Yours in the Struggle

Honoring 30 Years at NMAC

August 19, 2019 By Oriol R. Gutierrez Jr.

Paul Kawata is executive director of NMAC (formerly the National Minority AIDS Council). The non-profit organization seeks to normalize discussions about race and ethnicity within the HIV movement, bend the curve of new HIV diagnoses and retain people of color living with HIV in care. In 2019, Kawata commemorates 30 years leading NMAC.

What does your 30th anniversary at NMAC mean to you?

I came to Washington, DC, in 1985. It was the start of President Reagan's second term. We were told a cure or vaccine would happen in five years, so I left my family and my friends in Seattle kind of naively to help.

For me, this anniversary is about honoring the people who came before me and the leaders I got to meet along the way. I owe a great debt to so many who, for whatever reason, saw this kid and said, "Come to Washington."

This occasion also gives me the chance to talk about how we're finally going to end the HIV epidemic. Even if we were to end the U.S. epidemic in 2030, there would still be more than 1 million people living with HIV who will need care.

We have to make sure that we're building the next generation of leadership to continue to do the work.

Tell us your goals for NMAC's 2019 United States Conference on AIDS (USCA) and the Biomedical HIV Prevention Summit.

USCA will take place September 5 to 8 in DC, and the summit will be from December 3 to 4 in Houston.

Before USCA, the Centers for Disease Control and Prevention (CDC) will have released a funding announcement to 57 jurisdictions to put together their planning councils and build plans to end the epidemic in their jurisdictions.

As a result, USCA will focus on helping those jurisdictions. We believe there will be a short turnaround time for their plans, so folks need to hit the ground running. I've heard the federal

government is committing up to a billion dollars.

Since USCA is about building plans, the summit is about their implementation. What does it take to reconnect the 400,000 people who have fallen out of HIV care back into care? What does it take to get 1.1 million Americans on PrEP?

Advocates interrupted a speech by CDC director Robert Redfield, MD, at AIDSWatch in April in the wake of reports that the federal government wasn't using its patent rights to pre-exposure prophylaxis (PrEP). Will he attend USCA?

Dr. Redfield will attend. Instead of giving a speech, he will be interviewed onstage in the style of Sunday political shows.

A special guest will start the session with a one-on-one interview with Dr. Redfield. We'll then go to a few panel discussions to air out the topics raised.

We'll be planning for a protest to happen. USCA would not be USCA if there wasn't a protest. Protests are in the DNA of our movement, so we honor and support them.

I believe part of why HIV got the support it did was that advocates said, "No more." People had the courage of their convictions to stand up to systems that were unfair.

Protests are part of how oppressed communities get to speak their truth. Protests are a way for communities who do not have access to have a voice.

What is NMAC doing to help the next generation of leaders?

My generation is aging out. After 30 years, I'm getting close to retirement. I acknowledge that I have a responsibility to make sure the next generation of leaders is prepared to take over.

I had a meeting recently with PrEP advocates from the #PrEPforAll campaign. They were very impressive. I told them that part of what made them so important to me was that they are the next generation.

Early leaders have spent so much time just trying to stay alive and above water that I don't know if we've been as good at building up the next generation as we could've been. I worry.

I'm involved in many different projects that are looking at this challenge. I don't want to leave this next generation to have to solve all the problems by themselves.

You mentioned PrEP advocacy. Tell us your thoughts about Undetectable Equals Untransmittable (U=U) advocacy.

I wrote an article recently about the difference between treatment as prevention (TasP) and U=U. TasP was created by scientists. U=U was created by community.

I believe federal leaders need to understand that we have to listen to community. If we don't do

that then we're going to get solutions that don't speak to community.

Prevention Access Campaign made U=U part of the zeitgeist of our movement. U=U has inspired people living with HIV not to just take control of their lives but also to save their community. I think that is extraordinary and powerful.

You've been in the fight against the virus since the early days. Many people would consider you a long-term survivor, even though you are HIV negative. Please share any insights on how you've managed to continue on as an HIV advocate.

I am one of the founders of the defunct National Association of People With AIDS. There were 33 of us—I'm the last one alive.

I didn't understand it at the time, but now I do, that you needed someone there who could tell the reality of what those days were like. I unfortunately have that job.

I'm a mess. There were some very real long-term issues that I had to manage in my life because of what I had to do in those early days. There are ghosts that still haunt my life because of the number of hospital beds I visited and funerals I planned.

I was so young when I stepped into this job that I didn't understand how much it would stay with me. We are a generation of activists—whether we're living with HIV or not—who live with what I call posttraumatic stress from that time.

Sometimes we don't talk about it, so part of why I am talking is because there's so much stigma around mental illness, especially depression. There is this expectation that if you're a leader you have everything together. Well, my life isn't together. The memories of the people I lost continue to hurt me.

I say these things because unfortunately we are now seeing all these long-term survivors who are having real issues right now. I want everyone to understand that it's not their fault. We are messed up and with really good reasons to be.

Part of ending the epidemic is about healing. I got therapy during the darkest days of the epidemic. I'm going to be starting therapy again. It's a bit of a full-circle moment for me.

I want us to remember the amazing activists who are now gone. We get to end the epidemic because of their courage and bravery and sacrifice. As we do, we hopefully get to heal.

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