HIV at an Inflection Point:

Looking Ahead and Leaving No One Behind

Recognizing Latino Leadership and Extending HIV Advocacy to Tackle Broader Issues Can Strengthen Nations and Communities

HIV changed the world by recognizing how stigma, discrimination, and marginalization contributes to the manifestation of disease and death. But, building on the successes that have been achieved over the past four decades demands a new focus to avoid leaving anyone behind and requires a broader lens for assessing what more is needed. Our challenge today is to ensure that we continue our scientific advances and maintain the core framework of the HIV infrastructure domestically and globally that have brought us this far while strategically assessing and adapting our efforts to respond to current and future needs:

1. ELEVATE EMERGING AND OVERLOOKED POPULATIONS

Ending HIV strategies and models rightfully focus on the places with the greatest burden of HIV. The **Ending the HIV Epidemic (EHE) Initiative** launched by the Trump Administration, for example, is initially focused on 48 counties, Washington, DC, and San Juan, Puerto Rico, where more than 50% of HIV diagnoses occur, and an additional seven states with a substantial number of HIV diagnoses in rural areas, bringing the total number of prioritized jurisdictions to fifty-seven. Across federal programs, however, policies exist that strive to ensure that no place is left behind. States and territories are guaranteed a minimum HIV prevention award to ensure a base level of prevention capacity. In the Ryan White HIV/AIDS Program (RWHAP), there are several ways that the program can respond to unaddressed need including supplemental funding based on unmet

FIGHTING HIV IS ABOUT MORE THAN VIRAL SUPPRESSION

HIV treatment and prevention remain essential, but other issues demand attention:

Elevate Emerging and Overlooked Populations

HIV programs must remain dynamic and responsive to unaddressed needs and emerging challenges

There is a need to adopt a human rights framework and take steps to protect the rights and dignity of all people

Adopt a Forward Vision for Continued Progress

HIV advocates need to lead a reform agenda that expands our current efforts to address broader societal challenges that critically impact people with HIV

BRIEF 3: 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.**

LATINO HEROES OF THE HIV MOVEMENT

HIV always has heavily impacted Latino gay and bisexual men, but today, they comprise the largest share of new diagnoses (39% in 2022) while accounting for 81% of new diagnoses among Latinos. Transgender Latinas also are disproportionately impacted. While not an exhaustive list, as policy makers and advocates commit to prioritizing Latinos in the HIV response, let's acknowledge some of their history makers:

Pedro Zamora was a Cuban-American gay man who died of AIDS in 1994 at the age of 22. He was one of the first openly gay men with HIV to appear in popular media, appearing on one of the first reality television shows, MTV's "The Real World San Francisco". President Clinton credited him with personalizing HIV, especially for the Latino community.

Originally from Columbia, **Jairo Pedraza** lived in the United States for many years and became involved with ACT UP in 1985. His experience as an immigrant inspired his activism and led him to be a co-founder of the Latino HIV/AIDS Caucus of ACT UP and he was one of the first American HIV activists to become engaged in global advocacy, serving as a Northern Regional Representative of the Global Network of People Living with HIV and AIDS (GNP+).

Dennis deLeon was a human rights lawyer who served as the New York City Human Rights Commissioner. He was the Founding President of the Latino Commission on AIDS, serving until his death from AIDS in 2009.

Oscar de la O is a Los Angeles-based political activist who co-founded Bienestar in 1989. Bienestar has grown from being an AIDS project providing information on weekends to a comprehensive social services, support, and advocacy agency for the Latino community in the greater Los Angeles area.

Humberto Cruz was a strong and persistent voice for the Latino community, immigrants, and other marginalized groups at the state and national levels. He spent most of his career at the New York State AIDS Institute, ultimately serving as its Director. He was one of the founders of the National Alliance of State and Territorial AIDS Directors (NASTAD) and in 2010, he was appointed by U.S. President Barack Obama to serve on the Presidential Advisory Council on HIV/AIDS (PACHA).

Moises Agosto is a Puerto Rican who got his start as an HIV activist on the island but moved to the mainland in the early 1990s. At a time when HIV treatment advocacy was dominated by white gay men, he was one of the first people of color to advocate for treatment access for people of color, a role he continues to play to this day.

Rosie Perez is a Brooklyn-born actress. She starred in and directed the Spanish AIDS PSA campaign "Join the Fight" for Cable Positive and Kismet Films. President Obama also appointed her to The Presidential Advisory Council on HIV/AIDS (PACHA) in 2010.

Of course, many Latinos and the broader HIV community applauded President Biden's 2024 appointment of **Francisco Ruiz**, an openly gay Latino with HIV as the first Latino Director of the White House Office of National AIDS Policy (ONAP).

need and the Parts C and D programs allow the Health Resources and Services Administration (HRSA) to directly fund clinics where there are gaps in services. Nonetheless, there is a need to monitor trends and seek out populations and places where inadequate investments create the potential for outbreaks or a growth in cases that undermine our efforts.

Globally, within the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) Program and its partnership with the Global Fund to Fight AIDS, Tuberculosis, and Malaria, most of the effort and investment is focused on sub-Saharan Africa which has been the most impacted region in the world. If we are to achieve a bold vision of zero HIV transmissions and zero HIV-related deaths within a generation, however, the U.S. along with its partners need to maintain and enhance a commitment not to one region or one population, but to preventing and treating HIV across the globe

POLICY ACTION:

HIV programs must remain dynamic and responsive to unaddressed needs and emerging challenges.

As we prioritize the groups and places with the most HIV cases, we need to ensure that we respond to smaller populations and watch out for emerging issues. Tailored responses are needed that take into consideration unique facets of their history, experience in the U.S., economic status, primary language and other factors:

Latinos: Since the beginning of the epidemic in 1981, the share of the population made up by Latinos in the U.S. has increased and they now, at 19% of the population, make up the largest minority group in the U.S.[1] As with non-Hispanic Black people, they always have been heavily impacted by HIV, and their role throughout the U.S. epidemic is underappreciated. Now, however, new HIV incidence data from the Centers for Disease Control and Prevention (CDC) show that in 2022, Latino men who have sex with men (MSM) accounted for 39% of all new transmissions, more than any other group.[2] Other CDC data have found Latinos account for 26% of people with HIV.[3] While Latinos generally share a common first language of Spanish, both the cultural history of people with roots in diverse countries of Mexico, the Caribbean, and Central and South America and their experience in the U.S. can differ dramatically, and this calls for HIV services that are not monolithic and that are tailored to multiple diverse Latino populations.

American Indians and Alaska Natives (AI/AN): American Indians and Alaska Natives comprise a small share of the U.S. population and contribute few cases to the overall epidemic. In 2021, when there were more

than 36,0000 new diagnoses, there were fewer than 250 diagnoses among AI/AN populations, yet they are more likely to die of HIV than other groups.[4] The U.S. has special responsibilities to AI/AN people and they have unique needs. The U.S. is obligated under treaties ratified with many tribes to provide health care and it seeks to meet this obligation through the Indian Health Service (IHS). Historically, however, the IHS has been woefully underfunded and neglected. AI/AN people, however, also are U.S. citizens and have the same rights as other citizens to access other public programs and health care services. There are often distinct needs of American Indians living on reservations and those living in U.S. urban areas. The U.S. and the governments of Mexico and Canada must re-engage in trilateral efforts with tribal nations to support the elimination of HIV transmission and to provide high-quality health care services to indigenous people with HIV regardless of jurisdiction.

Asian Americans and Pacific Islanders (AAPI): Asian Americans and Pacific Islanders including Native Hawaiians also are a relatively small population and contribute relatively few HIV cases. In 2021, AAPI populations accounted for fewer than 1,000 new HIV cases, roughly 2% of all new diagnoses.[5] They have specific cultural and services needs, especially in specific regions and urban areas where they are concentrated, such as the West Coast of the U.S. focused on the major cities of Seattle, San Francisco, and Los Angeles, as well as New York City. They also have struggled in gaining adequate attention due to their small numbers being lumped into an "other" category when demographic data are presented. The AAPI category also does not sufficiently acknowledge the stark cultural differences experienced by persons based on different countries of origin. A focused effort must be undertaken to cut in half the number of new AAPI HIV cases through a population-based approach grounded in the unique needs and culture of the most highly impacted communities.

Transgender People: While an important part of the LGBTQ community, when considering HIV, transgender people can get swamped by the large numbers of HIV cases among gay and bisexual men. Transgender people, predominately transgender women, have been significantly impacted. According to the CDC, in 2019, they made up 0.3% of the U.S. population and accounted for 2% of new HIV diagnoses. While all parts of the LGBTQ community can face stigma and discrimination, transgender people often face the worst of it. Discrimination, for example, often can limit access to employment, which in turn, can lead to the limited option of sex work and increased risk for HIV and violence. Further, transgender health care is about more than HIV and nationwide, there is inadequate capacity to deliver culturally-affirming and gender-affirming health care. Increasingly, this population has been the focus of hostile laws that seek to limit this population's access to high-quality medical care and other services. Globally, they also have the highest HIV prevalence of the key populations tracked by UNAIDS with a median prevalence across countries of 10.3% for adults age 15-49, compared to 0.7% for all adults in this age group.[6] Supporting comprehensive high-quality healthcare, safe school and work environments, and strengthening housing and employment protections, are essential elements of population-based approach to reducing HIV and improving outcomes for transgender persons.

Being Black or Brown, poor, engaged in sex work, and using drugs often leads to incarceration. At the end of 2021, about 1.1% of persons in federal and state prisons in the U.S. were living with HIV.

People who use drugs: In 2021, about 8% of all new transmissions in the U.S. were in people who use drugs.[7] Globally, the median prevalence of HIV among people who inject drugs was 5% in a study of 50 countries, but this hides large population and geographic variations in HIV prevalence.[8] In the U.S., there is a concern that injection drug use will increase its role in ongoing transmission of HIV while at the same time, non-injecting methamphetamine and other stimulant use (i.e. cocaine) also is a significant driver of HIV transmission in some communities.[9] In 2022, there were nearly 108,000 overdose deaths in the U.S.[10] This is a critical national problem that demands urgent responses. Early in the HIV epidemic, the HIV community led efforts to develop the concept of harm reduction and promote syringe services programs (SSPs). While politically controversial and often charged with promoting drug use, these programs have been extensively documented to be an effective intervention for preventing HIV, hepatitis and other infectious diseases while not increasing drug use.[11] Today, many persons in law enforcement, faith leaders, and other civic leaders acknowledge the role of SSPs wherein injection drug use is recognized to occur and they provide sterile syringes, but they do not yet support efforts to create overdose prevention centers which create a safe space to test and use drugs and that can reduce the exposure of children and others through illicit drug use in parks, alleys, and other public places. Continued partnerships are needed to bring more civic leaders along to support evidence-based public health interventions.

Persons with Criminal Justice Involvement: Being Black or Brown, poor, engaged in sex work, and using drugs often leads to incarceration. At the end of 2021, about 1.1% of persons in federal and state prisons in the U.S. were living with HIV.[12] Globally, a

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meta-analysis estimated that HIV prevalence of adult male and female prisoners was 3.4%, but in three countries, Iran, Zambia, and Spain, HIV prevalence was more than 20%.[13] Most HIV transmission of justice-involved persons occurs outside of prisons and jails.[14] People who use drugs and those whose lives are subject to the prison, jail and justice systems (including probation and parole) experience not only stigma and discrimination, but also limitations in accessing scientifically sound HIV prevention strategies, HIV treatment, or peer-based services that could improve outcomes. Furthermore, even upon release these persons are limited by their record in housing, employment, and access to certain services. Legal barriers that result in recidivism and poor health outcomes must be removed and stronger support systems must be established in jails and post-incarceration supervision programs to link people with HIV, people who use drugs, and those with mental health conditions to care as a component of release.

People living in the southern United States and rural areas: The HIV epidemic in the U.S. is concentrated in the southern U.S. While urban and periurban areas of the southern U.S. continue to represent the largest proportion of new cases in the region, it also has much higher rates of people with HIV in rural areas than other regions.[15] Additionally, the southern U.S. has a higher composition of Black people than other regions and a more unequal access to HIV prevention and treatment services. Moreover, seven of the ten U.S. states that have not expanded Medicaid are in the southern U.S.[16] Due to high housing and other costs in urban and periurban areas, there has been a shift of more people moving to exurban and rural communities where the cost of living is lower. Black, Latino, American Indian, and other minority groups living in rural areas have higher than average rates of HIV.[17] As a result, the confluence of restricted Medicaid access, shortages of health care providers, low health literacy, and high rates of HIV stigma can lead to more HIV transmission and make it difficult to create a comprehensive system of care for people with HIV in rural areas.[18] As housing prices in urban areas continue to price lower-income people out of cities in the U.S. and throughout many countries worldwide, HIV prevention and treatment services must rapidly adapt. Further, the per-person cost of operating HIV programs is often higher in communities with smaller populations so the federal investment (as with funding for highways, the Internet and other utilities) will need to increase for building out HIV and other health and related services through physical or mobile structures. While telemedicine holds great promise, we cannot overlook the fact that 30-42 million people in the U.S. lack broadband internet access.[19] The Bipartisan Infrastructure Law of 2021 proposed by President Biden and enacted by Congress provides $65 billion to connect every home and community to broadband by 2030. Innovative solutions are also needed to deliver services to these populations.

Prevention of Perinatal Transmission and Care of Children with HIV: The transmission of HIV during childbirth, delivery, and during chest feeding is one of the most heartbreaking facets of the HIV pandemic. The landmark Pediatric AIDS Clinical Trials Group 076 study in 1994 showed that giving zidovudine to pregnant women with HIV reduced perinatal transmission by two-thirds. Since then, largely women mobilized to work to ensure that no more babies were born with HIV and we now have more tolerable and more effective treatments. In the U.S., only 36 babies acquired HIV perinatally out of 3,315 live births to women with HIV in 2020,[20] falling from a peak of 1,760 in 1991.[21] Globally, 82% of pregnant people with HIV had access to ART to prevent transmitting HIV to their babies during pregnancy and childbirth and to protect their own health.[22] According to UNAIDS, UNICEF, and the Global Alliance to End AIDS in Children, among the 1.7 million children (aged 0–14 years) with HIV, slightly more than half (54 per cent in 2020) are on treatment.[23] Greater efforts must be made to diagnose and treat children born to parents with HIV, especially those over 5 years of age who may have been missed early. Further, with the global resurgence of congenital syphilis dual testing strategies should be undertaken for all pregnant women and newborns.

POLICY ACTION:

There is a need to promote a human rights framework and take steps to protect the rights and dignity of all people.

Before we knew it was a virus, we called the disease "gay-related immune disorder (GRID)". We referred to the 4Hs, for the heavily impacted groups of homosexuals, Haitians, hemophiliacs, and heroin users. Stigma and discrimination are literally baked into the HIV response all around the world. Countering stigma and discrimination also has been a hallmark of the HIV response. In the U.S., the Congress enacted the Americans with Disabilities Act in 1990 to comprehensively outlaw discrimination on the basis

of disability including HIV status.[24] Further, health departments, churches and faith organizations, and civic organizations have sought to deploy numerous interventions to counter stigma.[25] There are many areas, however, where marginalized individuals and groups are not protected. In some states of the U.S. and in countries around the world, people with HIV are prosecuted for failure to disclose their HIV status before engaging in consensual sex and people can be prosecuted for spitting or biting despite these behaviors not being a mode of HIV transmission.[26] Economically vulnerable people including immigrants, transgender people and some people of color may turn to sex work for survival yet can be prosecuted for violating prostitution laws. Moreover, despite recognition that the "War on Drugs" has failed, people are routinely prosecuted and incarcerated for personal drug consumption. There are huge gaps in protections for LGBTQ people in employment and public life and in many places, there is a concerted effort to challenge the dignity and safety, in particular, of transgender people. Throughout the world, there are both nations with broad civil and human rights protections, but many more countries take even harsher approaches to these vulnerable communities, where, for example, homosexuality and drug use can be punishable by death.[27]

The history of HIV shows us that there is only one way forward. That is to protect the lives, health, and rights of all people. Globally, people who use drugs, people who engage in sex work, and people who are incarcerated, along with LGBTQ populations are all key populations at high risk for HIV and who experience the most stigma and discrimination while seeking healthcare. While policymakers can take different positions on whether the production and sale of drugs should be legalized, many agree that harm reduction strategies should be incorporated into a comprehensive approach to preventing and treating substance use epidemics. Criminalizing LGBTQ status or identity threatens our ability to engage productively to prevent and treat HIV and other infectious diseases. Countries like Thailand and Vietnam which have put addressing stigma and human rights at the center of their HIV response have long been in the vanguard of reducing new HIV transmission and also have been leaders in innovative HIV research and care.[28] Since 2019, Botswana, Gabon, Namibia, Angola, Bhutan, Antigua and Barbuda, Barbados, Singapore, Saint Kitts and Nevis, the Cook Islands, Mauritius, and Dominica have all repealed laws that criminalized LGBTQ people. The Global Partnership to Eliminate All Forms of HIV-related Stigma and Discrimination was established in 2018 and aims to catalyze and accelerate implementation of commitments to end HIV-related stigma and discrimination by UN Member States, UN agencies, bilateral and international donors, NGOs and communities.[29] As of March 2021, 19 countries had expressed their intention to join, committing to take action on HIV-related stigma and discrimination across six settings in the next five years.

2. ADOPT A FORWARD VISION FOR CONTINUED PROGRESS

Advances in HIV treatment and prevention have led to motivating campaigns and efforts such as the EHE Initiative. Some bold goals, such as "ending HIV by 2030", however, have created an ongoing misperception that the need for HIV funding and programs would diminish. For people with HIV, what is intended to be a positive effort to embrace further HIV progress (Ending HIV) has been viewed by many as a potential death knell to a long-term commitment to themselves and their communities. Similarly, global advocates, UNAIDS, and the United Nations system launched the 95-95-95 and related goals,[30] which has importantly spurred progress, yet which created a perception that it is possible for the global community to begin to wind down its investments in global HIV services. The U.S. and the global community need a long-term commitment to sustaining and continually improving the HIV response in the U.S. and around the world, but in a dynamic global environment that has changed significantly since PEPFAR and the Global Fund were established, there is a need for burden sharing and new strategies to promote productive collaboration even among countries which often act as economic and diplomatic competitors. Nonetheless, future progress demands that we focus on non-HIV-specific aspects of health care, as well as social services and other aspects of quality of life.

POLICY ACTION:

HIV advocates need to lead a reform agenda that expands our current efforts to address broader societal challenges that critically impact people with HIV.

In 1990, four members of ACT-UP—Keith Cylar, Eric Sawyer, Viginia Shubert, and Charles King—formed Housing Works to serve the tens of thousands of homeless New Yorkers with HIV. Three decades later, in the U.S. and around the world, there is a growing crisis of limited access to safe and affordable housing. Maintaining durable viral suppression is critical both for individuals and public health. People who are unstably housed, however, are less likely to achieve and maintain viral suppression.[31] Therefore, HIV policy makers and advocates need to be at the forefront of solutions that can ease the housing crisis for Americans and for people in other nations. The PEPFAR program has achieved remarkable successes, but strengthening broader health systems beyond HIV remains an urgent priority for which HIV stakeholders must do their part. Most nations are unprepared to meet the growing

THE NATION AND THE WORLD ARE FACING BIG CHALLENGES—THE HIV RESPONSE CAN OFFER SOLUTIONS

The challenges facing HIV are sometimes unique, but frequently they spotlight issues facing society as a whole. There is an opportunity to leverage the HIV response to identify solutions to benefit all of society:

High Housing Costs

The U.S. Housing Opportunities for People with AIDS (HOPWA) Program services people with HIV and their families to provides stable housing that enables people to remain engaged in care. Yet, limited funding means that the program reaches only 55,000 people out of an estimated 400,000 people with HIV with housing needs (National AIDS Housing Coalition, https://nationalaidshousing.org).

The U.S. housing crisis is bigger than HIV and while HOPWA plays an indispensable role, just as HIV advocates rallied with other consumer advocates to protect Medicaid and defend the Affordable Care Act (ACA), they need to play a significant part in championing a vision for and working to address the housing crisis. This cannot be simply signing onto letters asking for more appropriations, it requires the HIV advocacy movement to elevate housing as a core issue and demand structural changes that benefit all Americans.

Weak Health Systems

The clinical and community capacity to deliver services built by PEPFAR should be leveraged to achieve other health-related goals. Too frequently, however, program integration has the effect of reducing resources for HIV, diminishing what makes the HIV response special and effective. In the U.S., the needs of people with HIV spotlight the consequences of lack of Medicaid expansion and weak health systems, especially in the southern U.S. and rural areas. HIV advocates have much to contribute to continuing national health care reforms that go beyond access to tackle quality, sustainability, and simplicity and reduced bureaucracy.

Aging Population

People aging with HIV demonstrate the gaps in our aging services system, not only for health and long-term services, but also for income security and a focus on quality of life. The Older Americans Act was enacted nearly sixty years ago and is due to be reauthorized in late 2024. While the Biden Administration has updated its rules to better meet the needs of LGBTQ people and people with HIV, Congress must be educated and encouraged to do more in reauthorizing the program to ensure more resources to meet the needs of all older Americans and to make structural changes to account for the unique needs of people aging with HIV.

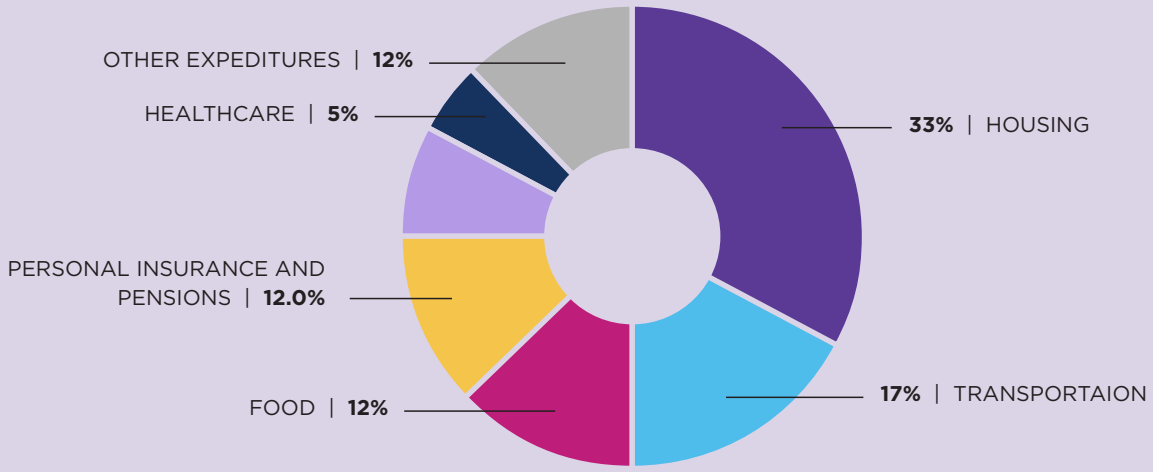
Maintaining a Commitment to Biomedical Innovation

New longer-acting products for HIV treatment and prevention are either available or on the horizon that will give users more options than taking a pill every day. If access can be assured, they could be transformative. Biomedical innovation is also delivering new and better therapeutic modalities for a range of other conditions. Ultimately, what will alter the long-term cost projections of responding to HIV is the development and promulgation of a cure. National biomedical research budgets and priorities need to be re-invigorated to enable HIV investments to continue producing advances to benefit HIV and all health conditions. This progress also is in danger of stalling unless we expand our investment in social science, behavioral, and population research.

HOUSING IS THE LARGEST SHARE OF HOUSEHOLD SPENDING

(AND ITS SHARE OF SPENDING INCREASED THE FASTEST FROM 2017 TO 2020)

Average expenditures on selected major components of consumer spending, 2022



Sources: U.S. Bureau of Labor Statistics https://www.bls.gov/news.release/cesan.nr0.htm

needs of people who are aging with disabilities and chronic conditions. The U.S. has no effective national financing system for long-term services and supports which has created a burden for Medicaid programs that they were not designed to accommodate. HIV also presents unique challenges for people who are aging both because it can produce accelerated and accentuated aging, and the populations most affected often have more limited resources and fewer family supports on which to depend.[32]

We end this series of briefs commending the important role the U.S. has played as a global leader global leader in both public investments in biomedical research (largely through the National Institutes of Health, NIH) as well as through a vibrant and diverse pharmaceutical industry. It is essential that the U.S. retain its leading position in supporting biomedical knowledge generation and innovation. In all these areas, HIV advocates and other stakeholders cannot achieve successful solutions on our own, but our forty-plus year history and critical experience give us a perspective and skills to play an important role.

THE TIME IS NOW

The HIV movement has accomplished so much, but our work is not finished. By continuing to support improvements in prevention and treatment while broadening our focus to encompass other facets of a high-quality life, and contributing more to broader societal challenges, we can keep changing the world.

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