



The mission of the CFAR is to provide a multidisciplinary environment that promotes basic, clinical, behavioral and translational research in the prevention, detection and treatment of HIV infection.

Center for AIDS Research

University of North Carolina at Chapel Hill

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NEWS BRIEF:

-MARK YOUR CALENDARS!!

December 1, 2011 is World AIDS Day! The theme this year is "Getting to Zero": Zero New HIV Infections, Zero Discrimination, and Zero AIDS Related Deaths. The UNC CFAR CODE Office is hosting a special outdoor yoga and awareness event on UNC Campus at the Pit from 2:30 to 3:30 pm on this date. More details to come soon! For general information on World AIDS Day, visit: www.worldaidscampaign.org/

-For more information on Julian's Heart to HAART project and a film trailer, visit: <http://www.dosomething.org/project/heart-haart-state-hivaidsmovement>

-The AIDS 2012: XIX International AIDS Conference is coming to the United States! The conference will be held from 22 to 27 July 2012 in Washington, DC. Now is the time to start working on abstracts and booking hotels! For more information, visit: <http://www.aids2012.org/>

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Looking Back to Look Forward: A Short History and Future Plans for the UNC CFAR and its Community Advisory Board

This past month, the Community Advisory Board (CAB) for our UNC Center for AIDS Research (CFAR) convened for their quarterly meeting. Dr. Ron Strauss, CODE Office Director, Executive Vice Provost of UNC-Chapel Hill, meeting facilitator and one of the CAB founders, has been organizing these meetings since 1998. Strauss told the CAB the story of the creation of the CFAR and the origins of its CAB.

Before the CFAR was even created, community members asked UNC to develop a research center to study HIV/AIDS. In order to successfully create such a research center to investigate relevant biomedical and social topics associated with HIV/AIDS, an organized community voice was needed. The CFAR Community Advisory Board was created as just such a forum for perspectives from the North Carolina community and it included researchers, students, activists, and people living with and affected by HIV/AIDS. At that time, Project LinCS was underway in the community and they were examining how to best link scientists and communities around issues of HIV/AIDS. Strauss and his fellow researchers had published newspaper supplements about their research results in local newspapers, made presentations on television, and on radio, and were seeking to communicate about AIDS research in jargon-free ways so that the community could be fully involved and engaged. Years later, the CAB continues to meet several times a year to assess the constantly changing needs of the community and ensure that research is being conducted in a way that is conducive to not only studying, but helping and contributing to the community.

At the fall 2011 CAB meeting, Dr. Strauss said to the members of the CAB, "Does this CAB meet your needs? If not, let's change it!" This attitude of respect for community members and their needs is one of the main reasons that the UNC CFAR has been so successful at bridging to communities. It was explained that "this CAB blends community participants, stakeholders, and researchers in a unique way"; this stands in stark contrast to other CABs which are often created for the purpose of advising one specific study (as opposed to a whole community and research center). A lively discussion ensued that highlighted the high esteem that individual CAB members from different walks of life hold for the board and the CFAR. CAB members told of their experiences as past research subjects, and brainstormed about how better to empower subjects in AIDS-related projects.

Sharon Parker, a UNC Social Work doctoral

student and member of the CAB for several years, commented that being a part of the board "lets me think more about the ethics of my own research" on a daily basis.

Parker made thoughtful suggestions about how to more effectively engage the community in current research projects. She proposed scheduling events for community input *before* a research project is begun and to more consistently provide community members and research participants with incentives and updates on the results of studies in which they themselves and their fellow neighbors participated. Parker stated, "My research is a voice for the people I represent", and the CAB was in complete agreement with her sentiment. In response, CAB member Randy Rogers informed the CAB of a research literacy curriculum currently being prepared for piloting by the LinCS 2 Durham project, which will serve to educate individuals on how to interpret and understand the research studies being conducted in their communities.

Rogers explained that problems often start at the initiation stage of a research project; conversely, if community members are included and educated from the start, the results are beneficial for all. Rogers said that "in order to effectively force strong ties in the community, a lot of research and ethnography is needed". Additionally, Rogers encouraged CAB members to "do the unconventional" in the communities of interest, such as working in a local clothing closet or thrift store and attending community fairs and events in order to become a familiar face as a research representative.

One HIV-positive CAB member shared, "With my own status comes a responsibility to contribute something to the world of research". He shared his experiences as a participant in Project SafeTalk at the UNC CFAR several years ago, and in a very heartfelt exchange, the CAB realized that one of the researchers involved in that very study was at the table now as a CAB participant. Virginia Thomas, CAB member and UNC student, explained that hearing the community voices at CAB meetings helps her to "break down the power dynamics of research" and allows her to "stay congruent with an ethics of moral justice" while working to pursue her career as an HIV/AIDS social researcher.



CAB members network and collaborate at the fall meeting

UNC CFAR and CAB, Continued from Page 1

In response to the original question posed by Dr. Strauss, CAB members suggested a few ways to improve the CAB. These included: sharing about HIV/AIDS or community work currently undertaken by CAB members, adding more community members to the board who are not researchers or involved with the university, using social media as a vehicle for communicating in-between CAB meetings, and collaborating to promote a CAB-sponsored event in the community.

UNC CFAR's CAB is a vibrant, on-going way to bridge between scientists and community members to assure that common goals are being pursued both in the choice of research directions and in the actual conduct of research.

Heart to HAART: A Dose of Hope in the Age of AIDS by Julian E. Wooten

I remember that day as if it were yesterday. Frantically I flipped through Inorganic Chemistry notes, while sitting in a drafty dorm room, trying to memorize the pertinent tidbits from weeks of lectures. The final exam was at 8 AM the next morning, and I had miles to go in my journey to be ready. I said another prayer, and prepared to dive into another chapter when softly my phone began to ring. The caller ID displayed the name of a very close acquaintance with whom I hadn't spoken for a while. I looked at my phone then back at my notes. The Inorganic textbook was calling my name but I wanted to acknowledge my old acquaintance for a moment.

"Long time no talk, stranger," I teased, waiting for him to jab back at me. There was silence.

"Hello," I asked gingerly. I could hear breathing but no words.

"Julian," a shaky, broken voice returned.

"Yes," I replied nervously.

The conversation was charged with a visceral gravitas that I can still feel.

"I have something to tell you, Julian,"

"Okay..."

"I found out yesterday..."

"What..."

"I have it. I have HIV,"

I was stunned. I felt empty. I felt helpless.

"What does this mean?" I asked. I was hoping and praying to hear something...anything that would assure me that the situation would be fine. Slowly we begin to talk about what had happened and how he came to discover that he had HIV. He used many terms that I had never heard before like viral load and T-cell count. Seemingly in an instant, he was dealing with this life changing event. Our conversation begin to wind down as we both digested the moment

"I wish I had known," he said quietly. We said our goodbyes and ended our call. I sat in silence taking in everything. His final words resonated with me. He never left my mind or my heart for the next few weeks. I called at the end of the month to follow up with him but I never reached him. Two years later, a mutual friend called me to inform me that he had passed away.

Again, I was devastated. I went back to that night and his words wishing that he had known more about HIV. Although I was alone, I promised him in my heart that I would do something to make a difference. I believe that he heard me.

I continued to work through the Biology and Chemistry program at the University of North Carolina, but I always kept in mind what I could do to make a difference. In the meantime, I read everything that I could about HIV/AIDS. In order to help others, I had to empower myself by learning all that I could about the infection.

A couple of years, after I graduated I begin to research the impact that HIV/AIDS on the state of North Carolina. I was devastated by the dramatic toll that HIV was taking on the state especially in the rural areas. I found an article that there were cuts in funding for the AIDS Drug Assistance Program which supplies medication to those that couldn't afford the expensive antiretrovirals. In the article, which interviewed a person who would be affected by the cuts, when asked what could people reading the article do to help, he answered the reader should spread the word to everyone possible about the cuts. Also, he requested coming to the NC AIDS Action Day at the NC State capital to lobby for more funding for the program.

I knew after reading that article that I would be there to do my part to lobby for the HIV/AIDS community, but I wanted to do more. To capture the stories and chronicle the struggle, I decided to make a documentary to give a voice to all the people who would be at the State capital advertising. I wrote up my idea and sent it local production companies to find partners that could assist in the camera work. I was amazed by the strong response that I received from the community. Ultimately I paired with a production company known as Tough Spun Productions, based in Winston Salem. On May 25, 2010 we recorded interviews from leaders in the movement for the HIV/AIDS community,

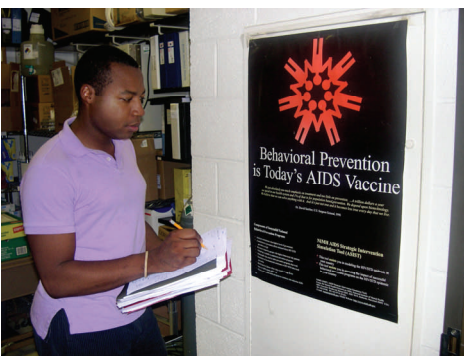
those living with the infection, and those who had a personal connection to fighting HIV/AIDS. On World AIDS Day, December 1, 2010 the documentary premiered to much press. It felt right, and it started my HIV/AIDS campaign.

Following this success, I wrote articles about HIV/AIDS for the local campus paper and found that people were very interested in the topic of HIV/AIDS. Each week after my columns would run, I would have people tell me that they learned a lot about HIV/AIDS from reading my work. I wanted to do even more on a grander scale, so I launched a national program titled, "Heart to HAART." In this program, I seek to record the stories of people living with HIV/AIDS and edit them into a video that will be distributed to our partners across the nation. There our partners will form a corps of peer educators that will use the video to advocate and educate about HIV/AIDS. The program begins a chain reaction of people helping people.

Even now there is much work to be done. We are in the process of forming partnerships across the nation and soon will begin recording stories of the people living with HIV/AIDS each day. In all that I do, I hope to make a difference in the fight against HIV/AIDS. Helping to do my part in the fight against the infection is what I promised to do those years ago. This is just the beginning.



Julian discusses his project with CAB members after the quarterly meeting



Julian does research for his Heart to HAART Project