Community Advisory Board
MEETING

Tuesday, August 4, 2015

Note - 5:30PM to 7:30 PM – dinner & meeting

LOCATION: CAL ANDERSON HOUSE 400 Broadway Seattle 98122 (B’way + Jefferson)

TO JOIN THE ONLINE MEETING:

Go to https://defeathiv.webex.com/defeathiv/j.php?ED=308257592&UID=499032687&RT=MiM0

Provide your phone number when you join the meeting to receive a call back.

Alternatively, you can call:
CALL-IN TOLL-FREE NUMBER: 1-866-325-4292 (US)
CONFERENCE CODE: 253 140 7682

AGENDA – NOTE - 5:30 PM START

I. WELCOME & INTRODUCTIONS (1 min)
II. MDC CAB REPORT (3 min) Laurie & Paris to report
   A. Meetings
   B. Other news
III. OUTREACH UPDATES (Michael) (1 min)
   A. Michael went to Umoja fest on Sat Aug 1st
IV. CAN GENE THERAPY CURE HIV?
   COMMUNITY EVENT with NOBEL LAUREATE DAVID BALTIMORE & PAULA CANNON (30 min)

Facebook event page: https://www.facebook.com/events/1041034839242216/
a. **GLOSSARY AS PROGRAM** – a prime educational time ---focus the glossary on gene therapy. Michael will design, but needs help with the work

B. **CAB MEMBERS TO DO:**
   i. Program greeting folks
   ii. Microphone coverage
   iii. Potential set change transition (drumming)
   iv. CAB to Ask questions from the audience so that no all from Paris
   v. A thank you gift for Baltimore and Cannon, + words of thanks?
   vi. Promote among your friends, get them to come, get them to like the Facebook event or share it
   vii. Someone at the door of the Thomas building
   viii. Someone in the parking lot
   ix. Members to work a CAB recruitment table
   x. What else? Clean up? Set up?

V. **GT4HIVCURE CONFERENCE – AUG 13 and 14**
   A. CAB Volunteers for conference
      a. Registration day of
      b. Dinner/poster session (Space Needle)
      c. An idea to have CAB members walk around and record conversations with poster presenters to make into a video, ask them to explain the science and its implications toward a cure

D. . **FYI - OUR CAB POSTER WAS ACCEPTED TO THIS CONFERENCE AS WELL**

B. **COMMUNITY MEMBERS FROM OTHER CABS WILL ATTEND**
   A. WELCOMING GESTURE FROM DH CAB –(LINDSAY)
   b. Other ideas – dinner? going out? Socialize?

C. **POST CONFERENCE COMMUNITY UPDATE / SLIDES –(ERICK, MICHAEL)**
   a. Erick suggested one slide from each presenter
   b. For our **TUES SEPT 1 CAB MEETING**, we will put these slides into a webinar and offer it starting 6-7:30 housed at The Hutch for recording of the audio
      i. It will be nice to have all CAB members come in person to this, to make the webinar a multi-voiced dialogue that summarizes our gene therapy conference
      ii. Michael to ask KJ or HPK to attend as well.

VI. **CAB ABASSADOR VISITS - UPDATES – Bringing cure presentations to the community**
   The visits the CAB decided upon:
   - To a Black group
   - To a Latino group
   - To a Native group
Each other these to emphasize reaching young people
All ambassador visits should strive to happen before June 30th (before June 1 even better)

A. ENTRE HERMANOS - Oct 14, 2015 translation of CUREiculum slides/event (CAB lead: Manuel)
   A. Need to simplify and translate the Basics module, train the EH staff
   B. Deliver it to a live audience
   C. Video record the event
   D. Request for Portuguese x3

B. KING COUNTY YOUTH ADVISORY COUNCIL –
   A. Tuesday August 11th Now Sept 8th 5:30 to 7:30 PM
   b. Ask the youth council what they already may have heard about an HIV cure;
      solicit some feedback around messages, present truncated science around cue;
      promote CAB
   c. http://pugetsoundoff.org/blog/king-county-youth-advisory-council-meeting

C. VISIT WITH AFRICAN AMERICAN GROUP – (CAB lead: PARIS)
   a. Try to schedule with the DELTAS again after September (Erick?)
   b. Somali Health Board or other foreign born group? (Laurie, Dirir)

D. SEATTLE INDIAN HEALTH BOARD (NATIVE) VISIT (CAB lead – Bill)
   a. Do we reach out elsewhere?
   b. Manuel has a connection at SIHB!

VII. UPDATE FROM IAS 2015 VANCOUVER BC, July 17-22 start by 6 PM
    A. CAB ABSTRACT “BRINGING COMMUNITY TO CURE” accepted for poster presentation to both Toward an HIV Cure Symposium and the IAS 2015 Conference
    B. CHRIS PETERSON PRESENTATION (30 min)
       a. Chris won Young Investigator Award Special HIV Cure Prize from the International AIDS Society and the French National Agency for AIDS Research (ANRS)
    C. UPDATES from CAB MEMBERS ATTENDING (60 min)
       a. PARIS
       b. JAY
       c. ERICK
       d. MICHAEL
    D. PARIS REPORTS on NATIONAL AFRICAN AMERICAN MSM LEADERSHIP CONFERENCE ON HIV/AIDS AND OTHER HEALTH DISPARITIES (hold til Aug 4)
       a. Overview of highlights
    E. Next steps – bring cure to NAESM

VIII. OUR NEXT dH CAB MEETING Sept 1st – 5:30 PM dinner, 6 PM WEBINAR CAB meeting as a community webinar about CGT4HIVCure2015 to be held at Fred Hutch room TBA

IX. ANY ITEMS or NEW BUSINESS from CAB MEMBERS?
OTHER ANNOUNCEMENTS & EVENTS:

A. THE FUTURE OF defeatHIV- recompetition for $$$ every 5 years

Martin Delaney Collaboratories for HIV Cure Research (UM1)


DUE DEC 7, 2015

SEE ATTACHED DOCUMENT FROM MDC CAB “OPTIMAL INDIVIDUAL COLLABORATORY COMMUNITY ADVISORY BOARD (CAB) FEATURES”

B. PLEASE LET’S HAVE SOME REPRESENTIN’ ON THIS WEBINAR: THURSDAY AUGUST 6, 2015 AT 8 AM PT

CELL AND GENE THERAPY IN HIV CURE RESEARCH

Dr. Jerome Zack, PhD | University of California – Los Angeles (UCLA)
Jeffrey Sheehy, University of California – San Francisco (UCSF); CARE CAB

C. STELLA STEPS OUT Thursday, September 10 | 6:00 p.m.
Georgetown Ballroom 5623 Airport Way South | Seattle, WA

D. WORLD AIDS DAY 2015 Concert(s) Dec 1/Dec 5 MHHAN to take on the producing of this event. Michael and Kim co-chairing this effort

PARKING LOT ITEMS:

I. A. defeatHIV GLOSSARY edits – UPDATE (10 min)
   A. Manuel broke up the suggested additions into an organized list
   B. Jay, Laurie and Manuel (and Erick?) expressed interest in helping
   C. Next steps? Oversee?

B.

b. COMMUNITY PRIORITIES for HIV Cure research – Paris & Laurie

D. UPDATES TO OUR GLOSSARY – what terms from cgt4hivcure to add?


D. 3 COMMUNITY ACTION STEPS from THE WORD ABOUT AN HIV CURE for our CAB
   i. Registry of potential transplant donors
   ii. Advocacy around transplant issues for HIV+ donors
   iii. Enrolling in clinical trials

E. JOBS, ROLES, & OTHER WAYS YOU CAN SHARE YOUR TALENTS?
   POLICY & ADVOCACY, EDUCATION, CAB ADMINISTRATION, CLINICAL TRIALS, OTHER
F. **TRANSLATE** Cure presentations/info into Amharic or Somali, as well as French (Portuguese)

### 2015 DATES of defeatHIV CAB DINNERS + MEETINGS

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**OPTIMAL INDIVIDUAL COLLABORATORY COMMUNITY ADVISORY BOARD (CAB) FEATURES**

- Include a CAB member on the Executive Committee of your Collaboratory. We believe this is the best way to integrate community engagement into your leadership structure and the most significant way in which to demonstrate your clear intent to meaningfully include the CAB in your Collaboratory.
- Include at least one joint CAB/Collaboratory Executive Committee meeting annually so that your entire leadership is familiar with your CAB members.
- Include CAB participation with your Scientific Advisory Board (SAB). A presentation on CAB activities should be part of the annual SAB review agenda. Pursuant to the RFA, CAB members should meet with the SABs.
- Include what you intend to do to engage with the larger community through your CAB in educational activities, such as webinars, town hall meetings or other related activities.
- Include CAB member input in the protocol development process for any clinical trial involving human participants. This is standard practice in all other NIH-funded research consortia, and will satisfy the RFA requirement for "providing feedback on ethical and practical concerns to Collaboratory leaders in ongoing or anticipated Collaboratory research, particularly as research moves toward clinical application." This will ensure interaction with the CAB before decisions are made, giving the community an opportunity to provide meaningful input.
- Include a CAB member or other qualified community person on all Collaboratory Safety Monitoring or Data and Safety Monitoring Committees.
- Include CAB review of all direct communications to patients, e.g. informed consents, patient information sheets, recruitment materials, etc. Such written material should be given to the CAB in sufficient time for a meaningful review, before printing, publishing or distribution to patients.
- Include financial support for CAB activities in your proposed budget. Funds should cover Collaboratory staff time for managing the CAB and community engagement, including management of community engagement by Collaboratory staff, regular teleconferences and meetings with community stakeholders, involvement in Collaboratory meetings and teleconferences and appropriate community education, outreach activities and all related costs pursuant to RFA requirements.
OVERARCHING MDC CAB

- Include two Collaboratory CAB representatives for the MDC CAB
- Include financial support for attendance at one annual face to face meeting for your MDC CAB representatives
- Include financial support for attendance at one an annual national scientific meeting for your MDC CAB members
- Include financial support for one monthly MCD CAB teleconferences and other calls as needed
- Include financial support for MDC CAB educational activities and projects, including webinars, community forums, CUREiculum project and other such initiatives
- Include financial support for an MDC website to increase interaction with the broader HIV community and to increase knowledge and awareness about the collaboratories, the research being conducted and about cure research in general
- Support for an MDC CAB coordination

Potential CAB Members - Names and contact information for CARE, DARE and defeatHIV CAB members: