30 Leaders Look to the Future of HIV

As POZ marks 30 years of service, we reflect on what's next.

March 25, 2024 By Mathew Rodriguez

Anniversaries present an opportunity to pause and reflect—not only on the progress that lies along a journey but also on the challenges ahead. In the HIV community, we know that these moments are great for sharing knowledge and refueling. That means POZ's 30th anniversary is a perfect time to share wisdom gained in the fight against HIV. To that end, we spoke to 30 leaders in the HIV community and asked them each a question about an aspect of the ongoing AIDS epidemic that they know best.

Their answers represent decades of experience, sweat, love, grassroots organizing and setting the table and sitting down at it. The people we surveyed span many disciplines within the HIV field: Some specialize in harm reduction, others in criminalization, some in prevention and others in treatment. Combined, they are just a small portion of the large number of people working to create a better world for those living with HIV as well as the communities that shoulder the heaviest burdens of the epidemic, including LGBTQ people, people of color, women and more.

These answers have been edited for length and clarity. The leaders are presented in alphabetical order.

GUY ANTHONY

President & CEO, Black, Gifted & Whole Foundation

Courtesy of Guy Anthony

How is education part of the fight for health justice for Black men?

Black queer men are more than their sexuality. They can be seen in their wholeness. If education is the great equalizer, then they must have access to the same resources, financially and emotionally, that their counterparts do. We awarded our last cohort, who are studying STEM [science, technology, engineering, mathematics] at their respective HBCUs [historically Black colleges and universities], $5,000 to offset costs. We have monthly, sometimes weekly, check-ins. We celebrate their small victories and hold them accountable when they fall short. We treat them like they matter because they do.

JEFF BERRY

Executive Director, The Reunion Project

Jeff BerryCourtesy of John Gress

What do long-term survivors have to offer in the ongoing fight against AIDS?

It’s critically important that we preserve and share the unique and diverse experiences of long-term survivors. Research advocacy is one area where we can provide mentorship and training. Many of us have been providing input on clinical trial design and research for years. Others of us have volunteered for studies, given blood, even carried out and published some of the research ourselves. There needs to be a more formalized structure to help train new research advocates.

KEIVA LEI CADENA

Co–Executive Director, Positive Women's Network–USA (PWN-USA)

Kevia Lei CadenaCourtesy of Kevia Lei Cadena

How can we continue to meet the needs of women and girls living with HIV?

Despite the high impact of HIV on Black women and trans women, we still aren't consistently practicing effective ways to dismantle anti-Blackness, misogynoir and anti-trans language and behaviors in our spaces. The threats against women's reproductive rights and gender-affirming care threaten our HIV work, and these issues disproportionately affect Black women and women of color living with HIV.

SHELBY CHESTNUT

Executive Director, Transgender Law Center

Shelby ChestnutCourtesy of Shelby Chestnut

How are the current pushes against transgender people in the United States and the fight for health justice interrelated?

I think these are so closely connected, because, ultimately, lawmakers are seeking to limit people's basic human rights and bodily autonomy. But we know firsthand that our communities are resilient and are working in broad coalitions to make sure they have access to health care. Conservative lawmakers are spending millions each year to target trans communities, and, even with limited resources, our communities are fighting back and stopping many of these unconstitutional laws from going into effect.

TORI COOPER

Director of Community Engagement, Trans Justice Initiative, Human Rights Campaign

Tory CooperCourtesy of Tory Cooper

How do HIV prevention and care factor into the fight for trans rights?

I see the trans and LGBQ communities as living through three epidemics: the ongoing fight against HIV/AIDS, COVID and an increase in anti-trans and LGBQ legislation and rhetoric. Society's loud conservative minority is attempting to legislate every aspect of our existence. These are folks who fought public health strategies based solely on personal beliefs. They fought against sex education and condom campaigns, and now, they are tying up the courts with frivolous and dangerous legislation to deny access to gender-affirming care.

PORCHIA DEES

Advocacy Consultant

Porchia DeesKevin McDermott

What about your work in the AIDS community gives you hope right now?

People born with HIV are now being included in discussions regarding HIV and aging and recognized as lifetime survivors. It gives me hope that we got onstage at USCHA 2023 and let the HIV community know who we are. We demanded inclusion and for the community to no longer make us an afterthought. We demanded that we be reflected in research, policy, programming and at decision-making tables. We demanded funding for dedicated initiatives designed and driven by our population.

DANIEL DRIFFIN, DrPH

Cofounder, Thrive SS

Daniel Driffin, DrPHCourtesy of Daniel Driffin, DrPH

How can the public health field better account for the experiences of Black queer men?

We need more Black queer men in meaningful positions inside institutions creating policy and implementing services. I can count the number of Black queer men at local and state health departments on less than one hand. When you extend the search to the federal government, it is the same story. I, along with others, have and will continue to create novel organizations and

initiatives detached from public health due to not having a space at the proverbial table.

GRISSEL GRANADOS

Senior Director of Youth Education, Planned Parenthood Los Angeles

Tami HaughtCourtesy of Grissel Granados

What about your work in the AIDS community gives you hope right now?

Mobilizing lifetime survivors is something I have been passionate about for a long time, and I am excited to see that things are finally coming together for a national community. This is the right time because we are now adults who can speak for ourselves, leverage our skills and expertise, and create a movement led by us directly without outside influence.

TAMI HAUGHT

Co–Executive Director, The SERO Project

Tami HaughtOctavio Jones

How has the conversation around HIV decriminalization changed in the past 10 years?

More people are working and talking about HIV decriminalization. For the first time, a president, President Biden, mentioned HIV criminalization in his World AIDS Day statement and boldly declared, “We have to follow science, and that means eliminating the laws that perpetuate discrimination, exacerbate disparities, discourage HIV testing and take us further away from our goal.”

KRIS HAYASHI

Director of Advocacy and Action, National LGBTQ Task Force

Kris HayashiTransgender Law Center

How are the current pushes against transgender people in the United States and the fight for health justice interrelated?

They are frankly one and the same. The conservative right seeks to advance laws, policies and narratives that aim to prevent trans people from receiving health care and from having accurate identification and trans youth from playing sports and that ultimately aim to eliminate our very existence and deny our humanity.

TIM HORN

Director, Medication Access, NASTAD

Tim HornKevin McDermott

What is the greatest roadblock to accessing pre-exposure prophylaxis (PrEP) nationwide?

HIV prevention is more medicalized than ever, yet we're contending with a highly fragmented health care system that continues to throw up all kinds of structural barriers: affordability issues, unnecessarily restrictive and overly complex insurance coverage policies, "churning" in and out of different types of insurance and government bureaucracy, to name a few. The levels of patience and determination people need to navigate such a system, which can also be discriminatory and stigmatizing, just aren't realistic. We can do much, much better than this.

JEREMIAH JOHNSON

Executive Director, PrEP4All

Jeremiah JohnsonCourtesy of Jeremiah Johnson

What is the greatest roadblock to accessing PrEP nationwide?

The root causes of PrEP disparities are systemic and structural. There are numerous co-occurring obstacles that individuals, particularly if they are marginalized, have to face to get PrEP. Those most in need of PrEP are disproportionately uninsured or underinsured, more likely to struggle to find an informed prescriber, more likely to experience stigma and less likely to receive accessible messaging about PrEP. We're calling for a National PrEP Program that removes many of the roadblocks and clears the pathway for equitable PrEP access.

KAMARIA LAFFREY

Co–Executive Director, The SERO Project

Kamaria LaffreyCourtesy of Kamaria Laffrey

What about your work in the AIDS community gives you hope right now?

What gives me hope is the ongoing pressure that many community groups continue to put on our federal government to hold them accountable about their plan to end HIV. I am inspired by the advocates who amplify the need to prioritize quality of life as a measured consideration in HIV plans. While we may end HIV transmissions through a biomedical response, that doesn’t include a cure and the ongoing care that requires funding, strategy and support to sustain a quality of life.

ARIANNA LINT

CEO, Arianna’s Center

Arianna LIntCourtesy of Arianna LInt

What has it been like to organize trans women in Florida, which has become the model for transphobic policies nationwide?

We’ve had obstacles to overcome—for example, having to hire a medical doctor instead of a nurse practitioner on our limited budget. However, policies can’t stop us from getting together and making progress.

DONJA R. LOVE

Playwright

Donja R. LoveBrandon Nick

How is theater a part of the fight for justice for people living with HIV?

Black and Brown people are the most affected by the virus. Redlining, poverty and lack of adequate health care and education are factors in high infection rates, but so is a lack of representation. Theatrical work often centers affluent cis white queer men: The Normal Heart, Angels in America. People who saw themselves reflected in the work felt heard, and those who didn’t got the message that our stories don’t matter. There is a direct correlation between whitewashing in AIDS representation and higher infection rates for Black and Brown people.

BRANDON MACSATA

Managing Partner, Purple Strategy Group

Brandon MacsataCourtesy of Brandon Macsata

How is HIV funding changing as LGBTQ rights are under attack?

Our political landscape is changing because what was once viewed as fringe with one political party has now become “acceptable.” That acceptance has normalized hate. That cancer is targeting not only HIV funding or LGBTQ rights but also reproductive rights, disability rights and parental rights, among others. The political landscape—fueled by misinformation and disinformation—can get even more toxic. Voter mobilization is probably the most important tool the HIV and LGBTQ communities have to combat this cancer.

MARNINA MILLER

Co–Executive Director, PWN-USA

Marnina MillerCourtesy of Marnina Miller

Who in the AIDS community has most inspired your work?

Naina Khanna, the founding director of PWN-USA, has been a pivotal figure. Naina's steadfast commitment to cultivating and nurturing new leaders and her unwavering allegiance to the well-being of all self-identified women and gender-diverse people living with HIV/AIDS have served as a guiding force in shaping my work. Her enduring legacy in this community will have a ripple effect that will be felt for decades to come. Her leadership is a constant reminder of the undeniable power of women living with HIV.

TAMARA OYOLA-SANTIAGO

Cofounder, Bronx Móvil

Tamara Oyola-SantiagoCourtesy of Tamara Oyola-Santiago

What about your work in the AIDS community gives you hope right now?

People who use and inject drugs who are harm reductionists give me hope. They are warriors who challenge us to consider a society and a world where human behavior is respected in all of its forms. They are at the forefront of saving lives, whether it be via dispensing syringes or providing naloxone.

JIRAIR RATEVOSIAN

Congressional Candidate, California’s 30th District

Jarair RatevosianCourtesy of Jarair Ratevosian

How can electoral politics help people living with HIV?

Electoral politics can significantly impact people living with HIV through the creation and implementation of policies that truly tackle social determinants of health, fight stigma and discrimination through modernizing laws, and mobilize significant resources to continue the unfinished business of fighting HIV here at home and around the world. That’s exactly why I am running for Congress.

VENITA RAY

Executive Director, Black South Rising

Venita RayCourtesy of Venita Ray

What about your work in the AIDS community gives you hope right now?

Black women and the broader HIV community give me hope because they continue to show up no matter what. They are unshakeable and unstoppable. It seems that we are continuing to advocate for the same things, like human dignity and intersectional non-biomedical approaches. The solutions continue to be top-down instead of based on community-designed responses. The people closest to the problem are also closest to the solution.

BRUCE RICHMAN

Executive Director, Prevention Access Campaign

Bruce RichmanCourtesy of Bruce Richman

What has it been like to see the message of Undetectable Equals Untransmittable (U=U) catch on?

I spent my last birthday with the Cambodia Positive People Living with HIV Network and hundreds of people parading on bikes, tuk-tuks and motorcycles with U=U banners for the launch of U=U in front of the ancient Angkor Wat temple's religious monuments. I was sobbing with joy to see such hope and courage in such a sacred place. The U=U movement's explosive growth is a testament to the power and resilience of people living with HIV.

JASON ROSENBERG

Member, ACT UP New York

Jason RosenbergCourtesy of Jason Rosenberg

How is health justice linked to the many other types of activism, including trans rights and queer liberation activism?

The fight against genocide and apartheid in Gaza is intrinsically connected to ending the epidemic and ensuring health care for all. Congress has proposed almost $1 billion in cuts to HIV/AIDS programs domestically and globally, all while our taxpayer dollars aid the destruction of health care infrastructures and contribute to the humanitarian crisis in Gaza. It’s our duty as AIDS activists to call for an immediate and lasting ceasefire and demand our government fund health care, not warfare.

FRANCISCO RUIZ

PhD Candidate, Harvard School of Public Health

Francisco RuizCourtesy of Francisco Ruiz

How can the public health field better account for the experiences of queer people of color?

Fully embracing and integrating the experiences of queer people of color starts with a representative workforce. As [diversity consultant] Vern¯a Myers insightfully put it, “Diversity is being invited to the party. Inclusion is being asked to dance.” But we need to go further: Equity is being able to set the playlist. Queer people of color must have a decisive role in creating strategies and policies. Their unique perspectives are central to the development of health initiatives, particularly in the response to HIV.

TYLER SPENCER, PhD

Executive Director, Grassroots Health

Tyler Spencer, PhDCourtesy of Tyler Spencer, PhD

How has your understanding of the epidemic changed in your 15 years in the field?

We started our work before PrEP and before we knew that U=U. My understanding of HIV prevention has become much more nuanced. We are ignoring some of the most critical ingredients of an effective HIV response. We need to continue to think about how we drive demand for prevention and care services in the communities that need them the most. If we want science to have an impact on HIV, we have to include and support interventions that foster trust, comfort and "resource literacy."

ANDREW SPIELDENNER, PhD

Executive Director, MPact Global Action

Andrew Spieldenner, PhDCourtesy of MPACT

How are the COVID-19 pandemic and the AIDS epidemic related?

COVID-19 further demonstrated the structural disparities for queer people and people of color. HIV prepared me for COVID because I knew how to manage the idea of risk and vulnerability after four decades of HIV in LGBTQ communities. As someone living with HIV, I had felt isolation before, and the lockdowns were more manageable because I knew this feeling. And as the waves of deaths hit the world, I was reminded of the lack of government action (and malfeasance) at the start of the HIV pandemic.

CHARLES STEPHENS

Executive Director, Counter Narrative Project

Charles StephensCourtesy of Charles Stephens

What role does storytelling play in the fight for health justice?

Bad narratives lead to bad policies. And before bad narratives, there were first a bunch of bad stories that culminated in that bad narrative: newspaper articles, social media posts, sermons, rumors, films. We must fight bad policies—not only in the realm of politics but also in the realm of art, in the realm of storytelling and in the realm of narrative change. In our age of misinformation, especially about marginalized folks, storytellers and artists are indispensable to the preservation of democracy.

MARVELL L. TERRY II

Public Health Strategist and Cultural Organizer

Marvell L. Terry IICourtesy of Marvell L. Terry II

Are long-acting injectables getting us closer to ending the AIDS epidemic in the United States?

Long-acting injectables do get us closer to ending the AIDS epidemic. However, there is still an issue of equity and access. We must correct the systemic problems to ensure those most impacted by HIV have access to long-acting injectables while also addressing the medical mistrust and distrust that exist among communities affected by the AIDS epidemic, specifically Black people. There are costs for clinics and consumers, insurance and rural accessibility.

KERRY THOMAS

Community HIV Decriminalization Strategist, The SERO Project

Kerry ThomasCourtesy of Kerry Thomas

How do storytelling and science work together in the fight for justice for people living with HIV?

In the realm where stories meet science, a compelling narrative unfolds—a narrative of resilience, activism and justice for those living with HIV. These stories serve as beacons of hope, illuminating the path toward understanding and compassion. In courtrooms and legislative halls, the echoes of these stories reverberate, shaping policies and laws that protect the rights and dignity of people with HIV. The fight for justice is not just a battle against a virus but a quest for equality, dignity and human rights.

DAFINA WARD

Executive Director, Southern AIDS Coalition

Dafina WardCourtesy of Dafina Ward

What do people misunderstand about the fight against AIDS in the U.S. South?

One of the greatest mischaracterizations is that Southerners are apathetic. People believe the injustices we experience are a result of some failure on the part of Southern communities. The systemic racism and hate codified in Southern states is the result of institutional intention. HIV is one result of these systems, as are voter suppression, misinformation and the weaponizing of religion. There is no one-size-fits-all solution to the South's HIV epidemic: It is a policy fight, a cultural fight, a misinformation fight, a rural and metropolitan fight.

MITCHELL WARREN

Executive Director, AVAC

Mitchell WarrenCourtesy of Mitchell Warren

What should the United States learn from the fight against AIDS globally?

The term “global health” has somehow become synonymous with the health of others, often those in resource-limited settings. We did not need COVID to remind us that infectious diseases do not respect borders. We need to embrace a definition of global health as truly global—north and south, east and west, rich and poor. The sooner we recognize that no one country has all the answers—and that disparities and inequalities exist everywhere—the sooner we will create the health systems that work for everyone, everywhere.

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