
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Elizabeth Johnson	Administrative Director, San Diego Center for AIDS Research and the HIV Institute	CAB Member	<a href="mailto:liz@ucsd.edu">liz@ucsd.edu</a>
Betty Uribe	Program Manager, Christie's Place	CAB Member	<a href="mailto:uribe@christiesplace.org">uribe@christiesplace.org</a>

Wanda London	Community Member	Guest	<a href="mailto:london.wanda@yahoo.com">london.wanda@yahoo.com</a>
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### **Commencement**

The CAB meeting began at 09:01 a.m.

### **Welcome from CAB Chair & Co-Chair and Introductions**

Mr. James Jackson and Ms. Judi Patterson Disparities Core CAB Chair and CAB Co-Chair, Dr. Jamila K. Stockman, Director Disparities Core CAB, welcomed the group to a brand-new year and facilitated introductions of leadership and participants via Zoom video conference. See attendee names, affiliations, and contact information above.

### **Research Project Presentation: LinkPositively**

Dr. Jamila K. Stockman introduced a new project entitled, LinkPositively, and noted today would be a great opportunity to present and receive feedback from the CAB. The project is officially entitled a trauma informed peer navigation social networking web APP to improve HIV care among black women affected by interpersonal violence. The goal of LinkPositively is to develop, and pilot test a multi-component and health intervention tailored to Black women living with HIV affected by interpersonal violence, with the goal of improving retention and HIV care ART adherence and viral suppression. The LinkPositively team will be led by Dr. Stockman (UC San Diego) and Dr. Keith Horvath (San Diego State University). The funding source is through NIH specifically the National Institute of Mental Health. The LinkPositively team would like guidance on prospective referrals, recruitment materials and strategies, and methods to identify peer navigators.

There are two main study aims and the first is to develop and refine the LinkPositively app through formative research. The team conducted focus groups with Black women and peer navigators to receive input on the components of the app. Refinement of the app has been completed. The next step is to test the usability of the app.

The second aim is to conduct a pilot randomized control trial to assess feasibility accessibility and the preliminary impact of the system. The primary outcomes for this trial will be retention in HIV care, ART adherence, and viral suppression. The team conceptualizes the systems as a mobile optimized website APP and what this enables us to do is to design, something that is suitable for both Android and iOS platforms in an economical and feasible way. Women, regardless of the type of phone they have will be able to access the system, as long as they have internet accessibility.

The LinkPositively webapp has five components: virtual peer navigation, social networking (similar to a Facebook feed), educational and self-care tips, GPS-enabled resource locator, and medication reminder and monitoring system.

Dr. Stockman shared her screen to show the group the LinkPositively App and showcased the various aforementioned components.

### **LinkPositively Peer Navigator Recruitment Discussion**

- Dr. Jamila K. Stockman inquired about the methods recommended for identifying qualified peer navigators.
- Ms. Judi Patterson responded and noted she has a connection at a women's local detention program that may be able to provide referrals. She noted that she may have at least four or five girls on probation that have been survivors of violence and assault that often times resulted in HIV so this may be a good avenue to explore.
- Dr. Stockman noted that she will connect Ms. Patterson and Ms. Danielle Campbell to discuss the process a little further.
- Ms. Wanda London recommended we contact San Ysidro Health's Our Place HIV Program as it would be a great place to get in touch with a case manager who can provide referrals. She added that if the LinkPositively team is looking for a prospective peer navigator that is actually in care that would be helpful.

- Ms. Patterson added that it may be helpful to have a bilingual peer navigator so as to help with prospective Spanish-speaking participants. Dr. Stockman responded by stating that Ms. Patterson raised an important point, unfortunately this particular project is for English speaking only because of limited funding.
- Mr. James Jackson suggested that since there are a lot of service providers in the CAB that can help spread the word if the LinkPositively team provides a brief description that explains what they are looking for. He added that the Faith Based Action Coalition meets monthly and stated he can share with that group as they may have some great ideas for peer navigators as well. Dr. Stockman and Mr. Jackson will connect about this offline.

Dr. Jamila K. Stockman transitions the discussion to explore participant recruitment strategies. She provided the CAB with a description of the eligibility criteria for participants which included: Cis- or trans-women, Black or African American, aged 18 and older, living with HIV, lifetime experience of physical, sexual, and/or psychological abuse by anyone, access to smartphone and internet, and English speaking. Recruitment strategies will include flyers that will be distributed to local health care clinics, organizations, social media, and general advertisements as well as non-traditional areas such as newspaper ads, bus stops, libraries, grocery stores, and open small businesses in the prioritized communities. Dr. Stockman stated they plan on initiating recruitment soon so they can develop a list of potential participants to be prepared when they're ready to launch which will be in the Spring. Dr. Stockman added that prospective participants will be screened, then randomized into groups with the goal of having 40 women to receive LinkPositively to use the app and then 40 women would be in standard of care Ryan White self-directed services.

#### **LinkPositively Participant Recruitment Discussion**

- Ms. Judi Patterson recommended that they reach out to recovery centers such as McAllister Institute and National Crossroads would be a great starting point as these facilities have community service requirements.
- Dr. Suzanne Afflalo provided some insight and stated that there are a lot of youth organizations that serve this population. She believed that the potential age range of these organizations are between 16 to 24 years old. Dr. Afflalo mentioned that she knows of a young gentleman that runs an informational type setting for human trafficking he may have more communication with the prioritized population. She also added the monthly Community Outreach Event that she and Ms. Patterson attend can be helpful for recruitment and flyer distribution. Dr. Afflalo noted that having literature that she can share with the community is beneficial as there is still stigma in the Black community about HIV and people may not just be willing or open to join the study without proper language. Dr. Stockman thanked Dr. Afflalo and noted that she will keep in contact with her regarding the literature. Dr. Afflalo will put Dr. Stockman in contact with the individual who runs the human trafficking group.
- Dr. David Moore noted that this is an awesome program and an awesome resource. Dr. Moore suggested that the team really pay close attention to how people get their cellphone coverage as he disclosed that a lot of people have pay as you go plans that work for 30 days every month so it would be helpful to ask their coverage status beforehand as much as possible. Dr. Stockman stated that is a great point and stated that they have decided to integrate that into the screening process and as about cellphone coverage connectivity data plans. She mentioned that there is a small amount of money that can offset the issue around data plans. She thanked Dr. Moore for his suggestion.
- Ms. Katherine Anderson mentioned that as an add on as recruitment criteria and ensuring that women have access to a smartphone with an internet browser as an alternative, they have discussed ways to speak with women about how they may access Wifi if data is not available and how to do that safely under circumstances of the pandemic so that is an ongoing conversation.
- Ms. Judi Patterson stated she will connect the team with Roosevelt Williams who has a virtual magazine, young Black and in business. They are looking for more connections within the African American community in reference to mental health awareness. They broadcast every month. She also suggested maybe going on a podcast as that is what the younger generation is using now. Dr. Stockman thanked Ms. Patterson.

Dr. Jamila K. Stockman transitions the discussion to the topic of content and how to make sure recruitment is mindful of some of the issues around stigma and how to appropriately advertise the study. Dr. Stockman emphasized that LinkPositively is a completely anonymous system, participants can select an avatar and it is overall very anonymous.

### **LinkPositively Advertisement Discussion**

- Dr. Suzanne Afflalo suggested that since the prioritized population are young Black women, cultural sensitivity and ensuring there are young beautiful black faces present is needed. In addition, she noted indicating that there is a Black woman leading the study may encourage participation, especially in the context of medical mistrust. In addition, she suggested that representation is important and if there is a woman that looks like them that is involved, they may feel safer to inquire about the study. Dr. Stockman thanked Dr. Afflalo for her insight and stated that they may connect with the IRB office on any sort of guidance they can provide on this topic.
- Ms. Wanda London also suggested that maybe putting African American females on the flyers and advertisements may increase interest.
- Dr. Afflalo also mentioned that it is important to make it known that the study will be anonymous to further show it is a safe place.
- Dr. Stockman thanked both Ms. London and Dr. Afflalo.

### **Book: The ABCs of HIV**

Dr. Jamila K. Stockman formally introduced Ms. Wanda London and her new book that is titled, *ABCs of HIV/AIDS*, Dr. Stockman transitions the presentation to Ms. Wanda London.

Ms. Wanda London stated the reason she wrote her book stemmed from her HIV diagnoses almost 30 years ago. She noted that when she was diagnosed, she lived in a small town in Midwest and expressed that there were limited resources, secure information, and stigma at the time and stated she is impressed with LinkPositively. Ms. London disclosed that it was difficult for her to get information and any resources regarding HIV in Indiana. Ms. London continued and stated she started working in a community as a spokesperson, and eventually advocate treatment and became an educational coordinator. That role allowed her to go into schools to educate kids on the basics of HIV/AIDS and noted that she was astonished about the questions raised by the students of the schools. When she started answering these questions, she wanted to be sure parents were also involved in this process as they should be able to sit down with their children in a comfortable environment and talk about HIV. Ms. London wanted to interject that she also worked with San Ysidro Heath and facilitated a positive women's work group that partners with women recently released from prison. She noted that what took her by surprise was that they were asking the same questions which is why she thought it would be a great idea to write a book. Ms. London made note that her book is based on the Center for Disease Control and Prevention. The book includes a chapter on the do's and don'ts of HIV/AIDS as well as STIs and HIV workshops.

Ms. Wanda London wanted to share her own experience living with AIDS with her community and to inspire and share with others how to live with HIV/AIDS. With that, Ms. London concluded her presentation. Dr. Stockman thanked her for her time and congratulated her on the release of her book.

Dr. Stockman informed the group that Ms. Wanda London's book is available for purchase via Amazon and Barnes and Nobles. Ms. London also noted that she has some copies locally in San Diego and if anyone wishes for a copy to contact her.

The link to The ABCs of HIV : <https://covenantbooks.com/books/?book=the-abcs-of-hiv-aids>

### **The Last Gift Project Meeting – DC CAB Representation**

Dr. Jamila K. Stockman introduced The Last Gift Study and stated she attended a meeting last Friday with one of the co-investigators of this research initiative. Dr. Karine Dube is working alongside Dr. Davey Smith, who leads the Infectious Diseases and Global Public Health in the Department of Medicine at UC San Diego. Dr. Stockman requested that 1-2 Disparities Core CAB members attend a meet and greet for the Last Gift Study on January 27, 2021, 9-10am.

The Last Gift Study is a project for individuals who choose to donate their body to science to help others in the future. Now traditionally these individuals who decided to donate their bodies to science are people living with HIV, who have since passed from HIV. The study has expanded to not only look at those who have passed but also look at those who are living with HIV with the aim to grasp and further understand the natural history of the disease. Historically, this particular project has primarily enrolled or been able to reach white men living with HIV, particular men of have sex with men (MSM) populations. Now, they would like to expand the diversity of their study population, for instance there is only one trans individual who is enrolled in the project and they would like to expand the breadth of participants in terms of gender and racial ethnic minority status. Dr. Stockman shared that the meet and greet will focus on describing the study. She shared her screen to show the flyer that encompasses everyone who can participate and eligibility criteria in addition to HIV/AIDS they will need to have another serious medical condition. For example, an individual living with HIV/AIDS and Cancer or HIV and ALS. The brochure shared on the call is available in both English and Spanish and this will be sent to the CAB members. The Last Gift Study Brochure: [http://lastgift.ucsd.edu/?page\\_id=354](http://lastgift.ucsd.edu/?page_id=354)

Mr. Dallas Davis informed Dr. Stockman that he can attend The Last Gift Study meet and greet. Mr. Davis mentioned he has used this program with a previous client who was living with HIV and a rare brain disease. He stated that it was a wonderful program and Ms. Susanna Garcia, the Coordinator, is very helpful. Mr. Davis also mentioned she is a good community liaison. Mr. Davis noted that he can definitely attend the meet and greet on behalf of the Disparities Core CAB

### **2021 CAB Topics:**

Dr. Jamila K. Stockman transitioned to the next agenda item which are 2021 CAB topics. Dr. Stockman wanted to ask the CAB if they would like to generate ideas for future CAB discussion topics.

Ms. Judi Patterson mentioned that she and Dr. Suzanne Afflalo have been working with community health workers who are part of different ethnic backgrounds and how COVID-19 is affecting the local communities. Ms. Patterson noted that the African American community is hesitant to getting the vaccine, her question is if the COVID-19 vaccine affects the HIV medication taken by people living with HIV? Ms. London noted that she has the same questions as Ms. Patterson, and she is unsure if there are any effects of the vaccine due to her HIV medications. She noted that to receive the vaccine a person living with HIV must be undetectable. Both Ms. Patterson and Ms. London wanted the combination of HIV medication and COVID-19 vaccine to be addressed in the meetings.

Dr. Suzanne Afflalo mentioned the good thoughts and questions posed. Dr. Afflalo stated she is not a resident expert on the COVID-19 vaccine, but she does know that there is still continued studies going on. She does not have enough information to know but she does know that they had to move forward quickly with getting the vaccine through its three stages and phases in order to get it out and try to save lives. Dr. Afflalo mentioned that we will have to weigh out the risk and benefits like with anything. She did note that people with chronic medical conditions and immunosuppression are the highest concern. However, it is a higher risk of getting the virus and dying from it than experiencing the side effects. Dr. Afflalo mentioned that maybe getting Dr. Susan Little to further explain may be helpful.

Mr. James Jackson also mentioned the importance of circling back to introduced projects and participate in the World AIDS Day that may be a great thing to do. In addition, he mentioned participating in local events would also be helpful.

Ms. Danielle Campbell shared with the group the reminder that next month is Black History Month and National Black HIV and AIDS Awareness and encouraged the group to get out and get involved virtually in activities that are happening across the United States to support the increase of awareness of how HIV impacts the Black community.

Ms. Elizabeth Johnson noted that University CAB is hosting in the future a presentation by Dr. Susan Little focused on COVID-19 vaccines. She will send Ms. Janine Lopez the information to send to the CAB members.

Dr. Jamila K. Stockman thanked the group for their suggestions and noted that the next meeting is scheduled for Tuesday, March 30<sup>th</sup> from 9:00am to 11:00am.

Mr. James Jackson and Ms. Judi Patterson thanked everyone for their input throughout today's meeting!

### **Adjournment**

Meeting adjourned at 10:45 am