

HIV at an Inflection Point:

A Renewed Political Commitment is Needed

A New National Commitment is Needed to Sustain Progress Toward the Vision of Zero HIV Transmissions and HIV-related Deaths in the United States and Around the World

As with World War I and the Great Influenza Pandemic of 1918-1920 at the beginning of the 20th century, HIV changed the world in dramatically reshaping science, culture, and the lives of millions of people and their communities around the world. That change is most evident when considering the impact of HIV on the still nascent movement for the civil rights of lesbian, gay, bisexual, transgender, and queer (LGBTQ) people initiated mid-century by the Mattachine Society in Los Angeles and galvanized by the Stonewall riots of 1969 in New York. As the virus spread rapidly into a modern plague during the 1980's, HIV transformed the lives of LGBTQ people and furthered their demands for respect and dignity resulting in changes in society and law. Now, we need to ensure that the commitment and political movements that HIV generated remain vibrant for the next phase of our collective work amid signs that some policy makers and members of the public want to move on from HIV and prioritize other concerns.

So, after more than 40 million deaths, we now have a broad range of effective treatments and prevention modalities that, with the right clinical, social, and legal supports, can keep the virus suppressed and can virtually stop HIV transmission.¹ Foremost, the public needs a greater appreciation for the many ways that HIV research and care is improving health in other areas. For example, while all parts of the health system responded to COVID-19, it was the infectious disease specialists with the experience studying viruses, with infection control, and experience working with

U.S. LEADERSHIP REMAINS CRITICAL TO FIGHTING HIV AT HOME AND AROUND THE WORLD

The response to HIV is unprecedented in human history. Steadfast U.S. leadership remains essential:

Maintain HIV as a Priority for the LGBTQ Community

The LGBTQ community needs to re-prioritize HIV in all its federal, state, and local advocacy and through volunteerism, civic participation, and philanthropy

Engage and Support Congress to Provide Focus and Accountability

Congress needs to invest more attention on HIV by establishing a Select Committee to assess the impact of current programs and consider long-term resource needs

Congress needs to reauthorize the PEPFAR Program and consider updates to the Ryan White HIV/AIDS Program (RWHAP)

Elevate HIV Strategic Leadership Across the Administration

The White House Office of National AIDS Policy (ONAP) must have its mandate and role reinvigorated to provide greater presidential leadership on HIV

BRIEF 1: This is one of three briefs resulting from consultations with people living with HIV and community, government, corporate, and philanthropic stakeholders held from March through May 2024. Convened to examine progress toward global and domestic prevention and care goals, the dialogues yielded a recurring realization: **The HIV response is at an inflection point.** Will we keep innovating to develop better prevention and treatment tools and ultimately a cure? Will we keep expanding access to health care and social services? Will we keep removing the scourge of a global crisis? OR: Will we accept persistent disparities, increased polarization, and reduced commitment that results in more HIV and greater challenges? This moment demands that all stakeholders affirm their commitment to the long-term effort to support all people with HIV and the people and places for whom HIV remains a serious threat. **We hope that these documents further a critical dialogue.**

communities to serve marginalized populations that enabled us to quickly respond. Operation Warp Speed, the Trump Administration Initiative that successfully and quickly developed mRNA vaccines could not have happened but for the prior investments in HIV vaccine research and its trials network that created the platform to use mRNA technology. It is notable that the 2014-2016 West African Ebola outbreak that spread death and fear around the world did not occur in the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) Program partner countries where American investments in HIV services created a health infrastructure and laboratory capacity to respond to an emergent disease like Ebola.

Many people with HIV can now experience a near normal lifespan, but those not benefitting from these advances are often falling back into the shadows. Everyone is tired of HIV. Increasingly, there are signs of fatigue among philanthropic donors and declining participation in AIDSWalks and other fundraising efforts. HIV has virtually fallen off the political agenda of the LGBTQ community and the broader society. Through a mix of homophobia, racism, and an incomplete understanding of the social and other factors that drive the pandemic, charges of HIV exceptionalism also have created resentment and often a perception that HIV has garnered too much attention or too many resources. We must counter these claims in order to maintain our successes and help others better understand how the HIV movement continues to benefit everyone:

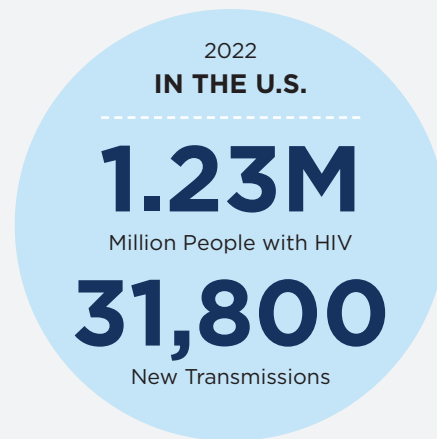
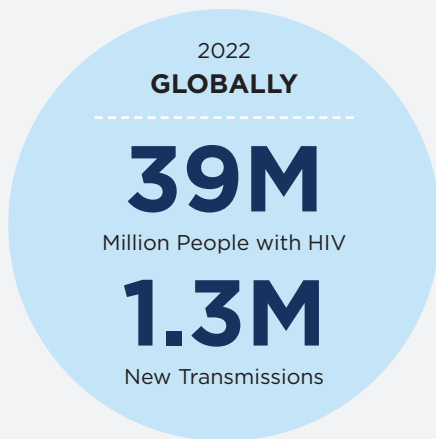
1. MAINTAIN HIV AS A PRIORITY FOR THE LGBTQ COMMUNITY

The story of the HIV response begins with a small group of men meeting in the home of Dr. Larry Moss and led to the founding of Gay Men's Health Crisis (GMHC). It grows into the eleven men living with HIV who stormed the stage at the National Lesbian and Gay Health Conference in 1983 announcing the "Denver Principles" that ignited the global HIV

advocacy movement. Next came the AIDS Coalition to Unleash Power (ACT-UP) and a culture of protest in the face of silence, government inaction, discrimination, violence, and mounting deaths. One notable facet of this early response arose from the Treatment and Data Committee of ACT UP, which later became the independent organization Treatment Action Group (TAG). This activism also led to the establishment of the American Foundation for AIDS Research (amfAR). Previously, activists could be dismissed as being untrained, but these advocates gained a mastery of the science of HIV and were able to engage at a deep level and gain the respect (and sometimes trust) of researchers and clinicians to push for more aggressive drug development, revamp how clinical trials are conducted, expand access to experimental treatments, and force other policy changes. While many people look back with pride on HIV advocacy successes, this was no lovefest. Taking over the New York stock exchange, holding vigils and die-ins at the National Institutes of Health (NIH) and the Food and Drug Administration (FDA), disrupting mass at New York's St Patrick's Cathedral and speeches by elected officials were not met with support. They were met with anger, hostility and arrest.

It is necessary to correct the historical narrative that removes African Americans and racial and ethnic minorities from the early days of the United States (U.S.) HIV epidemic. It is especially important to highlight Black gay men such as Reggie Williams who in 1984 began organizing to address the growing number of cases affecting Black gay men resulting in the National Task Force on AIDS Prevention (NTFAP)² and Craig Harris, who rushed the stage and took the microphone with the powerful words of "I will be heard" in 1987 when no Black panelists were included at the American Public Health Association Annual Conference's first session focusing on HIV/AIDS despite the disproportionate impact reported among Black gay men. In his remarks, he announced the formation of the National Minority AIDS Council (now called NMAC) which remains a critical national organization in the U.S.

The 2014-2016 **West African Ebola outbreak** spread death and fear around the world. Notably, **it did not occur in PEPFAR partner countries where American investments in HIV services had created a health infrastructure and laboratory capacity to respond** to an emergent disease like Ebola. The Democratic Republic of the Congo continues to have Ebola outbreaks, but its HIV/TB lab capacity, built with PEPFAR funding and technical assistance, enables it to respond on its own without needing external operational support.



Sources: Joint United Nations Programme on HIV/AIDS (UNAIDS), UNAIDS Data 2023 (2023); U.S. Centers for Disease Control and Prevention, *HIV Surveillance Supplemental Report: Estimated HIV Incidence and Prevalence in the United States, 2018–2022* (May 2024).

The courage, resilience and success of the LGBTQ community did not go unnoticed and as it intertwined with advocacy by and for people with HIV spurred the global HIV advocacy movement. Similar stories as those in American cities played out around the world such as when the Treatment Action Campaign (TAC) and others in South Africa had to take on an AIDS denialist president to demand treatment. The fact that many people were literally dying and willing to take risks so that we could end this plague led to a vast mobilization from LGBTQ communities and advocates for people with hemophilia, people who use drugs, and across many highly impacted sectors, especially the arts, fashion and hospitality industries. Faith communities often stepped up with support, the philanthropic community eventually stepped up, and brave national leaders, such as Representatives Henry Waxman, Phillip Burton, and Ted Weiss and Senator Ted Kennedy championed our people and our cause. We are coming to the end of a whole cohort of congressional champions who have been committed to the HIV response, not the least of which is Speaker Emeritus Nancy Pelosi who in 1987 was elected to Congress with the express purpose of fighting AIDS and gave her maiden speech on the House floor on the subject.³ As has been seen with reproductive rights and voting rights, however, vigilance is urgently needed to prevent a reversal of our progress. Amid an anti-LGBTQ backlash, we must recognize that responding to HIV is interconnected to countering violence against transgender people and advancing related civil and human rights for all parts of the community—and that LGBTQ people have the power to command political action.

POLICY ACTION:

The LGBTQ community needs to re-prioritize HIV in all its federal, state, and local advocacy and through volunteerism, civic participation, and philanthropy.

The 1980s were a time when the health care system often was unwilling to treat LGBTQ people and queer women and men were more divided. Yet, lesbian supporters stepped up to provide care (diligently holding vigils at the bedsides of dying men who had been abandoned by their families) and joining in advocacy for gay and bisexual men and transgender people in a way that strengthened the bonds of the LGBTQ community. We must honor their legacy by continuing to care about all people with HIV. Today, seven in ten new HIV diagnoses in the U.S. are among gay and bisexual men and transgender women, yet there is sometimes a perception that HIV is no longer a threat to the health and well-being of these populations.⁴ HIV may receive a mention but is rarely a top advocacy priority for most major LGBTQ civil rights organizations. Increasingly the stigma and shame of HIV, homelessness, drug use, and mental health conditions are resulting in a deleterious silence even as many of the historic gay and lesbian organizations are threatened with deep financial cuts.

White gay and bisexual men, in particular, need to be called upon to do more. In the U.S., they have a one in fifteen lifetime risk of acquiring HIV. On its own, this is a stark statistic, but it pales compared to a one in three and a one in five lifetime risk for Black and Latino gay and bisexual men.⁵ Earlier in the epidemic, it was often white gay men who used their inherited privilege and resources to create HIV services organizations (including GMHC in New York, AIDS Project Los Angeles, and the San Francisco AIDS Foundation) and to transform small volunteer-driven, primarily STD clinics into large multiservice health centers (as with Boston’s Fenway, Chicago’s Howard Brown, New York’s Callen-Lorde, and Washington’s Whitman-Walker). Comparable organizing was present in other places such as London, Paris, and Cape Town. White gay and bisexual men often benefitted the most from systems of HIV care resulting from the mobilizations of a large coalition of allies. Today, as HIV services systems have been woven into more integrated health systems, there

The LGBTQ community must rediscover its role and responsibility in continuing to keep HIV on the political and community agenda

is a growing threat that the needs of many people, particularly those who are aging, unstably housed, or have complex social needs, are not being met.

Due to their continuing cultural, political, and financial power within society, LGBTQ leaders have a civic obligation to put their time and resources behind championing services that meet the needs of other LGBTQ people and other people with HIV whether it is young gay Latinos that make up the largest share of new diagnoses,⁶ Black women who make up more than half (54%) of diagnoses among women,⁷ or transgender women for whom every day can be a battle for dignity and respect. This requires ensuring that HIV is once again a leading policy priority for the LGBTQ community, that LGBTQ funders re-prioritize services for all people with HIV and at risk for HIV, while also supporting the next generation of activists and policy experts that can advance a pro-active agenda suited for today, and re-engage in community-level volunteerism to address gaps in social services needed by people with HIV and other health conditions while supporting our allies working to advance racial justice, sexual and reproductive rights and health and other issues. Women, transgender people, and people of color do not need to take a back seat to white men, but everybody needs to be at the table.

2. ENGAGE AND SUPPORT CONGRESS TO PROVIDE FOCUS AND ACCOUNTABILITY

While support still exists in Congress and state legislatures, we are losing too many true champions.

Many of our most stalwart supporters in the Congressional Black Caucus have recently retired or are nearing the end of their terms, especially noteworthy are Representatives Barbara Lee, Sheila Jackson Lee, Eleanor Holmes Norton, Maxine Waters, and the late Congresswoman Eddie Bernice Johnson who all championed both domestic and global HIV initiatives throughout their careers. In the Senate and House leadership, there are few people who understand the full consequences of HIV on their constituents or the continuing threat to global health security. The silence and inaction seen during the recent rise of syphilis cases and deaths, along with the unequal access to COVID-19 and mpox vaccination sets dangerous precedents for the future. People with HIV, LGBTQ leaders, and others need to make concerted efforts to identify, recruit, and bolster actual HIV champions by engaging with them at the local level and ensuring that they see the impact of our HIV investments in their districts. Further, community stakeholders need to do more to bolster and highlight their HIV leadership in Congress.

POLICY ACTION:

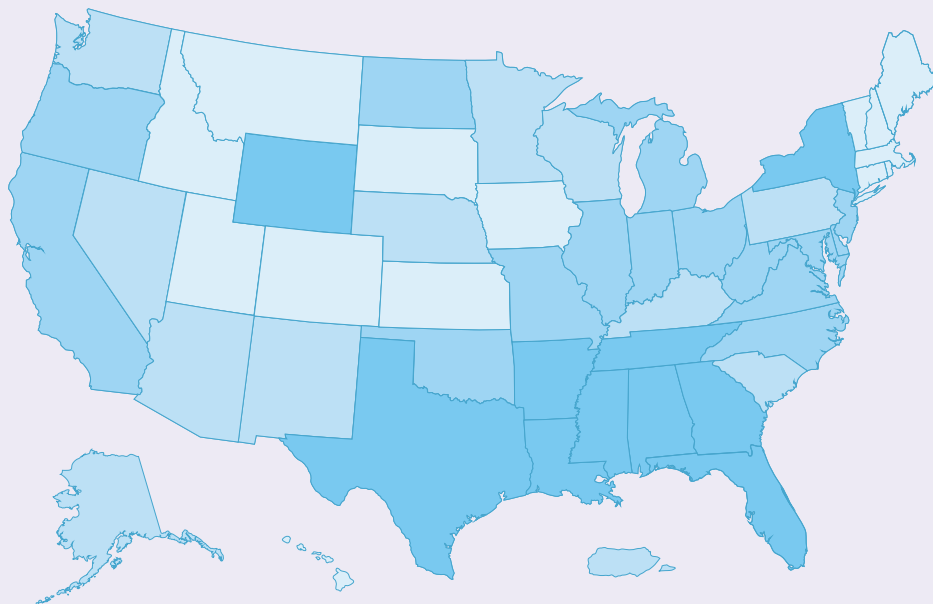
Congress needs to invest more attention on HIV by establishing a Select Committee to assess the impact of current programs and consider long-term resource needs.

As of FY 2022, the U.S. government provided \$43 billion annually to respond to the HIV crisis in the U.S. and around the world.⁸ Sixty-three percent was mandatory spending that consists of income support for people receiving Social Security disability benefits and health care provided through Medicaid and Medicare. Twenty percent of the federal HIV budget commitment was for domestic discretionary programs including prevention, care, research, and housing programs. Sixteen percent went to support global HIV efforts, most of which supported the PEPFAR Program and U.S. support for the Global Fund to Fight AIDS,

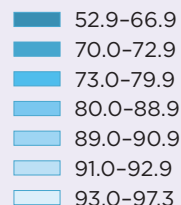
The LGBTQ community as a whole and white gay and bisexual men, in particular, have a civic obligation to put their time and resources behind championing services that meet the needs of other LGBTQ people and other people with HIV whether it is young gay Latinos that make up the largest share of new diagnoses, Black women who make up more than half (54%) of diagnoses among women, or transgender women for whom every day can be a battle for dignity and respect.

THE RYAN WHITE HIV/AIDS PROGRAM (RWHAP) ACHIEVES IMPRESSIVE RESULTS

In 2021, **only 66% of all people with HIV** in the U.S. were virally suppressed. Yet, **90% of RWHAP clients** were virally suppressed. Most of these individuals also have Medicaid, Medicare, or private insurance and the RWHAP ensures coverage is affordable and fills in gaps in services. The enactment of Medicaid expansion in the 40 states plus DC that expanded is a critical driver of this progress and the states that have not expanded Medicaid are among the states with the lowest rates of viral suppression.



VIRAL SUPPRESSION (%)

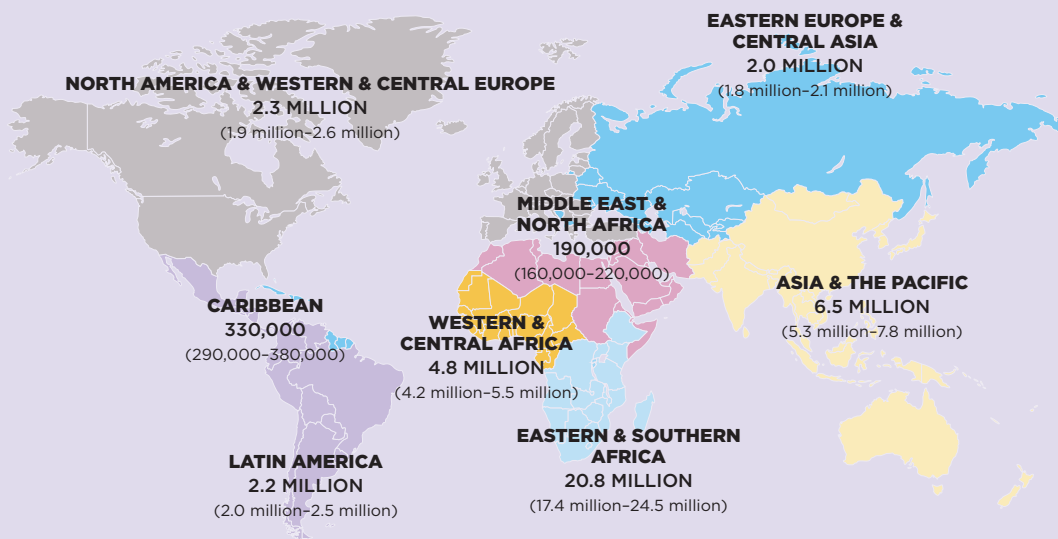


Sources: U.S. Centers for Disease Control and Prevention, *Fast Facts: HIV in the United States* (April 22, 2024), <https://www.cdc.gov/hiv/data-research/facts-stats/index.html>; Patrick S. Sullivan et al., *A Data Visualization and Dissemination Resource to Support HIV Prevention and Care at the Local Level: Analysis and Uses of the AIDS Vu Public Data Resource*, 22 J. Med. Internet Res., Oct. 2020; Health Res. and Ser. Admin., *Ryan White HIV/AIDS Program Annual Data Report 2022* (Dec. 2023), <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/rwhap-annual-client-level-data-report-2022.pdf>.

THE HIV PANDEMIC IS HIGHLY CONCENTRATED IN SUB-SAHARAN AFRICA

(Heavy Impact on Key Populations and Women and Girls)

ADULTS AND CHILDREN ESTIMATED TO BE LIVING WITH HIV (2022)



TOTAL
39 MILLION
 33.1 MILLION–45.7 MILLION

NEW TRANSMISSIONS

Women and Girls

Women and girls accounted for 46% of new HIV transmissions in 2022; in sub-Saharan Africa, adolescent girls and young women accounted for 77% of all new infections among young people age 15–24

KEY POPULATIONS

While they are smaller populations, the following key populations have a very high prevalence of HIV, yet generally receive inadequate HIV prevention and care services:

- Transgender people
- Gay and bisexual men
- People who inject drugs
- People who engage in sex work
- People who are incarcerated

Source: Joint United Nations Programme on HIV/AIDS (UNAIDS), *UNAIDS Data 2023* (2023), https://www.unaids.org/en/resources/documents/2023/2023_unaids_data.

Tuberculosis, and Malaria (Global Fund), with a smaller U.S. contribution to support the Joint United Nations Programme on HIV/AIDS (UNAIDS).

HIV is a very complex disease and social condition. In Congress, there are several committees with oversight and appropriations authority that encompass HIV and sexually transmitted infection (STI) prevention, substance abuse and mental health services, housing, research, and protecting civil rights, and those responsible for the United States diplomatic, national and global health security concerns, yet there is insufficient coordination to synergistically address these components of the HIV response. This is further complicated by disjointed funding, inadequate coordination, and multiple levels of authority in overlapping local jurisdictions. Congress must establish a select committee with members from all committees of jurisdiction to assess the effectiveness of current HIV resources and to consider what resources will be needed to achieve zero HIV transmissions and zero HIV-related deaths.

POLICY ACTION:

Congress needs to reauthorize the PEPFAR Program and consider updates to the Ryan White HIV/AIDS Program (RWHAP).

Early in the U.S. HIV epidemic, there was no health care system equipped to respond and there were fears that so many people sick and dying would overwhelm our hospitals. Out of this need, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted in 1990 to provide a community-oriented nationwide system of HIV care. The Ryan White HIV/AIDS Program (RWHAP) is the cornerstone of the domestic HIV response, but the program has not been reauthorized since 2009. The program would benefit from a considered review by the Congress. This could include an examination of changes in need caused by migration and housing dislocation, aging, anticipated access challenges for new longer-acting therapeutics, as well as consideration of new resources to bring persons into care who have been diagnosed with HIV but are not receiving regular HIV care.

Despite warning signs of an evolving global health threat, early reports of HIV in sub-Saharan Africa also were met with inaction until political pressure led President Clinton to announce the LIFE (Leadership and Investment in Fighting an Epidemic) Initiative in 1999. In 2000, the United Nations and the White House National Security Council declared HIV a global security threat putting the U.S. Departments of State and Defense, and agencies such as the Peace Corps and USAID at the forefront of the delivering life saving strategies with partner countries in Asia, Eastern Europe, Central America and the Caribbean, and in Africa. President Bush built on the LIFE Initiative's \$100 million allocation when he called for the enactment of what is now the \$6 billion PEPFAR Program, which after a short 20 years is a cornerstone of American diplomacy and leadership. It is enabling 5.5 million babies to be born HIV-free to mothers living with HIV, it is providing critical care and support for 7 million orphans, vulnerable children, and their caregivers, and it has averted 25 million deaths.⁹ It is supporting antiretroviral therapy (ART) in partner countries from Jamaica to the Philippines for nearly 20.1 million people who might otherwise die.¹⁰ Despite this success, PEPFAR has gone through a bruising process in the 118th Congress that in May 2024 produced only a short-term reauthorization lasting through March 2025 raising questions as to whether our nation's leadership is prepared to meet the long-term challenges of addressing HIV. The global effort has generally been overseen by a single authority with a mandated focus, the Office of the Global AIDS Coordinator (OGAC). As HIV is subsumed into a larger bureau within the State Department, there is a need to ensure that the focus on producing solid HIV outcomes for America's substantial investments is not diminished.

Even though these and other programs have continued through annual appropriations, there are costs to not reauthorizing them. The committee process to review legislation including the markup of draft legislative text is a critical way to educate busy legislators on core HIV issues in a way that can deepen their commitment. There are reasonable political barriers that have prevented long-term reauthorization of these vital programs. As the country has become more divided along partisan

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lines, there is a fear that, as has happened in the past, a reauthorization of the RWHAP, in particular, could become enmeshed in political point-scoring. A new bipartisan commitment is needed to collaborate on reviewing and reauthorizing these programs in a manner that neither party believes undermines the core purpose of each program or our commitment to alleviate the human suffering caused by HIV.

3. ELEVATE HIV STRATEGIC LEADERSHIP AND COLLABORATION ACROSS THE ADMINISTRATION AND FEDERAL GOVERNMENT

HIV remains a serious public health threat. The extreme disparities in HIV cases wherein gay and bisexual men comprise less than 3% of the population yet account for seven in ten new diagnoses are rarely observed in medicine. It always has been a challenge, however, to get the political system and the Executive Branch to give the issue adequate attention since its impact is so heavily concentrated in a few specific groups. This led to the creation of the White House Office of National AIDS Policy (ONAP) in 1993. **Having an office in the White House is critically important to maintain a strong response to the pandemic. This is not because this single disease is more important than other health threats, but because it provides a way to address the complex challenges of communities that also bear a heavy burden from other infectious and chronic diseases, poverty, discrimination, and stigma.** ONAP has played a central role in responding to issues facing these communities including responding to the 2022 mpox outbreak, tackling STIs, promoting access to curative treatments for hepatitis C, and elevating policy issues facing other people with disabilities.

POLICY ACTION:

The White House Office of National AIDS Policy must have its mandate and role reinvigorated to provide greater presidential leadership on HIV.

Starting in the Clinton Administration, ONAP has been a component of every presidential administration until President Trump never formally staffed the office. Significantly, the Biden Administration re-established the office, but its role has evolved into a subject matter expert at seemingly a lower level that diminishes its potential impact. To provide the critical presidential leadership on HIV at this juncture, we recommend that this Administration under the capable leadership of the current ONAP Director, Francisco Ruiz (or a future Administration) consider a few steps: 1) expand the role so that the ONAP Director once again meets directly with the President

once or more per year and communicates directly to the President through memoranda on critical issues; 2) return the role to again encompass global HIV policy. Even with the National Security Council retaining lead responsibility for global HIV issues, the ONAP Director should be engaged on all global HIV policy issues, should meet regularly with the National Security Advisor, and serve as a White House contact for international partners; and, 3) the office must once again have a dedicated budget to support the office and the director, whether through an ear-marked appropriation (which has been enacted in the past) or an Administration commitment commensurate with prior appropriations (adjusted for inflation).

THE TIME IS NOW

A strong and vibrant HIV response through the activism and engagement of people with HIV and their communities, along with political, cultural, social, and philanthropic engagement remains vital. Americans can rightly be proud of what we have accomplished together, but now is the time for LGBTQ communities, Congress, and the President's Administration to re-affirm their commitment and leadership to working toward ending HIV as a public health threat.

ENDNOTES

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- 3 Congresswoman Nancy Pelosi: California's 11th District, *Leadership on HIV/AIDS*, <https://pelosi.house.gov/issues/leadership-on-hivaids> (last visited July 3, 2024).
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- 10 U.S. Dep't of State, *Results and Impact - PEPFAR*, <https://www.state.gov/results-and-impact-pepfar/> (last visited July 2, 2024) (reporting PEPFAR impacts as of Sept. 30, 2023); U.S. Dep't of State, *PEPFAR-Supported Countries and Regions*, <https://www.state.gov/pepfar-supported-countries-and-regions/> (last visited July 2, 2024).



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