

## INVITED PERSPECTIVE

# Persistence Is Resistance: The fight to END THE hiv EPIDEMIC hangs in the balance

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### INTRODUCTION

The unprecedented federal assault on HIV research funding, The Centers for Disease Control (CDC) Division of HIV Prevention, Medicaid, immigrants, academic freedom, as well as attempts to erase LGBTQ+ people and Diversity, Equity, and Inclusion initiatives have swiftly caused devastating harms to the research, public health programs, and communities that we cherish and serve. We are all hurting and struggling in these chaotic and surreal times. HIV community activists and long-term survivors have called us to action[1], and our silence is not an option. Atlanta artist, activist, and educator, Kipper Jones, recently said “I am 64 years old. I am not tired of fighting for anything. There is no tiring because the fight continues.” Persistence is critical for the foreseeable future. By persisting in our efforts to ensure that all people have

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access to HIV prevention and care and that HIV research continues, we are resisting efforts to turn back the clock on the monumental progress that we have made in controlling the HIV epidemic to date.

### **HIVMA Advocacy on the Hill**

HIVMA Board members and Ryan White Medical Providers Coalition members from across the country took to Capitol Hill on May 19<sup>th</sup> to meet with more than 130 Congressional offices covering 26 states. There, we advocated for funding for HIV prevention, care, and research and educated members on the importance of the Medicaid program to people with HIV (PWH), the life-saving benefits of the Ryan White Program[2], the advances made possible only through global health research, the value of the NIH, and the importance of our Public Health infrastructure. Most importantly, we shared stories about how funding cuts, delays, and partial awards are impacting their constituents. It was clear in both Republican and Democratic offices that our advocacy provided valuable information about the impacts of the administration's actions 'on the ground.' A continuous drumbeat of advocacy is needed at all levels of government for policymakers to understand the human impact of their policy actions and the harms to hard-earned scientific progress. Legislative staff encouraged us to continue speaking out and to amplify personal stories of people impacted by the recent cuts to public health programming and research.

### ***What's at Stake***

The ID and HIV communities are living in real-time the impacts of federal funding cuts. We call out below what's at stake and what you can do to persist and mitigate the impacts of the attacks on our field. This is a non-exhaustive list.

### **Unraveling hiv research**

Science has transformed a once-fatal AIDS diagnosis into a manageable chronic condition and given us medications to prevent HIV that are >95% effective. Yet, the effects of recent attacks on HIV research are staggering: grant terminations, staffing cuts at NIH, delays in issuing notices of awards or partial awards, disruptions in the HIV clinical trials networks, restrictions on foreign subawards halting global health research, and proposed draconian cuts and reorganization of the NIH all threaten to reverse the advances we have made in fighting the HIV epidemic. According to the Association of American Medical College's analysis of NIH grant terminations, 1424 NIH grants have been terminated representing \$2.5 billion in lost grant funding. HIV/AIDS-related grants and mental or behavioral health grants accounted for the largest number of grants terminated with each accounting for 38% of the total grant terminations.[3] The future of science, the next generation of HIV researchers, and the communities disproportionately affected by HIV are all in peril.

## **Threats to CDC's HIV Prevention Program**

While there remain >30,000 new HIV infections in the US annually[4], rates are lower than ever before-- underscoring the remarkable progress of our HIV public health response. However, in April 2025, personnel from the CDC Division of HIV Prevention were fired including those that oversaw HIV research, pre-exposure prophylaxis (PrEP) clinical practice guidelines, and capacity building for HIV testing and prevention services. While some CDC staffers have been rehired, the President's fiscal year 2026 budget proposes to eliminate the CDC's domestic and global HIV prevention programs completely.[5] A large majority of the \$793 million in domestic HIV prevention goes directly to state health departments, community-based organizations and HIV surveillance programs.[6] AmfAR estimates that by 2030, eliminating CDC's HIV prevention program would result in 143,486 new HIV infections, 14,676 AIDS-related deaths and cumulative lifetime costs from new HIV infections of \$60.3 billion.[7] We must leverage our voices to prevent and mitigate these cuts and avert preventable and costly increases in new HIV infections, deaths from AIDS, and babies being born with HIV.

## **Unprecedented Cuts to Medicaid**

The Medicaid program is the single largest health insurer for people with HIV, covering 40% of non-elderly adults. H.R. 1 (the so-called "One Big Beautiful Bill") would cut the Medicaid program by \$1 trillion dollars and take health coverage away from 17 million Americans. The losses are largely due to mandating that most Medicaid expansion enrollees document monthly work hours, requiring eligibility redeterminations every six months, and imposing mandatory cost sharing up to \$35 for some services.[8] Similar Medicaid work requirements implemented in Arkansas in 2018 resulted in 18,000 people losing coverage and did not increase employment before being rescinded.[9] With cuts to Medicaid, people with HIV will lose healthcare which will drive up healthcare costs and cause needless illness and deaths.

## **Ryan white HIV/AIDS program**

Under the President's 2026 budget proposal, Ryan White Parts A through D would be maintained, but the budget calls for elimination of Part F which funds the AIDS Education and Training Centers (AETC), the dental program, the Special Programs of National Significance or SPNS, and the National Clinician Consultation Center. The Ryan White Program would be subsumed under a to-be-created Administration for a Healthy America. The AETCs have been a crucial component of training the next generation of HIV providers. For example, the Southeast AETC conducted nearly 14,000 HIV training events and almost 160,000 HIV training and capacity/building technical assistance hours for clinics and providers in the last 5 years. The destruction of these longstanding networks for HIV education and support would leave a dangerous gap in key areas of HIV education and care provision.

## **Join the Movement and Support Each Other**

The real-world impacts of the recent funding cuts are not always understood by lawmakers, and it is incumbent upon us to shed light on these devastating actions. Advocating for HIV policies and programs and the populations served can take many forms including an email, a letter to the editor for your local paper, a phone call or an in-person meeting. Host a “power-hour of advocacy” in which groups can gather virtually or in-person to phone bank or email to their elected representatives and tell the stories of how these policies are affecting us and the people we serve. Participate in collective action when able or simply continue to do the work you do daily and speak up for those who cannot speak up in the current environment. Any action is valuable and none is too small.

## **Leverage HIVMA and IDSA Resources**

HIVMA and IDSA are expanding the tools and resources available to support member advocacy. As a first step – join the **Member Advocacy Program**[10] (membership in IDSA/HIVMA not required) to stay current on the latest policy actions and advocacy opportunities. IDSA and HIVMA’s **Take Action**[11] center makes it easy to weigh in with your members of Congress on a wide variety of issues impacting the field of infectious diseases and HIV. While it may seem that sending an email is unlikely to affect real change against what seems like a tsunami of harmful policies, each email, phone call, or message builds upon the cumulative foundation of advocacy that we are creating to demonstrate our persistence and resistance.

## **Organize locally**

Unlike Congressional staff in Washington, DC, in-state or district office staff are more likely to be local to the community and will be more familiar with the needs and issues affecting constituents and with state institutions and organizations. Use IDSA and HIVMA’s guide for organizing and scheduling in-district Congressional office visits[12] and consider inviting your colleagues and HIV community partners to join. IDSA and HIVMA also have developed talking points and state-specific fact sheets to help.

## ***Engage with the Media***

Educating the public on the effects of these devastating policies is crucial. Submit letters to the editor or op-eds to your local or hometown newspaper.[13] Contact a local reporter who covers health issues to offer to be a resource on infectious diseases and HIV. Host an educational forum or teach-in on your area of research or clinical program and invite local media and politicians.

## **Persistence is resistance**

Despite having the tools to end the HIV epidemic, we are faced with the deliberately cruel and nonsensical destruction of the incredibly successful HIV infrastructure built over decades through the hard work, advocacy, passion, and lives of those who came before us. While it seems

like the attacks on science and truth itself continue daily, as Mr. Jones said, we in the HIV community cannot tire of fighting. We must persist in our resistance.

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