

# Ending an Era of

# Denial

Nearly 25 years after the first AIDS diagnosis, the role of foundations remains critical at home and abroad.

Today, there finally appears to be a global consensus that the crisis of HIV/AIDS requires the attention and resources of donor and affected governments, international organizations and the private sector. This was not always the case.

As recently as a few years ago, there was little global discussion about the epidemic and the world's leaders rarely talked about it in their speeches or placed it very high on their policy agendas. This has changed, of course, as evidenced by the prominence placed on the epidemic by United Nations Secretary-General Kofi Annan and by the leaders of many nations, including our own. HIV/AIDS has entered the political dialogue of heads of state as different as Presidents Bush, Chirac, Mbeki and Mogae. Not all leaders are doing as much as

they should do, but the era of denial appears to be over.

Despite increased political attention, however, significant challenges lie ahead. On the global front, the resources brought to bear from both the public and private sectors do not come close to matching estimated need, and often come at the expense of other health and development efforts. In addition, enduring skepticism that anything can really be done may be the biggest threat to truly scaling up the fight against HIV/AIDS. At home, there is a perception that HIV/AIDS is now largely over, a false notion that itself fuels the epidemic's continued impact within our country.

## The Role of Foundations

Foundations have always played a critical role in responding to HIV/AIDS.

Early on in the epidemic in the United States, several foundations responded by supporting existing and new community-based organizations and paving the road before governments were willing to act. But by the mid-1990s, research on grantmaking trends conducted by Funders Concerned About AIDS and others indicated that funding had begun to decline. Only recently has it increased again, primarily for international efforts. And there still remains a relatively small subset of foundations providing the bulk of that support. Others have never entered the arena and some have left.

Foundations, like governments, have sometimes been reluctant to get involved in HIV/AIDS. Addressing HIV/AIDS necessarily involves sex, drugs, politics and sometimes deeply divisive moral issues. Some may

worry that the problem is too big for their efforts to have an impact. The global arena is complicated and difficult to navigate, particularly for those wanting to begin work in this area. Often HIV/AIDS doesn't fit neatly into the program areas and objectives already crafted by foundations. Domestically, the misperception that the epidemic is over, or "AIDS fatigue" for those with histories of giving in this area, may make it hard to see what still needs to be done or may have prompted foundations to turn elsewhere.

Of course, this reflects larger public attitudes and perceptions. U.S. public opinion polls, regularly conducted by The Henry J. Kaiser Family Foundation, indicate that while the public understands the global challenge posed by HIV/AIDS, and supports U.S. involvement, it is skeptical that more money can

# Here is a brief description of the **Henry J. Kaiser Family Foundation's** major HIV/AIDS related work:

## Policy

The Foundation's work in HIV/AIDS policy seeks to provide the latest information, research and analysis on major domestic and global HIV/AIDS policy issues. This includes monitoring of key epidemic trends, global and domestic spending on HIV/AIDS, and programs that provide prevention, care and treatment to people at risk for and living with HIV/AIDS; analyzing the role of coverage and care for people with HIV in the United States (by the Kaiser Commission on Medicaid and the Uninsured, the foundation's largest operating program); assessing public opinion about HIV/AIDS; and highlighting the impact of the epidemic on those populations and regions of the United States and the world that have been most affected, including young people, women and minority communities. We seek to be a "translator" of critical policy information and data for key audiences in ways that inform their decisionmaking and choices. For example, each year, we assess the status of state AIDS Drug Assistance Programs (ADAPs), which provide prescription drugs to people with HIV/AIDS who are uninsured or underinsured, and we track the U.S. government's commitment to fighting HIV/AIDS at home and abroad. Much of this information is communicated through fact sheets, reports, briefings and extensive use of online information.

## Online Information: Kaisernetwork.org

The foundation established [kaisernetwork.org](http://kaisernetwork.org) to serve as a free online resource. It provides non-partisan, timely and in-depth coverage of health policy developments, debates and discussions. It features the Kaiser Daily HIV/AIDS Report—summaries of the latest press coverage of HIV/AIDS from around the world. In an effort to make this resource as widely available as possible, it is not only free, but we also greatly encourage its syndication and use by other websites. Kaisernetwork also provides background information on key HIV/AIDS policy issues; live and archived webcasts and transcripts of congressional hearings, conferences and briefings; and searchable polling information on HIV/AIDS. The foundation, through [kaisernetwork.org](http://kaisernetwork.org), will be the exclusive webcaster of the International AIDS Conference in Bangkok, Thailand, this July, in an effort to help bring the conference to people all over the world who cannot be there in person.

## Media Fellowship and Internship Programs

Another key audience for us is journalists; we run several programs that allow journalists to gain firsthand experience reporting on HIV/AIDS that they might not otherwise have. This includes fellowship and internship programs and site visits in the United States and around the world focused on the impact of HIV/AIDS in different settings. The purpose is to encourage in-depth reporting on the health, social, economic, political and cultural implications of HIV/AIDS. To that end, we will soon sponsor a major conference for news editors focused on the domestic HIV/AIDS epidemic. And, with support from The Bill & Melinda Gates Foundation, we are about to launch a new initiative to train journalists from around the world about reporting on HIV/AIDS.

## South Africa

In addition to the other activities of the foundation, we have a longstanding and unique role in health and development in South Africa that dates back 17 years. Over the past decade, we have sought to contribute in various ways to the country's fight against HIV/AIDS, working in what has obviously been a challenging political environment. In 1999, the foundation also took the lead, in partnership with a consortium of leading South African public health organizations and the South African government, in launching loveLife—a national comprehensive campaign to reduce the rate of HIV infection among the 45 percent of South Africans younger than 20. With additional support from private foundations and the South African corporate sector, the loveLife campaign quickly established itself as an initiative of unprecedented scope, combining a sustained multi-media HIV awareness and education campaign with nationwide services. It is now the largest HIV prevention campaign for youth in the world.

## Entertainment Media Partnerships

We have our own “formula” for working with the entertainment media, based on our belief that the media are critical for reaching much of the public. While we know media outreach is not the whole solution, we also know the power of media in providing health information—and misinformation. Indeed, most Americans get their HIV/AIDS information from the media. The foundation partners with for-profit media companies to develop multi-faceted public education campaigns, with a particular focus on reaching young people with information about HIV. The partnerships combine targeted public service messages with special programming or editorial and other forms of outreach, including free resources such as toll-free hotlines and websites that reach millions of young people. Among our numerous media partners are MTV, BET, Univision, Nickelodeon and *Seventeen* magazine. Last year, we launched an HIV/AIDS media campaign with Viacom, one of the largest media companies in the world. Viacom has committed more than \$350 million to this campaign during its first two years. The success of this approach has led us to begin this work internationally. In January, the foundation, along with UN Secretary-General Kofi Annan and UNAIDS, convened a meeting of the world’s media leaders and launched a new Global Media AIDS Alliance to launch media campaigns around the world. This is an area of work that is new, promising and ripe for partners.

make a difference. Opinion polls also show a steady drop in concern about the epidemic in the United States, despite the 40,000 new infections each year and infection rates that may be on the rise among some subpopulations. Media coverage seems to mirror those trends—a forthcoming Kaiser Family Foundation study of news coverage of HIV/AIDS since the epidemic’s beginning will report a marked decline in total coverage over time, with a recent increase in coverage of the global epidemic offset by a simultaneous drop in coverage of the domestic epidemic.

Yet foundations remain critical to the response, not just in terms of resources (although these are, of course, important) but also in terms of leverage, flexibility and innovation. Foundations have always pushed government and corporations to create openings and focus on things that others do not want to.

This is a particularly important time for foundations to stay involved and to (re)engage in HIV/AIDS—globally, to help leverage the increased response that is still needed and demonstrate that pro-

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grams can be brought to scale, and domestically, to counter the AIDS fatigue that has pervaded much of America’s perception of the epidemic at home.

### Building on Strengths

The Kaiser Foundation is not the largest foundation active in HIV, but we have made a commitment disproportionate to our size and tried to craft an effort that builds on our particular organizational strengths.

The Henry J. Kaiser Family Foundation is a nonprofit private operating foundation focusing on the major U.S. healthcare issues. We are an independent voice and source of facts and analysis for policymakers, the media, the healthcare community and the general public. As an operating foundation, we develop and run our own research and communications programs, often in partnership with outside organizations.

Our mission dictates that we focus most on those health policy issues that rise to the top of the national agenda—issues like Medicare and Medicaid, the uninsured and healthcare costs. When we re-made our mission and redesigned our orga-

nization in the early ’90s, we decided that we would make some other issue priorities and one of those is HIV/AIDS. However, HIV/AIDS is not a discrete program at the foundation. It cuts across all areas of our work and includes both a U.S. and global scope.

### Looking Forward

Overall, we make no claim that the areas we work in are the most important ones for addressing HIV/AIDS, only that we have tried to make a contribution in the two areas where we have the greatest capacity and strength—health policy and health communications. The scope of the epidemic requires that governments take the lead in mobilizing resources for the fight against HIV/AIDS, but foundations also have a vital role to play. We particularly hope that as foundations confront the global epidemic, which needs their attention, they do not forget about the one at home. **FN&C**

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