

THE END FALLS ON US: ELEVATING THE CONTINUED NEED FOR COMMUNITY LEADERSHIP IN ENDING THE HIV EPIDEMIC

by Edric Figueroa

Interview with community leaders Angel Fabian, Venton Hill-Jones, and Evany Turk

On Feb. 5, 2019, President Trump announced a federal plan to End the HIV Epidemic (EHE). EHE will invest financial resources in 57 of the highest-HIV-incidence cities, counties, and states in the U.S. in order to ramp up testing, prevention, treatment, and related services. The ultimate goal is to end the domestic epidemic by 2030.¹ Communities of people living with HIV and those invested in addressing the societal inequities that increase HIV transmissions in these jurisdictions have been mobilizing for accountable, effective, and inclusive EHE planning and implementation since the announcement. Now, more than halfway through 2020—a year of debilitating impacts of COVID-19—meeting the goals of EHE requires revitalized local action and the political will to sustain safety nets for the communities most affected by both viruses. TAGline interviewed three community leaders for their perspectives; they pointed to several key themes surrounding COVID-19’s impact on progress to end HIV in the U.S.

The contemporaneous challenges and commitments to survival

“In the era of COVID, many of the same detrimental policy issues to ending the HIV epidemic are at play: poverty, systemic racism, lack of expanded Medicaid, and the need for universal healthcare and economic justice,” says Evany Turk, national field organizer at the Positive Women’s Network (PWN). Still, there is a heightened attention to survival among PWN members.

“We have lost members ... our members have lost family, friends, and employment. We are first and foremost trying to support our base,” Turk said. PWN is offering up to \$250 to



Angel Fabian: Advocacy Coordinator, Fijate Bien Mpact Global

its members for assistance with basic needs and is maintaining a virtual support group to combat the sense of isolation. “Our members understand that no one is going to advocate for us, women living with HIV, so we have to do it.”

Even before the COVID-19 pandemic, Angel Fabian, Fijate Bien advocacy coordinator at MPact, was organizing listening sessions and advocacy trainings at the U.S.-Mexico border, in Puerto Rico, and across the Central Valley of California. They reported that HIV was not a high priority for most of the Latinx gay and bisexual men and transgender people they had met with. Instead, access to basic needs such as food, housing, and income took precedence.

Fabian grew up in California’s Central Valley, which is a site of mainly migrant agricultural communities. In this area, there is only one community health center (CHC) that provides services to over 1,000 low-income and/or uninsured community members living with HIV. California currently has a \$54 billion

budget deficit as a result of COVID-19.² Fabian worries that without the right advocacy, the first programs to get cut will be safety-net programs such as Medicaid, Medicare, emergency rooms, food stamps, and CHCs. “People who depend on the AIDS Drug Assistance Program and other Ryan White HIV/AIDS programs get all their services from this one source. If this clinic shuts down or is forced to reduce services, I can’t imagine the consequences this will have on people living with HIV and on the HIV epidemic in the Central Valley.”

“Black communities have always been in a state of emergency when it comes to public health disparities in the South,” says Venton C. Hill-Jones, founder and chief executive officer of the Southern Black Policy and Advocacy Network (SBPAN). “When we are dealing with any epidemic in this country, Black communities are the first to feel its full impacts.” Hill-Jones said that the higher death rates in communities of color from COVID-19 and HIV are about social justice: “In addition to biomedical strategies to fight these epidemics, we need strategies to address anti-Black racism in health departments in the South.”

The need to build and actualize local and collective power

COVID-19 has limited the capacity of health departments to offer necessary HIV care and prevention services.³ Engaging the community members who are at risk of HIV because of a lack of access to resources for feedback on EHE plans has become a harder, but still crucial, task. A task that is also a requirement under two major EHE funding sources for public health departments and qualified health centers, the Centers for Disease Control and Prevention (CDC) notice of funding opportunities PS19-1906⁴ and PS 20-2010⁵.

Fabian moves sensitively through the larger Latinx community: “In many of these communities, individuals have never heard of a federal plan to end the HIV epidemic.” Fijate Bien conducts trainings, largely for recent immigrants and monolingual Spanish speakers, which center the value of community-led solutions. Fabian hopes leaders will walk away ready to create their own processes to effectively address HIV prevention, care, treatment, and advocacy.

At PWN, many members are part of planning coalitions for ending the HIV epidemic. Turk reports hearing that members



Evany Turk: Field Organizer, Positive Women’s Network

across different states don’t believe that their community of women living with HIV (the majority of whom are Black and women of color) is being listened to. As a result, PWN leaders continue to advocate for leadership from women living with HIV in EHE. Through monthly policy updates and member engagement in local coalitions, PWN is raising its community voices when it comes to EHE and other policy issues affecting women living with HIV.

When founding SBPAN in 2018, Hill-Jones did not want to duplicate efforts already taking place in the South. “We brought in women, Black gay men, young people, adults over 55 living with HIV, faith leaders, and trans communities into a Southern Black HIV/AIDS Network,” he said. Hill-Jones created the network to advance the capacity of its members to affect federal, state, and local HIV policy, programs, and research. SBPAN was activated immediately after the announcement of the first EHE funding opportunity, PS19-1906. When health departments finally submitted EHE plans on behalf of their communities in December 2019, many SBPAN members had not seen the draft plans. As a result, over 20 members in nine Southern states sent a letter to the CDC and the Department of Health and Human Services

calling for the inclusion of Black Southern voices in EHE. The CDC provided feedback to the EHE plans submitted by health departments and extended deadlines for revisions thanks in part to the advocacy of groups like SBPAN.

An increase to national-level consciousness demands equally profound commitments to human rights

Since its inception, PWN has been committed to advancing racial justice and unlearning racism, but the Black Lives Matter (BLM) movement warranted deeper conversations on anti-Black racism. PWN supported its Black staff members to establish a day that celebrates and honors Black women living with HIV, and in 2021 the organization will launch a series of inaugural events that will educate and honor Black women living with HIV. The first #CelebrateAndHonorBlackWomenDay will be March 12, 2021.

PWN has also maintained fervent advocacy on molecular HIV surveillance, a key feature of the “Respond” EHE pillar.¹ Molecular HIV surveillance is genetic sequencing of viral fragments of HIV, which indicates their variation in ways that can be used to track and intervene in clusters of new HIV transmissions. Like many activists, Turk cautions that putting this data into a larger data assemblage that could make determinations about transmission directionality may have criminalizing implications for communities that are already experiencing disproportionate burdens of stigma and racism.⁶ Through the support of its members and in collaboration with other HIV advocacy organizations, PWN launched the Health Not Prisons Collective in direct opposition to implementing methods like molecular HIV surveillance without assurances that such data will not be shared with the criminal justice system. The collective serves to highlight the ways that carceral solutions to public health issues cause unnecessary harm and to invest in community-led solutions to undo structural harms.

“The Black Lives Matter uprisings revealed what HIV advocates already knew ... there is a strong need to address racism, transphobia, and homophobia, particularly in the South, where the full consequence of not addressing these issues can be seen,” Hill-Jones said. “An increasing number of HIV criminalization cases, more targeted attacks to communities of color, and less political will from leaders to improve conditions” are just a few of the implications of the institutionalized

prejudices he names. “As we have conversations around the preservation of Black lives in the context of policing, we also have to have it about public health ... so many Black lives have been lost due to COVID-19⁷, HIV, and other preventable illnesses.”

In February of 2020, SBPAN launched an HIV Advocacy Needs Assessment: Health Policy and Advocacy Opportunities for Black Communities in the South. Hill-Jones hopes that “no matter their previous advocacy experience, communities will find it useful for developing a more informed and better equipped engagement of systems affecting HIV health outcomes for diverse Black communities in the South.”



Venton C. Hill-Jones: Chief Executive Officer of the Southern Black Policy and Advocacy Network

The rising rates of HIV in Black and Latinx communities in the South are also no surprise to Fabian, who says that the living conditions and the socioeconomic challenges are similar in both communities.⁸ “The BLM uprisings illuminated the prejudice overlooked for too long in the Latinx community,” Fabian said. “We have been forced to have conversations around racism ... with our grandparents, parents, and even with the Spanish media that perpetuates anti-Blackness.” Fabian hopes this moment will help communities focus on how to better show up for each other and build intentional coalitions.

For Fabian, making the links between HIV and the human rights violations occurring in migrant communities across the U.S. is critical. “The administration is not helping EHE and is using the COVID-19 pandemic as a scapegoat to violate international law by deporting asylum seekers back to their countries of harm.” These deportations are in direct contradiction to what experts say will help stop the global spread of COVID-19: a suspension of all deportations.⁹

Preparing for all possible scenarios

PWN has “known for a long time how to end the epidemic,” Turk said. “A big part of our successes is that members tell their personal stories of how structural barriers have prevented them from accessing key services as a tool for interpersonal and systemic change.” Turk said that the work of PWN has always been to prepare its base for whatever is ahead, even if it is resistance. Of course, she said, PWN would love to have an administration that’s willing to work with them. Either way, Turk said, they are “ready to do the work.”

“We have a very important role ... to make sure that our ideas are included with intention and ensure that EHE plans have the strong foundation necessary to be successful,” Hill-Jones said. “Hopefully, what this moment in history has taught us is to understand the specific approaches necessary to end HIV in diverse communities.” For Hill-Jones, such an approach must go beyond just listening to Black communities and toward advancing advocacy that dismantles the anti-Blackness embedded in U.S. institutions.

“This moment is an opportunity for everyone to ask themselves how they can become better allies to each other’s struggle,” Fabian said. Whether it is the current or a new administration, U.S. leadership must use this sentiment as a guide and engage meaningfully with the community leaders whose input is critical to achieving the 2030 EHE goal.

Evany Turk is national field organizer at the Positive Women’s Network. Angel Fabian is advocacy coordinator for Fijate Bien at MPact Global Action for Gay Men’s Health and Rights. Venton C. Hill-Jones is founder and chief executive officer of the Southern Black Policy and Advocacy Network.

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