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Bringing community to cure

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Background: Community engagement is essential for successful HIV Cure Research. Individuals with HIV will need to be aware of the potential and risks of HIV cure research in order to make informed decisions about participating in clinical trials. Those with and affected by HIV are needed for advocacy, ethics discussions, and messaging feedback. The defeatHIV Community Advisory Board (dHCAB) is an effective catalyst for community engagement and feedback between HIV cure researchers and the community, as well as for collaboration among different local HIV-related CABs, such as those for CFAR, ACTU, and HVTU. The dHCAB is the local CAB for the defeatHIV Martin Delaney Collaboratory based at Fred Hutchinson Cancer Research Center in Seattle, WA, one of three NIH-supported cure collaboratories.

Methods: The dHCAB has employed multiple strategies for community engagement, including: community forums with HIV cure research leaders; opportunities to meet Timothy Ray Brown; providing multi-cultural food and music at education events; holding community events at different community organizations and venues; visiting agencies to engage them in cure research; tabling at events such as the annual AIDS walk and pride festivals, theater productions, etc; webinars; active use of social media, including Facebook, Twitter and Youtube. Those on the dHCAB have had the opportunity to attend and present at scientific meetings and to provide input to researchers on protocols, informed consent documents, and recruitment.

Results: Over 1000 community members have participated in dHCAB events and we have reached thousands more through outreach. The dHCAB currently consists of 12 members. Members range in age from high school to senior citizens and include women, gay and straight men, individuals in recovery, newly diagnosed individuals and long term survivors, African-Americans, Asians, Latinos, and Native Americans. Programs typically bring in dozens to hundreds of participants. The defeatHIV investigators consider the dHCAB a valuable asset and partner and have taken feedback to heart. We have learned about community concerns and provided meaningful pathways for education and dialogue.

Conclusions: With creativity, perseverance and respect it is possible to engage the community and researchers in meaningful ways that will advance HIV cure research.