



## Health Equity Community Advisory Board

**Community Advisory Board Meeting**  
**May 25, 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>
Judi Patterson	Case Manager, Mental Health America	CAB Co-Chair	<a href="mailto:jpatterson@mhasd.org">jpatterson@mhasd.org</a>
Eileen Pitpitan	Associate Professor, San Diego State University, and the School of Social Work	Co-Director, Disparities Core and CAB	<a href="mailto:epitpitan@sdsu.edu">epitpitan@sdsu.edu</a>
Argentina Servin	Assistant Professor, UC San Diego, Division of Infectious Diseases & Global Public Health	CAB Member	<a href="mailto:arservin@ucsd.edu">arservin@ucsd.edu</a>
David Moore	Associate Professor in Residence Department of Psychiatry, UC San Diego	CAB Member	<a href="mailto:djmoore@ucsd.edu">djmoore@ucsd.edu</a>
Susanna Concha-Garcia	California NeuroAIDS Tissue Network	Guest	<a href="mailto:sconchagarcia@ucsd.edu">sconchagarcia@ucsd.edu</a>
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>
S. Giovanna Carr	UC San Diego, Division of Infectious Diseases & Global Public Health	Clinical Interventionist, Disparities Core	<a href="mailto:s3carr@health.ucsd.edu">s3carr@health.ucsd.edu</a>
Dallas Davis	Program Supervisor, The Neighborhood House Association	CAB Member	<a href="mailto:drdavis@neighborhoodhouse.org">drdavis@neighborhoodhouse.org</a>
Ilana Goldberg	San Ysidro Health Center	CAB Member	<a href="mailto:igoldberg@syhealth.org">igoldberg@syhealth.org</a>
Suzanne Afflalo	Medical Director, Alliance Health Clinic	CAB Member	<a href="mailto:suzanneafflalo@sbcglobal.net">suzanneafflalo@sbcglobal.net</a>
Danielle Campbell	UC San Diego, Division of Infectious Diseases & Global Public Health	CAB Member	<a href="mailto:dacampbe@health.ucsd.edu">dacampbe@health.ucsd.edu</a>
Wanda London	Community Member	CAB Member	<a href="mailto:london.wanda@yahoo.com">london.wanda@yahoo.com</a>

## **Commencement**

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

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

Mr. James Jackson, CAB Co-Chair, welcomed the group and facilitated introductions of leadership and participants via Zoom video conference. See attendee names, affiliations, and contact information above.

## **CFAR Announcement: Office of AIDS Listening Session**

Dr. Eileen Pitpitan shared that the Office of AIDS research at NIH is holding a series of regional listening sessions across the US. They are seeking input from community stakeholders, scientists, and other stakeholders on the current NIH HIV research priorities to also consider emerging scientific areas that they are going to be supporting over the next five years. Dr. Pitpitan informed the group that these discussions can help inform their pragmatic and budgetary decision making. A listening session will be hosted by San Diego CFAR on May 27 from 2:00 - 2:45pm specifically for community stakeholders. Dr. Pitpitan shared there are slots available and to let her, Dr. Stockman, or Ms. Elizabeth Johnson know. Ms. Johnson stated that anyone interested can email her directly or she will provide them with additional information. Mr. James Jackson stated he will be participating in the listening session and that he is looking forward to it.

## **Research Project Presentation: 2VIDA!**

Dr. Argentina Servin introduced a new research project, *2VIDA!*, which stands for SARS-CoV-2 Vaccine Intervention Delivery for Adults in Southern California. Ms. Servin shared her screen and provided a PowerPoint presentation that outlined *2VIDA!*

## **Background**

- More than half of COVID-19 cases in the US have been among Latinx and African American individuals, despite the fact that these groups comprise less than a third of the total US.
- Acceptance and uptake of COVID-19 vaccines are instrumental to bring the pandemic under control. 85% of Americans need to be vaccinated
- Public confidence in vaccination is fragile, especially among racial and ethnic minorities
- Federal data indicates that only about a third of the more than 25 million doses distributed nationwide have been administered to people
- 48.2% of California's have received at least one dose
- 33.1% are fully vaccinated
- 5 million individuals in CA have not received 2<sup>nd</sup> dose

## **Specific Aims**

Aim 1: To evaluate the preliminary impact of *2VIDA!* compared to the standard-of-care for COVID-19 vaccination services among Latinx and AA adults >18 years (N=1000) in San Diego

Aim 2: To assess feasibility, acceptability, and intervention effects of *2VIDA!*

## **Study Design**

- Randomized Control Trial (RCT) with San Ysidro Health across six of their clinics. Three clinics will receive the intervention and the other three clinics will just do their standard-of-care for their COVID vaccine. Through health literacy education and different community engagement forums and events as well as intentional targeting through social media, the intervention will increase interest and uptake of the vaccine.

**Sample size:** 1000 individuals

## **Phase 1**

- COVID-19 individual awareness and education
- COVID-19 community outreach and health promotion
- COVID-19 individual health education and linkages to medical and supportive services

## **Phase 2**

- Vaccination stations in community parks
- Provide vaccines at participating Community Health Centers (CHC) and mini-vaccination stations
- Data collection
- 2<sup>nd</sup> vaccine dose
- Focus groups with Latinx and African American communities
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#### **Intervention**

- Latinx and AA adults +18 years or older that live in the three communities (intervention sites- San Ysidro, Lincoln Park/Valencia Park, Logan Heights)

#### **Controls**

- Chula Vista
- Paradise Hills
- National City

#### **Other Items**

- Identifying community engagement events
- Guidance regarding outreach education materials
- Questions?

#### **Discussion**

- Mr. James Jackson posed a question regarding identification of community engagement events. He stated that there are a couple of different groups such as the faith-based initiative that are connected to different community engagement groups and asked if there may be a bullet point, flyer, piece of literature that he could share with the different communities that would give them an idea of what the goals are at these community engagement events.
  - Dr. Argentina Servin responded and stated that they do have a summary and infographics that they've developed for specific topics stemming from the community such as a missed period and fertility. Ms. Servin stated she is more than happy to share these with the group so members can share among the community. She also mentioned they would also be open to having some members of their team go directly to meet with the communities to have an open forum with them about what questions or concerns they may have and bring an expert to answer those questions.
  - Dr. Servin posed a question to the CAB regarding what the review process would be regarding sharing some infographics she has developed and getting feedback from the CAB.
  - Dr. Eileen Pitpitan followed up on Dr. Servin's question and asked the CAB whether anyone had an idea about the process for feedback and review of materials. She asked if it is usually ideal, they come in with those materials to the CAB meetings or if they are circulated over email.
  - Ms. Judi Patterson responded and mentioned it's a combination of all things since the CAB is a collaborative group they share information as a whole. Ms. Patterson added that Dr. Jamila Stockman is excellent in getting information out to all members via email. She also added that at Mental Health America they have an outreach team so she can personally disseminate any information into the community via their outreach efforts. Ms. Patterson commented that she thinks the father to child program would be a good program for them to share information with given that they work closely with the Black and infant population. Ms. Patterson offered to help in any way possible.
  - Dr. Servin thanked Ms. Patterson and mentioned she would be happy to circulate the materials via email to get feedback and to ensure that the messaging is appropriate. If appropriate, Dr. Servin encouraged the CAB to share the materials with all their networks.
- Ms. Judi Patterson posed a question regarding the age they are looking to target since she works with youth.
  - Dr. Servin responded and stated they are working with adults who are 18 years or older, even though the vaccine has been authorized for 16 and older, at the time the study was approved the CDC had not authorized for 12 years and older, so they are limited to 18 years old. Dr. Servin hopes that by the next CAB meeting she might have an update to share regarding the possibility of expanding the study to younger adults
- Dr. Servin posed a question regarding what the best way would be to circulate the resources they developed to get some feedback.
  - Mr. James Jackson responded and asked Dr. Servin to share the resources with the CAB members present in the meeting via email.

- Dr. Eileen Pitpitan suggested it is important to make sure the language is simplified so that the take home message is loud and clear. Dr. Pitpitan also suggested to break up the text into different versions as well as make the text bigger. Dr. Pitpitan asked whether it would be easy to paste the material into a Google sheet and then distribute out the CAB members so that everyone can edit.
- Mr. Jackson and Ms. Patterson agreed to provide some feedback on the Google sheet. Dr. Pitpitan agreed to send it out to the CAB members for feedback.
- Mr. Jackson thanked Dr. Servin for the presentation and introduced the next presentation from Ms. Susanna Concha-Garcia.

#### **Presentation: California NeuroAIDS Tissue Network/The Last Gift**

Ms. Susanna Concha-Garcia introduced the California NeuroAIDS Tissue Network (CNTN) study. It is a study through the HIV neuro-behavioral research program. Ms. Concha-Garcia is one of the research analysts as well as community outreach representatives for the study.

#### **CNTN Study – To Learn How HIV and AIDS Affect the Human Brain**

- The purpose of the study is to understand how HIV disease affects the brain and central nervous system and to develop a bank of organs, tissues, fluids and samples that can be used for scientific research which may lead to improved treatments for HIV+ or HIV- brain diseases.
- The participant living with HIV is examined over a period of months or years with various in-life assessments. At death the person donates their organs, tissue and fluids for a neuropathological examination. A report is written that characterizes the organ donations from each donor.

#### **Assessments During Life**

- Neuropsychological evaluations to perform thinking skills, which measure memory, concentration, reasoning, quickness, and alertness
- General physical examination of how well your brain and nervous system are functioning
- Neuromedical interview takes a history of the participants health, substance use and emotional history
- MRI to look at the structures of the brain, at a point in time
- Lumbar puncture to collect Cerebral Spinal Fluid (CSF) using a local anesthetic at the low back, and removal of fluid with very fine needle
- Visits and assessment are over months or multiple years to provide a window into how the brain is functioning for each participant

#### **Organ Donation for NeuroAIDS**

- Each participant signs an Organ Donation Autopsy consent
- At death a pathological examination is done to provide a validation of the in-life assessments
- Contribute to bank of organ, tissue and fluids for other researchers studying the effects of HIV
- Understanding how HIV affects the brain may eventually lead to newer and better treatments
- Postmortem examination allows for an assessment of cumulative effects of other conditions

#### **People Participate in CNTN Because...**

- Participants are making a gift in honor of those who died before them of AIDS
- Generosity and empowerment to be able to donate their organs to science so others may benefit from important treatments in the future
- Leave a legacy from their DNA, genetic material in their cells, in which a new medication or treatment may be discovered
- Through organ donation, the tissue and fluids banked, and DNA analysis may provide important information that would be unavailable during life

#### **The Last Gift: End of Life Research Model for HIV Cure Research Current State of HIV**

- A person without HIV can live an average of 79 years
- A person with HIV diagnosed at age 20 taking current HIV medicines can live up to 71 years
- A person with HIV diagnosed at age 20 not taking current HIV medicines can live up to 32 years
- Undetectable = Untransmittable - People with HIV, who are taking effective treatment, cannot pass on HIV through sex

### **Why do we need a cure if HIV treatments works so well?**

- Still a global issue
- 36.9 million people living with HIV
- 2 million new HIV infections
- 1.2 million AIDS-related deaths
- Most cases and deaths in Africa
- Having HIV is still associated with stigma, discrimination, violence, and poverty
- HIV is a very persistent virus
- Only very few persons have been cured from HIV so far

### **Clearing HIV Reservoirs is Hard**

- Established during primary HIV infection
  - In peripheral blood cells
  - In anatomic sites and solid tissues
- HIV plays “hide and seek” with the immune system and antiretroviral therapies (ART)
- Source of viral rebound when ART is stopped
- Studies in living people
  - Hard to reach anatomic sites safely
- Autopsy studies
  - Often poor-mortem characterization- data collected is too remote before death, 6 months to years
  - Autopsies rarely performed quick enough-hours to days later

### **Proposed Solution**

- Altruistic persons living with HIV with a terminal illness
- Follow them to collect clinical data, urine, vaginal cells, anal cells and blood
- Perform a Rapid Autopsy to collect organ, tissue and fluid samples
  - Done before in cancer research
  - Within 6 hours of death – to collect the best samples
  - Preserve quality of RNA and proteins for research

### **The Last Gift Study**

- Started in July 2017 (Principal Investigator: Davey Smith, MD)
- Goal: To characterize the HIV reservoirs in the blood and in various anatomic tissues
  - To determine the dynamics of HIV rebounding variants after ART interruption
- Enroll 5 participants/year

### **Conclusions**

- Emergence of large, clonal, intact HIV RNA populations after stopping ART, which repopulated tissues throughout the body
- Multiple sites can act as hubs for dissemination of HIV within host, predominately blood, gut and lymph nodes
- Viral exchanges occur within brain areas and across the blood brain barrier
- Viral dynamics are associated with low HIV divergence between sites and high HIV diversity at the recipient site

### **Social Science Behavioral Component**

- Goal: To better understand the experiences of the loved ones or family members and participants in the Last Gift Study
- To collect information about the perspectives of loved ones of family members about the Last Gift study protocol
- To administer a questionnaire that asks for the opinion on the Last Gift study from participants and loved ones
- To ask for suggestions on how to improve the protocol

### **Study Contacts**

- Program Representative: Susanna Concha-Garcia (619) 543-5000
- 24-Hour on call pager: (858) 616-1214 Organ Donor and Tissue Acquisition Coordination

## **Discussion**

- Mr. Dallas Davis shared with the group that he has participated in the program a few years with a client that had terminal brain cancer. Mr. Dallas mentioned it was really tough but that the client was well taken care of and that it was such a good thing that happened all around. The burden was taken off the parents because the team helped the client get into hospice. Mr. Dallas added that the whole study was very well done and dignified and that the best thing about the study is that there is a legacy left with the client. He also mentioned that if later down the road anyone has questions on how to refer participants to the study, they can call him.
- Ms. Susanna Concha-Garcia added that the reason she is here at the meeting is to spread the word about anyone who knows someone living with HIV, they have a variety of other studies at the HNRP and AVRC. The HNRP offers anyone who walks into the office the opportunity to be an organ donor for research purposes. Ms. Concha-Garcia thanked the CAB members for the opportunity and reminded everyone to spread the word that there is a place for people who are living with HIV to donate their organs.
- Dr. David Moore thanked Ms. Concha-Garcia for the presentation and added that the Last Gift is amazing and really does intensive sampling characterization at the end of life which allows them to do rapid autopsies. Dr. Moore added that it differs from the California NeuroAIDS Tissue Network (CNTN) since it follows people in life for a long time at a much less frequent basis. He added that if people are not at the end of life they can enroll in CNTN if they meet the criteria and get some life assessments.
- Ms. Judi Patterson shared with the group a personal testimony regarding organ donation. Ms. Patterson added that she appreciates the work that they are doing and that she is very grateful.
- Ms. Concha-Garcia thanked Ms. Patterson for sharing her testimony and mentioned that it is very valuable and precious what they hear from family members and the loved ones of the organ donor. Ms. Concha-Garcia added that the little pink dot on driver's license is incredibly valuable because it not only includes donating viable whole organs like heart, skin, and kidney, but it also allows for donating tissues and other parts of the body for research.
- Dr. Moore added that they do collaborate with Life Sharing, which is a donate life organization so if there's ever the possibility that someone can make an organ donation that can be used for the purposes of transplant then those tissues would go there. Dr. Moore also thanked Ms. Patterson for sharing.
- Dr. Suzanna Afflalo thanked Ms. Concha-Garcia for her presentation and shared with the group her personal experience with organ donation. She mentioned that the biggest hurdle is getting the Black and Brown community involved and explaining organ donation because it is such a taboo in their culture and that we should continue to raise awareness.
- Ms. Concha-Garcia thanked Dr. Afflalo for sharing and added that she also does volunteer work for Life Sharing and that there is no age limit or health condition, that anyone can have a pink dot on their license or ID and that they can be a potential organ donor for other individuals or for research purposes. Ms. Concha-Garcia thanked the group for their time and mentioned she does a lot of community outreach presentations and that she works with another group to put out a HIV women's conference every year.
- Mr. James Jackson thanked Ms. Concha-Garcia for such a great presentation as well as Mr. Dallas, Dr. Moore, and Ms. Patterson for sharing their personal experiences.

## **Open Discussion**

- Mr. James Jackson thanked everyone in the meeting for everything that they do and opened the room for an open discussion.
- Ms. Judi Patterson shared that we are connected through our lived experiences and compassion and that everyone in the meeting is passionate about enhancing quality of life for our communities. She shared she is honored to be in the presence of individuals in which she can share her personal stories.
- Mr. James Jackson asked the group if there are any other comments.
- Dr. Eileen Pitpitan thanked Mr. Jackson and stated that it's a pleasure to be a part of the CAB. Dr. Pitpitan thanked the presenters for their excellent presentations and for stimulating such great conversations. Dr. Pitpitan thanked Ms. Patterson and Mr. Jackson and reminded everyone that it would be the last CAB meeting for a few months since they usually take a break in the summer. The next meeting will be held in August, with the possibility of coming together in-person. More information will be shared in the coming months.

## **Adjournment**

Meeting adjourned at 10:37 am