

## Summary Report of the 2017 National CFAR CAB Coalition Meeting Oct 31<sup>st</sup> – Nov 2<sup>nd</sup>

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Day 1:

We started the meeting off with introductions from the Director of the DC CFAR Dr. Alan Greenberg, Dr. Andre Ford chair of the NCCC, and Marcia Ellis the chair of the DC CFAR CAB. Followed by the “CAB Minute” presentations from all the attending CABs. Then we held the NIH/NCCC roundtable with Maureen Goodenow, M.D. and Gina Brown, PhD, from the NIH Office of AIDS Research. A number of good questions were posed by the group regarding community involvement in the prevention, treatment, and cure activities. They emphasized that the needs of the communities should be a driving force, and that communities need to be persistent in guiding the directions of research. Dr. Goodenow also specifically spoke of interfaith outreach, touching on some of the ideals Dr. Keifer is advocating. She also mentioned Rochester as a good location due to it being “rural” outside the South.

After lunch, we began with a presentation from the UNC CFAR Director Dr. Ronald Swanson. He presented a somewhat balanced accounting of the reasons for and against having the 2019 CFAR National meeting in North Carolina. We had our discussions about what way the NCCC would suggest to the CFAR as a whole as to whether or not a new location should be looked into. There was a vote, and this is when the majority decided to defer the matter until we could get insight from our local trans community. Informally, the feeling of the room is opposed to going to North Carolina at this time.

We then started regular NCCC business with a short presentation and discussion about the history of the word outreach. The main point was that “outreach” described the activity of going out and teaching the uneducated, but not working with them. That historically agencies would keep people boxed in, dumping information on them, but not providing any avenues for advancement from without the organization. The presenter suggests retiring “outreach” and instead encourage the use of the word, and the action of, “engagement.” Following that discussion we moved onto the concepts of community, and what it means today. For example, how community is truly everyone, and there can be smaller communities within the larger whole, but that we should try not to lose focus on the whole, while building stronger relationships with the smaller. Again, the idea of moving beyond outreach was presented, and to broaden the focus on being “community builders.” In that vein the topic of new Inter-CFAR working groups was discussed. Again Dr. Keifer’s name came up as someone who believes in and encourages CAB involvement. They will be sending out a list of inter-CFAR CAB working groups, and any CAB members who are interested are welcome to join in. I will pass it along when I receive it.

We met in our sub-committees. I chose to join the Mentoring sub-committee, which focuses on helping new CABs when they are starting up. I thought it would be a good idea, as we have often talked about how our CAB has stagnated a little bit, and I might get some new ideas, or resources to re-invigorate our engagement. In a turn of events I wasn’t expecting, I am going to be assuming the role of the chair of the sub-committee. I will keep everyone apprised of things as that moves along. The last bit of business we discussed for the day is that the NCCC has run out of funding. In 2014 the CFARs were asked for a small donation to fund the NCCC, at that time only 1/3 of the active CFARs gave any money, and fewer still gave the full amount asked for. There will be a new funding letter sent out soon which will ask for funding at a tiered level based on CFAR site size. I have already begun the conversation with our CFAR Administrator Laura, and when the letter comes out I suggest we advocate for the funding of the NCCC.

Day 2:

After breakfast we began our day of “Community Sessions”, four panels discussing different aspects of community engagement. They were all very informative, and I do not think I could do them justice to simply summarize them here. Below are some points made by the panels, thoughts from myself, and standout comments from others are below:

#### Session 1: Integrated HIV Prevention and Care Planning and Opportunities for CFAR

- Comment – CFAR might want to consider investigating the possibility of a national participant bill of rights.

#### Session 2: Community Engagement: Grassroots strategies to finding your own solutions

- We want a healthier, more research literate community
- Communities should seek to partner with investigators in the early stages of their careers to help guide their focus.
- Email has become an ineffective method of keeping people engaged, simply due to the amount of email people receive nowadays.
  - Texting and other more modern forms of engagement should be encouraged.

#### Session 3: We’re all in this Together: Community Engagement and HIV Research in the District of Columbia

- How does information make it back to the community?
  - Lay people do not read scientific journals, and when they try they are often overwhelmed by the scientific “jargon.”
  - Many in the community, especially the black community which has a sordid history with “scientific” research, that researchers are selfish “users.”
    - Helicopter researchers, who fly in get what they need, and then leave. Often never returning to continue to engage or even discuss the outcomes of their research
- Women in DC have begun to take up PrEP, but only at 1:10 the ratio of at-risk men. (2015 Q1)
- Dr. Michael Kharfen noted that in discussions with patients he no longer uses the term AIDS, but rather uses what he considers the more accurate term of HIV Stage 3. This is not a change in the science, but simply a recognition that AIDS has such heavy connotation and it isn’t accurate in the modern treatment era.

#### Session 4: Innovative approaches to disseminate research findings in community settings.

- More discussion of the use of social media to get the word out
- The use of more dynamic graphical flyers and information over word-heavy pamphlets.

We concluded the NCCC meeting with a wrap up, and a picture.



That evening I attended the CFAR Faith and Spirituality Research Collaborative Meeting presented by Dr. Keifer. It was a small meeting but was attended by those who are very active in their faith communities. Khadijah Abdullah gave a presentation about the National Faith Aids Day initiative where they held a rally in DC and other locations around the US on the last Sunday of August. The intention is that this will become a yearly event.

The final day was the CFAR Scientific Symposium at the National Academy of Sciences. The highlight was Dr. Fauci's afternoon plenary presentation: "Ending the HIV/AIDS Pandemic: Follow the Science." The speech was essentially a summary of his, at the time, most recent article in the Journal of the American Medical Association. In which he talked specifically on the role of a vaccine in ending the epidemic. He asserts that while it may be technically possible to end the HIV epidemic without a vaccine, it is unlikely happen. He actually focused a bit on the broadly neutralizing antibody study which Dr. Kobie presented to our CAB in September. He also discussed how even though many other vaccines have an efficacy in the 90% range, the target for an HIV vaccine to turn the tide would be in the 50-60% range. I have obtained a copy of the article for anyone who might be interested in it.

Thank you again for sending me as the representative for our CAB, and I look forward to discussing the ideas I have brought back from it in future meetings.